VISION STATEMENT

The vision of the National Organization on Fetal Alcohol Syndrome (NOFAS) is to create a global community free of alcohol-exposed pregnancies and a society supportive of individuals already living with Fetal Alcohol Spectrum Disorders (FASD).

MISSION STATEMENT

The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. NOFAS, the only international FASD non-profit organization, is committed to prevention, advocacy and support.

NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities, and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. By ensuring that FASD is broadly recognized as a developmental disability, NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families.
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The National Organization on Fetal Alcohol Syndrome (NOFAS) has been advocating for better prevention, identification and treatment services for individuals with Fetal Alcohol Spectrum Disorders (FASD) and their families for over sixteen years. I am proud to have been involved with NOFAS from those very early years. My first meeting with NOFAS occurred just after I had discovered that my then sixteen year old daughter, Karli, who had been diagnosed with cerebral palsy years earlier, actually had Fetal Alcohol Syndrome (FAS). I was so excited to learn of NOFAS, and immediately offered to volunteer to help disseminate materials, and to share our “story” at NOFAS workshops and events. Once our journey of advocacy and public awareness began, there was just no stopping us. We found that our story really seemed to touch people; it appeared that the “personal story” was a great teacher in preventing FASD. Today, I am blessed to report that I work for NOFAS and serve as the organization’s Vice President and National Spokesperson. My entire family agrees that our lives have been truly blessed because of the many opportunities that NOFAS has offered us to make a difference.

This publication is dedicated to all of the individuals and families who are out there spreading the FASD prevention message and advocating for individuals with FASD. Every day enthusiastic people contact NOFAS and ask, “I want to make a difference and help to prevent FASD. How can I help? Where do I begin?” NOFAS has compiled this step-by-step guide to assist you in advocating and building awareness for FASD. This guide is a tool that includes resources and proven methods on how to reach the primary systems that address and serve individuals with FASD. It is designed to assist the lone mom or dad as well as the already formed group or organization.

Margaret Mead is quoted as saying: “Never doubt that a small group of committed individuals can make a difference; Indeed it is the only thing that ever has.” Over the years I have met some of the earth’s most impressive people that prove Mead’s statement to be true. These are not people that you will likely read about in People Magazine, or who are discussed on CNN. These are everyday folks, whose lives or families have been affected by FASD. They are individuals that are working tireless hours--often unpaid--spreading the message on the risks of prenatal alcohol exposure. This guide was developed for these unsung heroes. It has truly been a labor of love; a true collaboration of NOFAS staff and experience. NOFAS hopes that this helps your invaluable work spreading the message. On a personal level, it has been exciting and rewarding to have shared in this process. I hope this guide saves valuable time and energy in all of your FASD awareness efforts!

- Kathleen Tavenner Mitchell
ACKNOWLEDGEMENTS

The National Organization on Fetal Alcohol Syndrome (NOFAS) would like to thank all of the dedicated FASD individuals, families and advocates who have contributed their time, knowledge and incomparable experience to this resource. NOFAS hopes that this guide will encourage and inspire families, friends, and communities to unite in the mission to prevent FASD.

As with all projects of this kind, this guide was woven together by many hearts and minds. The primary authors are Annie Acosta, Christina Marsigli, and Kathleen Mitchell. Other NOFAS staff who contributed countless hours to this publication include Torrance Brown, Navoneel Dayanand, Kelly Raiser, and Lara Terrell. NOFAS is especially thankful to Elaine Arkin for sharing her vast experience in public health education and helping NOFAS organize this publication into a coherent and practical resource.

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INTRODUCTION

WHY A PUBLIC AWARENESS GUIDE?

Since 1990, NOFAS has responded to requests for information on FASD. The organization has fielded calls, letters and emails from tens of thousands of concerned individuals seeking information, resources and help about the risks and consequences of drinking alcohol during pregnancy.

People who contact NOFAS come from all walks of life and have a broad variety of needs. Often they are looking for ways to get involved in the issue and their motivation to be an advocate is as varied and unique as they are. For example:

“I need to educate my son’s school about his disability. Where should I start? Should I meet with the principal or do I need to go to the school board? How do I approach them?”

- Parent of a child with FASD

“Most of our clients have problems with alcohol; so many of their children have learning disabilities and behavioral problems. I need materials to share with both our clients AND my colleagues on FASD.”

- Service provider

“My sorority is interested in taking on the issue of FASD for our community service project. What can we do to help educate our community?

- College student

In responding to such requests over the years NOFAS has amassed a wealth of information on effective strategies and state-of-the-art resources. This guide is a way for NOFAS to share the organization’s ideas and knowledge with the small but growing number of FASD advocates.

F.Y.I.
NOFAS has also developed a companion publication focusing on legislative and consumer advocacy designed to help you become an effective advocate in the legislative and policy arenas. Contact NOFAS for more information.
WHO CAN USE THIS GUIDE?

This guide is for anybody who is concerned about alcohol consumption during pregnancy and would like to get involved in their community. The primary purpose of the guide is to enhance public awareness about the risk of prenatal alcohol consumption, Fetal Alcohol Spectrum Disorders, and the needs of people and families living with the disorder. It can be used by dedicated FASD activists: persons with a personal and/or professional connection to people living with FASD such as parents/caregivers, service providers and researchers; or it can be used by people with no connection to the issue but a passion for public service. This guide is for anyone interested in putting a stop to the leading known preventable cause of birth defects and improving the life of families in need.

NOTE TO USERS OF THE GUIDE

There are many strategies and resources presented in this guide. Some are very easy to research, adapt, and implement on your own. However, others may require more time and resources than you have available. Family members who face the daily challenges (and joys) of caring for someone with FASD and people with little or no free time can still make a difference by absorbing the information presented here and passing it on to people they meet in their daily lives such as their extended family, friends, neighbors, and co-workers.

You can use the guide to help educate the systems serving your FASD child while others may chose to become activists. For those of you that have been “bitten by the FASD bug” and plan to spread the message far and wide, the guide also offers more advanced strategies. However ambitious you may be, NOFAS encourages you to review the entire guide as the resources and strategies presented here may prompt your own ideas for future public awareness opportunities.

This resource is simply meant to spark your creativity—to get an idea, make it your own, and then run with it. You do not need to attempt to undertake all of the suggested activities or utilize all of the resources to make a difference.

REQUEST TO USERS OF THE GUIDE

NOFAS intends to periodically update and reprint the guide. Therefore, we need to hear back from you! We want to know what you have tried, what challenges you encountered and how you overcame them. In addition, we want to learn about any new FASD programs or resources you may have developed or discovered that are not included in this resource. This guide was created based on the experiences of others and their willingness to share that information. NOFAS thanks you in advance for your commitment to share your experiences.
HOW TO USE THIS GUIDE

Each section of this guide has the following icons to help you locate information easily and quickly:

- **Objectives.** Describes the learning objectives for each section.

- **What People Need To Know.** Presents FASD-relevant facts and information that are specific to each audience.

- **Tip.** Offers useful tips for reaching targeted audiences.

- **Strategies.** Describes methods for reaching a particular audience.

- **“Real World” Public Awareness.** Highlights true life examples of people who have made a difference.

- **Extra Resources.** Provides additional materials for public awareness efforts.
RESOURCES

TEXT RESOURCES: “Ready to Use” text resources are included in the document. You may use these as they are or you may tailor them to a specific audience.

- **Fact sheets.** Features general information on FASD and related topics.
- **Scripts.** Introduces sample talking points for you to use with specific audiences.
- **Letters.** Presents sample correspondence for various audiences.

ELECTRONIC RESOURCES: There are two types of electronic resources:

- **Web-based documents.** These include books, chapters, handbooks, and fact sheets.
- **Web-based searchable databases.** These are searchable tools that contain relevant data, such as programs operating in your area.

Many of the resources offered in this guide are web-based. NOFAS recognizes that not everyone has access to a computer. Fortunately, most public libraries offer access to the Internet free of charge. If no such resource exists in your community, NOFAS can help you access web-based resources. Contact NOFAS via telephone, e-mail or fax to request hard copies of documents or the results of specific Internet searches.
NOTE ABOUT TERMINOLOGY

Since the recognition of Fetal Alcohol Syndrome (FAS) in 1973, the terminology used to describe the characteristics of the alcohol-related disorders other than FAS has evolved. This can be extremely confusing for someone who is attempting to familiarize themselves with the issue.

For the sake of clarity, the term Fetal Alcohol Spectrum Disorders (FASD) will be used consistently throughout the guide to incorporate FAS and the entire range of disorders associated with prenatal alcohol exposure. The following definitions have been broadly adopted by the FASD community to define various terms.

TERMS & CHARACTERISTICS

Fetal Alcohol Syndrome (FAS) Characterized by 1) brain damage (central nervous system (CNS) dysfunction), 2) specific facial dysmorphology and 3) growth deficits. Confirmed maternal use of alcohol may or may not be documented.

Fetal Alcohol Effects (FAE) Outdated term originally used to describe alcohol-exposed individuals whose condition did not meet the full criteria for FAS.

Partial Fetal Alcohol Syndrome (PFAS) Evidence of some of the specific facial features found in an individual with FAS combined with either low birth weight or decelerating weight over time. Also characterized by behavioral or cognitive abnormalities that can not be explained by family history or environment such as learning difficulties, deficits in school performance, etc. Confirmed maternal alcohol exposure.

Alcohol-Related Birth Defects (ARBD) Describes the physical defects linked to prenatal alcohol exposure, including heart, skeletal, kidney, ear, and eye malformations.

Alcohol-Related Neurodevelopmental Disorder (ARND) Functional or cognitive impairments linked to prenatal alcohol exposure including structural brain abnormalities and a pattern of behavioral and learning difficulties (In the absence of the distinct facial features of FAS or growth retardation).

“FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.”
OBJECTIVES:

- Learn about the historical recognition of Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorders (FASD)
- Learn about the latest information on FASD prevention, identification, and intervention
HISTORY OF ALCOHOL AND PREGNANCY AND FETAL ALCOHOL SPECTRUM DISORDERS

The idea that alcohol is harmful to a developing embryo or fetus is not a new concept. There is evidence as far back as Biblical times attesting to the dangerous effects of alcohol. It was reported that when Sampson's mother first learned of her pregnancy she was visited by an angel, who appeared at her bedside and said “behold, thou shalt conceive, and bear a son; and now drink no wine or strong drink” (Judges 13:7). In Problemeta, Aristotle writes, “foolish, drunken, or harebrain women most often bring forth children like unto themselves.” In the 1700’s a gin epidemic in England led to a plea by an association of physicians before Parliament to have stricter laws controlling the trade of gin in part to prevent the birth of, “feeble, distempered children.” Medical findings on the adverse effects of alcohol during pregnancy were also used to justify Prohibition in the United States (Health Canada, 2001).

It was not until 1973 that Fetal Alcohol Syndrome (FAS) was first described in the United States. Two researchers from the University of Washington, Dr. Kenneth Lyons Jones and Dr. David Smith, described a pattern of birth defects they observed in a group of children born to alcoholic mothers. The characteristics included growth deficiency, a specific pattern of facial features, and central nervous system (CNS) dysfunction. Since the publication of their findings in the Lancet medical journal, more than 2,000 human and animal studies have confirmed these results as permanent consequences of prenatal alcohol exposure (MOFAS, 2002). By 2004, the term Fetal Alcohol Spectrum Disorders (FASD) had been accepted as the primary term for describing the range of effects linked to prenatal alcohol consumption.

FETAL ALCOHOL SPECTRUM DISORDERS TODAY

There has been great progress in the field of FASD since 1973. However, overcoming the challenge of public awareness regarding the risks of drinking alcohol during pregnancy and the lack of diagnostic criteria for the full spectrum of effects still pose significant obstacles to developing the field. The public at-large still has many misconceptions about the risks of alcohol during pregnancy and health care and social service workers continue to give mixed messages on the subject.
OBJECTIVES:

- Understand the meaning of public awareness and its application to FASD
- Understand how public awareness on FASD is unique
- Learn the basic steps of developing a public awareness plan
- Recognize the importance of evaluation
- Learn simple, cost-effective techniques for evaluating your efforts
WHAT IS PUBLIC AWARENESS?

Public awareness refers to the level of understanding that your community has about a particular issue. A public awareness project is a great way to bring attention to an important issue like FASD. A good place to start is with FASD prevention—educating communities that drinking at any time during pregnancy can result in FASD.

In your community you will be working towards producing changes that directly affect the lives of those around you. By raising awareness about the risks of drinking during pregnancy and the resulting personal and societal costs, you can initiate change at the local, state, and/or national level.

WHY IS FASD PUBLIC AWARENESS UNIQUE?

Educating the public on FASD is unlike advocating on other common disabling conditions such as Down syndrome, muscular dystrophy, or deafness. When educators for other disability groups seek attention, they rarely have to explain what the disability is or what caused it, or have to over come so many myths and misconceptions. With FASD, the lack of public awareness, the misinformation, the social stigma of drinking during pregnancy, and the lack of complete guidelines to diagnose the full spectrum of FASD pose unique challenges. Each of these factors needs to be kept in mind when planning public awareness efforts.
**DEVELOPING A PLAN**

Before jumping right into your education and awareness efforts you should think about what you hope to accomplish and the necessary steps to achieve your goals. It is useful to remember this simple acronym: **SMART**.

- **S**pecific
- **M**easurable
- **A**chievable
- **R**elated to the goal
- **T**ime-oriented

The first thing to think about is what you are asking for through your efforts. What areas in the illustrated graphic below are you seeking to improve?

Here are some basic steps to define your plan:

**Step 1 : Identify your overall goal**
Example: To prevent FASD.

**Step 2: Clarify your objectives**
This will help you determine what kind of impact you would like to have in your community.
Example: To increase the number of women in the community who abstain from drinking alcohol during their pregnancy.
Step 3: Define a broad approach to reach your objective. By first defining a broad approach you leave it open to carry out a number of more specific activities, depending on your focus at the time and the degree of help and support you have (CDC, 1998). Example: To reach women with accurate information about the effects of alcohol on a developing fetus.

Step 4: Outline specific activities that fall under the broad approach. Example: To make alcohol and pregnancy informational brochures readily available in doctors’ offices and clinics throughout the community.

Step 5: Define a specific task to support the activity. Example: Provide an FASD 101 training session for local health professionals and provide them with materials to disseminate.

Prioritize your efforts. As you read through the guide and explore some of its resources you may learn more about the best messages and strategies for reaching different target audiences. Once you tackle one audience you may decide to move on to another. However, be realistic about the amount of time, resources, and energy each might require. It is essential to prioritize your activities and view each small achievement as a building block to something greater.

EVALUATING YOUR EFFORTS

The following suggestions are simple methods to track your efforts. Collecting feedback will help you assess your work and make modifications for improvements. Tracking your efforts will provide documentation that you have done the work and will give you a report on the success of those efforts. Having this documentation can be instrumental in securing funding for future efforts.

There are two main types of evaluations:

A process evaluation is the mechanism for assessing the progress of your activities at various stages (CDC, 1998). A well thought out process evaluation:

- Can help detect small problems before they become big ones
- Provides preliminary encouragement if the program shows signs of success
- Leads to the replacement of ineffective activities
- Determines if the program is on schedule
- Assesses the number of individuals being reached by your efforts

An outcome evaluation will help you measure the overall success of your efforts by looking at the impact you make (CDC, 1998). This type of evaluation can:

- Demonstrate the results of your efforts and provide evidence of success for future funding opportunities
- Be used to improve the future effectiveness of your program
- Encourage others to aid in your efforts
EXAMPLES OF COST EFFECTIVE EVALUATIONS

Activity/Task Assessment

The activity/task assessment is a type of process evaluation that is extremely simple to manage. This method is generally used to provide an ongoing account of what is occurring in a program (Green and Kreuter, 1999). It will not measure changes in knowledge or behavior but can demonstrate how effective you have been in reaching your target audience. Essentially you are recordkeeping, or just counting numbers. For example:

- Number of physician offices visited
- Number of posters and brochures disseminated
- Number of ads placed in a paper
- Number of calls received following a public service announcement
- Number of trainings conducted at the community center

Recording these numbers allows you to quantify the community’s exposure to your activities. It is affordable, time sensitive, and the results are easily understood (CDC, 1998).

Pre/Post Tests

An evaluation taken before and after a program activity can be useful in demonstrating the effectiveness of your program (CDC, 1998). A pre/post test is an example of an outcome evaluation that is an easy way to assess gains in knowledge among your target population. The process is simple—the same test is given before and after an activity (such as an FASD training)—and the results are compared. If there is not significant improvement in the scores, it may be necessary to revise the activity so more time is spent on certain areas to assure comprehension.

A sample pre/post test on FASD is included in the Resources section on pg 91.

RESOURCES ON PROGRAM EVALUATION

An Evaluation Framework for Community Health Programs
Centers for Disease Control and Prevention
http://www.cdc.gov/eval/evalcbph.pdf

Evaluating Community Programs and Initiatives
The Community Tool Box
http://ctb.ku.edu/tools/en/part_J.htm

Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide
Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/folicacid/prev_guide.htm
THE TASK FOR FASD PUBLIC AWARENESS
By Diane Malbin, founder of FAScETs
Fetal Alcohol Syndrome
Consultation, Education
and Training Services, Inc.

After accidentally discovering FASD and grieving, I realized there were two options: Ignore or act. I wanted to ignore, but my kids needed help: A reluctant leap.

1. Read, read and read the literature to understand.
2. Grieved, came to accept, and redirected this energy born of grief into action.
3. Developed a key informant survey to find out who in the community knew about FASD and what were they doing? Found there was no one doing anything.
5. Realized outcomes looked grim yet my children and others were doing well. Decided to figure out what didn’t work and why not, what works and why.
6. Set up clinical practice and developed information and support groups and began to generate an approach through working together with parents and professionals.
7. Included clinically-based hopeful information into group discussions and training. Developed support information and materials.
8. Developed peer-reviewed courses and started teaching.
9. Established a non-profit organization.
10. Designed and implemented research that tested the approach of working with parents and professionals (it worked).
11. Worked collaboratively on projects in different communities.
12. Accepted how long it will take to accomplish a shift in thinking across communities.
13. Next steps, establish a training and living center to meet some of the biggest needs.
14. Now: Very different. From feeling alone, now there’s an amazing community of warm, dynamic women and men working together toward healing, healthy families and communities, and prevention.

To quote Sir Winston Churchill: “Never give in—never, never, never, never”
OBJECTIVES:

- Connect families with existing FASD networks to increase access to support and resources

- Expand and improve the existing network of FASD-related groups by providing the tools individuals need to start new networks

- Inspire individuals to seek support or improve existing networks through real life examples and accomplishments

- Become familiar with common barriers to forming and maintaining networks
THE VALUE OF FASD SUPPORT GROUPS

Support groups provide an invaluable resource for families and individuals touched by the lifelong consequences of FASD. They offer a safe, open environment where individuals are free to express themselves and their feelings without the threat of being misunderstood or judged. Members will likely find themselves at different stages of understanding of the disability. A support group presents a unique opportunity for participants to learn from each other as they share personal experiences. FASD support groups help families feel reassured that they are not alone and that there is a support network available to them. Naturally, support groups are also the most likely source for identifying and developing FASD grassroots activists.

LOCATE AN EXISTING FASD SUPPORT GROUP

NOFAS provides a state-by-state listing of available FASD support groups through their National and State Resource Directory. See: http://www.nofas.org/resource/directory.aspx

Meetup.com has a national directory of thousands of interest groups, including FASD. Go to http://www.meetup.com/browse/ then type in “fetal alcohol syndrome” in the topic window. (While most of these groups are newly formed and still quite small, Meetup.com is an excellent and frequently updated resource)

The Fetal Alcohol and Drug Unit of Washington University has a large network of families of persons with FASD. Telephone 206-543-7155 or go to: http://www.depts.washington.edu/fadu/Support.Groups.US.html

The Office of Fetal Alcohol Syndrome at the Alaska Department of Health and Social Services provides a list of available groups in the Alaska area http://www.hss.state.ak.us/fas/resources/default.htm

Many people caring for persons with FASD live in rural areas where physical distances may make it impossible to identify and/or meet regularly with other families. Other people may not have the time available for regular meetings. For these reasons, on-line support groups and networks may be more practical.
ON-LINE FASD SUPPORT GROUPS:

- Circle of Hope, a network of women, who have used alcohol during pregnancy and have or may have children with FASD.
  http://www.nofas.org/coh/default.aspx

- FASlink, a free Internet mail list for individuals, families and professionals who deal with FASD.
  http://www.faslink.org

- FAS forum, a group for professionals and families living and working with individuals who were prenatally exposed to alcohol.
  http://health.groups.yahoo.com/group/FASForum

- FASD Birth Parents Mail List, a group for birth parents of persons with FASD.
  http://groups.yahoo.com/group/FASDBirthparents

- FAS Support Network Message Board, an on-line forum for parents and caregivers to discuss FAS.
  http://www.fetalalcohol.com/bb/signup.asp

- FASonline, an on-line FASD support, including state specific forums.
  http://www.come-over.to/FAS/fasonline.htm

- International FAS Meet up, an on-line resource that connects parents and caregivers to other people dealing with FAS in their local area.
  http://fas.meetup.com

- Worldwide FAS Meet up Message Board, an on-line forum for parents and caregivers to discuss FAS.
  http://fas.meetup.com/boards
My family started providing foster care for babies with medical needs in 1982, many of whom had health issues related to prenatal alcohol and drug exposure. We spent a lot of time in clinics and at hospitals. In 1991, after years of sitting and visiting with other parents raising kids with FAS and FAE, a small group of us decided we needed to come up with another way we could get together. We wanted to talk about our shared experience, learn more about the disabilities our children experienced, and get more information about how to raise them successfully.

The stars must have been in alignment, because at the same time, a psychology grad student was looking for a thesis project. Through Vickie Hild, the Area FAS Coordinator for the Alaska Native Medical Center, we met up with Susan Baxter who was willing to do the ground work to get a support group up and running and facilitate our meetings for the first year. That was great, because we parents had to-do lists longer than our arms already.

Invitations were sent out to families using the local hospital clinics, therapy offices and the school district’s special education parent resource center. Our first meeting was held in October of 1991 at the SEPRC, with childcare provided for $1.00! Eventually, the childcare charge went away, but we have always tried to have trained care providers available at meetings to give the parents a couple hours of respite.

Over the years the group has grown and shrunk, meetings times have changed from evenings to daytime, kids have played at our feet or in locations a mile from the meeting place. Our meeting locations have included all six SEPRC sites as well as member’s homes, local churches and support agencies. Through all the moves and changes, one thing remains constant. We are birth, grand, foster, adoptive parents and relative caregivers supporting each other as we all learn and grow along with our babies, children, teens and adults who experience FASD. (By the way, we came up with P.E.G. after one parent described trying to fit our “square peg kids” into societies “round holes”.)
STARTING YOUR OWN FASD SUPPORT GROUP

If you are unable to locate an FASD support group in your area then you may decide to start your own group in your community. Before you take on this challenge there are many things to consider. It is important to be honest with yourself about the realities you will face to establish and maintain the group (Stone Soup Group, 2002).

STEP 1: ASK YOURSELF KEY QUESTIONS

- **Do you have the time to devote to this project?** There is a time commitment involved in just getting the group started, not to mention your devotion to organizing and attending recurring meetings.

- **Will your family and friends support your commitment?** After all, it will take time away from them.

- **Are you prepared to keep your personal beliefs to yourself?** A group leader cannot attempt to push their beliefs on other members.

- **Are you ready to act as a role model for others?** Members of the group will often look to you as an example of how to manage different obstacles or successes that present themselves.

- **Can you sacrifice your personal time?** Members might unintentionally take advantage of your own time while looking for answers or help on a problem.

STEP 2: FIND OTHERS WHO SHARE YOUR INTERESTS

- **Ask professionals that have helped your family.** They may connect you with other families in similar situations (Stone Soup Group, 2002). Make yourself available as a referral for their new clients.

- **Identify related agencies and organization.** Look in the phone book under social services, schools, churches, child care, disability services, respite, and treatment facilities (Stone Soup Group, 2002). Contact them about your group and encourage them to take an interest. Sometimes professional groups may serve as a sponsor for your group and donate space or print materials for your sessions.

- **Utilize your on-line FASD support groups.** This will help identify potential members for your group.

- **Contact diagnostic clinics and clinicians in your area.** Follow this link to locate the nearest diagnostic clinic [http://www.nofas.org/resource/directory.aspx](http://www.nofas.org/resource/directory.aspx)

STEP 3: PLAN YOUR FIRST MEETING

- **Set a time and place.** Hospitals, libraries, and community centers can be good places to hold a meeting. If your group is small consider alternating between different members’ homes. It is important that the space be comfortable, accessible to all members who attend, suitable for a “round robin” chair set-up, and that the time is accommodating for parents who work.

- **Publicize your group.** Be sure to include the time, location, and date of your meeting on all publicity materials.
Ask your local newspaper to list your meeting in their health calendar or other appropriate section.
- Post flyers in community health clinics, diagnostic centers, etc.
- Ask your local or neighborhood newspaper to write an article featuring your group
- Send press releases to the local media announcing your meeting

The NOFAS Capwiz Tool connects you directly to local media in your community. Visit: http://capwiz.com/nofas/home/. See Section 8: Reaching The Media, pages 76 - 82 for sample results.

- Provide childcare whenever possible. Experience has shown that people are more likely to attend when this is provided. You will need to provide a separate space and structure the time with activities or movies. Be sure your daycare provider or volunteer is educated on FASD. If food is provided to the children, please be mindful of food allergies and avoid offering sugary snacks to children with FASD.
- Limit the first meeting to families living with FASD. The group may decide to welcome professionals and other community members later but this should be a group decision (Stone Soup Group, 2002).

STEP 4: SET UP A MEETING
These are a few suggestions on organizing a meeting. Please feel free to design your meeting around the needs of the group.

- Provide refreshments
- Provide NOFAS fact sheets that will be useful to your members
  Print out your state’s FASD resources located at: http://www.nofas.org/resource/directory.aspx
- Create a welcoming environment. Be friendly to members who arrive late or new members who decide to join the group.
- Organize the chairs in a circle to stimulate conversation. The facilitator should also be included in the circle, not standing up in front of the group.
- Provide nametags for the members to get to know each other. This may not be necessary for all meetings. Have a sign up sheet for members to post their contact information.
- Provide a flip chart or chalkboard to display the meeting agenda. This will help the group stay organized throughout their discussion.
- Designate someone to take minutes for the group.

STEP 5: HOLD THE MEETING
- Establish and reiterate ground rules. There must be a group consensus to respect each other’s privacy and confidentiality. Allow the group to establish their own rules. They will be more likely to stick to them.
- Emphasize everyone’s right to share. Each group member should have equal opportunity to talk about their own experiences. No one person should monopolize
the group’s time (Stone Soup Group, 2002). It is also important to refrain from pressuring individuals into talking if they do not feel comfortable.

- **Discuss the idea that all emotions are acceptable.** Members must feel that it is okay to express anger, sadness, joy, shame and every other emotion along the spectrum (Stone Soup Group, 2002).

**SUGGESTED TOPICS FOR FIRST MEETING:**

- **Introductions.** Have members introduce themselves and talk about their history with FASD.

- **Goals of the group.** Have a brainstorming session where everyone can identify what they want to get out of the group and how to accomplish it. The goals may evolve and change as new members are welcomed into the group.

- **Time and locations of meeting.** Come to a consensus about meeting times and locations. (For example, the NOFAS Support Group meets every three months on the third Saturday from 1:00 p.m.–3:00 p.m. at a local hospital.)

- **Future topics and interests.** Talk about topics that the members would like to learn more about. Discuss bringing in guest speakers and professionals that could provide information on those subjects. Sample topics for discussions:

  - Support group events, conferences, fund raisers, guest speakers, social meetings, membership dues
  - Pharmaceutical interventions that work
  - Strategies for educating children with FASD
  - Diagnostic facilities for FASD
  - Available services for both children and adults with FASD
  - Residential programs
  - Latest research
  - Respite care
  - Advocacy
  - Shame/guilt experienced by birth parents of children with FASD
  - Activities for International FASD Awareness Day
  - NOFAS Hill Day
SUSTAINING YOUR SUPPORT GROUP

- **Look for in-kind donations.** Ask department stores, warehouse shopping centers and other retail stores from your community to make an in-kind donation of goods and services such as food, gift certificates event tickets, etc.
- **Ask for small contributions from your support group members.** A small donation from each member of $1 or $2 a month can help pay for incidentals.
- **Ensure buy-in from your members by assigning tasks.** These can be small activities, such as taking notes or mailing out information.
- **Have a fundraiser.** Simple activities such as bake sales or car washes can raise significant contributions to sustain the group. You can also raise money by selling, raffling or auctioning donated items.
- **Continue publicizing group activities.** If you have funds available, continue to recruit new members by putting up flyers or posting meeting notices on bulletin boards and in newspapers.
- **Identify** any group activities that may be appealing to the local media. The publicity can attract new members.
- **Develop a parent to parent network** where parents with experience raising children with FASD could serve as mentors to families with a new diagnosis.

**SUPPORT GROUP RESOURCES**

- **Family Empowerment Network/Pen (FEN/Pen) Newsletter**
  http://www.fammed.wisc.edu/fen/fenpen.html

- Parent to Parent of PA provides an on-line manual to starting and running your own support group plus a lot of other useful information about grant writing and fundraising to sustain your group.
  http://www.parenttoparent.org/Sup-run-t.htm

- The Stone Soup Group FASD Parent Support website provides a lot of good information for parents including strategies and available resources.
  http://www.stonesoupgroup.org/fas/index.html
One of the first activities I pursued when I began working at NOFAS was to start a parent support group. I posted an ad in the Health Section of the *Washington Post* and created flyers that I distributed to all of the local genetics clinics (there were no FAS diagnostic clinics). I found space in the local hospital where one of the diagnostic clinics was located. It was not uncommon to find myself sitting in an empty room waiting for families to show up. I was determined not to give up and continued to seek out other families living with FASD. I continued to advertise the support group by informing every person that contacted NOFAS, continually visiting the genetics clinics (being sure that I gave the flyer to different staff members), running ads in newspapers, and distributing flyers at every FASD workshop that I presented.

Little by little, families trickled in. For the first few months there were two other families, then came the third, and then they kept coming. We kept our group very open and casual. We welcomed new members by sharing short introductions about how FASD has affected our lives. We have free flowing conversations, share feelings and problems and as a group we do our best to identify solutions and support each other. We also occasionally invite guest speakers. We continue to meet on a quarterly basis and encourage new members.

I have found that attendance in the group seems to go in about three year cycles. Most families attend regularly in the first two years. In the third year attendance often slows down after they have dealt with the intense emotions of receiving a diagnosis of FASD for one of their family members. By constantly recruiting you will always have a support group with members in various stages of the three year cycle. Hosting a FASD support group is a commitment but the benefits are well worth the effort. I can honestly say that I have met some of the most endearing people in the NOFAS group and have come to love many of them like family.
OBJECTIVES:

- Understand the role of non-profits
- Learn how to become a non-profit organization
- Recognize the benefits of being a 501(c)(3) non-profit organization
- Learn about resources available to Non-profit organizations
- Learn about NOFAS Affiliates
**WHAT IS A NON-PROFIT ORGANIZATION?**

A non-profit organization is an organization whose resources and mission are devoted exclusively to charitable, educational, or recreational purposes. They include associations, community groups, non-government organizations and political campaign organizations (Rutgers, 2004). Non-profits are typically funded by tax-deductible donations from the private or public sectors. A majority of Fetal Alcohol Spectrum Disorders (FASD) oriented non-profits are comprised of concerned family members that are run by less than five people and have annual budgets of less than $200,000. A few have become self-sustaining through grants, in-kind donations and contributions.

**ROLE OF AN FASD NON-PROFIT ORGANIZATION**

A non-profit organization can serve as your agent to address FASD in your community or state. FASD organizations work to raise awareness about the condition, prevent its occurrence and improve the quality of life for those living with FASD. They do so in a variety of ways, including promoting the latest information and messages about alcohol and pregnancy, advocating for the needs of FASD families at state and local levels, providing support for families and helping to develop programs with other nonprofit and state agencies.

**BENEFITS OF INCORPORATING AS A NON-PROFIT ORGANIZATION**

- Exemption from federal and/or state corporate income taxes
- Possible exemption from state sales and property taxes (varies by state)
- Opportunity to apply for grants and other public or private funding available only to IRS-recognized, 501(c)(3) organizations
- Opportunity to accept tax-deductible contributions and accept tax-deductible goods and services to fulfill your mission
- The public legitimacy of a charitable organization providing a public service
- Discounts on US Postal bulk-mail rates and other services such as printing and publishing of materials, discounts on facilities, hotels and conference rooms etc.
- Eligibility to be a NOFAS Affiliate (See explanation on Page 25 about the NOFAS Affiliate Program)
FIRST STEPS TO ORGANIZING A NON-PROFIT ORGANIZATION

Becoming a non-profit organization involves several steps. Although the procedures may vary from state to state, the following are the most important common steps of non-profit incorporation.

STEP 1: DEVELOP A MISSION STATEMENT

Your mission statement will describe the purpose of your organization, its method and operation, and values. Your mission statement should be a brief document consisting of your organization’s core purpose. It should be clear, focused, and no longer than a few sentences. Include the organization’s name, the services it provides, and the population it serves. It is important to keep the statement short and direct. Details can be saved for the organization’s strategic plan, which will change and expand as the organization grows. The mission statement, however, remains constant and changes only when there is an important shift in the organization’s core purpose.

SAMPLE MISSION STATEMENT:

The National Organization on Fetal Alcohol Syndrome (NOFAS) is the leading voice and resource of the Fetal Alcohol Spectrum Disorders (FASD) community. NOFAS, the only international FASD non-profit organization, is committed to prevention, advocacy and support.

NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. By ensuring that FASD is broadly recognized as a developmental disability, NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families.

STEP 2: DEVELOP A CONCEPT PAPER

A concept paper can be used to present your proposed organization to potential board members, contributors, and the community. The concept paper should be approximately three to five pages typed and include a summary of the following elements:

- Purpose and mission statement
- Statement of the issue(s) and problem(s)
- Description of the organization
- General goals and activities
- Future plans and vision

Sample Concept Paper:
http://brc.dc.gov/ search for “Concept Paper” or “Tots for trees concept paper”
STEP 3: ESTABLISH A BOARD OF DIRECTORS

The Board of Directors will ensure that your organization’s mission is carried out and provides legal accountability for its operations. The primary functions of the board of directors are often financial oversight and fundraising. As necessary, the board of directors is responsible for the following:

- Determining the organization’s mission and purpose
- Ensuring effective strategic planning
- Hiring a competent executive director and providing appropriate supervision and support
- Evaluating and approving the organization’s programs and services
- Establishing policies
- Ensuring adequate resources
- Financial oversight and compliance
- Assessing its own performance

Sample Description of Non-Profit Board of Directors:
http://www.nonprofits.org/npofaq/03/02.html

See NOFAS Board of Directors 2005:
http://www.nofas.org/about/directors.aspx

STEP 4: DEVELOP BYLAWS

Bylaws define how the nonprofit organization will be managed and operated. Bylaws serve the following functions:

- Define the basic organizational structure of the nonprofit
- Determine which staff and board members have authority and decision-making responsibilities and how those responsibilities should be carried out
- Define the requirements and responsibilities of membership
- Create a framework for the organization, and aid in resolving internal disputes
- Describe the rules for calling board meetings and specify board member election procedures

Keep your bylaws as simple and flexible as possible

Outline the frequency of board and membership meetings, officer responsibilities, and officer selection procedures

Include procedures for making changes to the organization’s policies, operations, structure, and bylaws.

Sample Bylaws: http://healthinfo.montana.edu/volclin/bylaws.html
STEP 5: DEVELOP A STRATEGIC PLAN

Your Strategic Plan details the organization’s direction, focus, and vision for the next one to three years. It describes the organization’s programs and services, as well as outlining its plans for operations, marketing, fundraising, and financial management. A strategic plan is dynamic—it can be updated as often as practical and should reflect current changes in the organization, its environment, and long-range vision.

Sample Strategic Planning Document: http://www.allianceonline.org/FAQ/strategic_planning

STEP 6: DEVELOP AN ORGANIZATIONAL BUDGET

You will need to develop a projected budget whether or not funds have been pledged to your organization or you have received contributions. If you have been promised funds, include that amount in your budget as revenue. Project your expenses for your upcoming fiscal year including how much money you will need for personnel, employee benefits and payroll taxes, rent and other expenses to run your office, postage, printing, local travel and other expenses.

Sample Budget format: http://npguides.org/guide/budget.htm

INCORPORATING AS A NON-PROFIT ORGANIZATION

With the above documents prepared, you are now ready to apply for non-profit incorporation for your organization. You will need to determine the correct office in your state which would accept applications for non-profit incorporation. The Secretary of State, Business & Public Filings Division is generally the appropriate office to find and file your completed incorporation forms.

In order to apply for your non-profit status, you will need to file your articles of incorporation with the appropriate office. You can do most of the work yourself, but it is advisable that you get legal help in filing the articles of incorporation and applying for your tax exempt status. Having an attorney on your board of directors can help in this regard.

Guidance for Non-Profits in Locating and Utilizing Attorneys: http://www.managementhelp.org then click on “Legal Information”

STEP 1: DEVELOP ARTICLES OF INCORPORATION

Develop your Articles of Incorporation: These are to be filed with the Secretary of State or other appropriate state office. This is the first legal step in forming a non-profit organization.

Sample format for articles of incorporation for non-profits: http://www.managementhelp.org/legal/articles.htm
STEP 2: OBTAIN A FEDERAL EMPLOYEE IDENTIFICATION NUMBER

Apply for your Federal Employee Identification Number (FEIN), also known as Federal Tax Identification Number. It is assigned by the US Internal Revenue Service to non-profit and for-profit corporations and other entities for tax filing and reporting purposes. The FEIN is like a Social Security Number for your non-profit organization.

The following are your options to apply for the FEIN:


Write to or Call: Internal Revenue Service, Attn: Entity Control, Philadelphia, PA 19255. Toll Free: (866) 816-2065.


STEP 3: COMPLETE NON-PROFIT INCORPORATION STATUS

You will be required to fill out forms available from your Secretary of State or other appropriate state agency. Most states require that you reserve and register your corporate name and logo. Although application forms and fees may vary from one state to another, a few basic forms are used by most states including the Application for Reservation of Corporate Name and Application to Register Articles of Incorporation.

National Association of Secretary of State Office Locator:
http://www.nass.org/sos/sos.html

APPLYING FOR 501(C)(3) TAX EXEMPT STATUS

To be tax-exempt as an organization described in the Internal Revenue Code (IRC) Section 501(c)(3), an organization must be organized and operated exclusively for one or more of the following purposes: charitable, religious, educational, testing for public safety, prevention of cruelty to children or animals, etc. The term charitable is used in its generally accepted legal sense and includes among others, relief for the poor, distressed, defense of human and civil rights secured by law; public awareness and education etc.

STEP 1: COMPLETE INTERNAL REVENUE SERVICE (IRS) FORM 1023


It is best that you apply for your 501(c)(3) Tax Exempt Status within 15 months of non-profit incorporation. In order to be eligible to receive funds, you may want to apply for your 501(c)(3) immediately after incorporation.
STEP 2: COMPLETE IRS FORM 8718

Fill out Form 8718 – User fee for Exempt Organization Determination Letter Request (this is the cover page for your application) available at:

STEP 3: FILE IRS FORMS

File the Forms (1023, 8718 and other supporting documents) with the appropriate IRS office. Offices vary based on your location.

STEP 4: APPLY FOR STATE SALES AND USAGE TAX EXEMPTION

Contact your Secretary of State Office or your state Department of Commerce or Revenue (names and departments may vary by state) to seek an application form to apply for Sales and Use Tax Certificate of Exempt Status.

IRS Local / State Office Locator:

TIP
In at least 31 states, non-profits are exempt from state sales tax on telecommunications services. If you are unsure if your state offers this exemption, you should contact your state’s Department of Treasury.

NON-PROFIT REGISTRATION RESOURCES

IRS Publication 557. Tax-Exempt Status for an Organization to apply for your 501(c)(3) status. This document has a detailed list of all that you need to know about this process. Application forms are also included.

Internal Revenue Service Non-Profit and Charitable Organizations Overview

http://brc.dc.gov/nonprofit/nonprofit.asp
To find the correct amounts for user fees and the length of time to process a request, call the IRS at 1-877-829-5500 for assistance.
NOFAS AFFILIATE PROGRAM

NOFAS started an affiliate program in 2004 to develop formal relationships with parent and professional groups working in the FASD field. NOFAS currently has 14 affiliates. All nonprofit organizations that work to prevent, identify, and provide support to persons with FASD are eligible to apply. NOFAS and its affiliates meet for an annual Affiliate Summit and collaborate on a broad array of public awareness and support activities. NOFAS is actively seeking to expand to every state in America and to countries around the world. Most of the affiliates started out as small, family-based support groups. All groups have since received their tax-exempt non-profit status.

BENEFITS OF AFFILIATING WITH NOFAS

- Free or discounted materials
- Free or discounted attendance to NOFAS events and activities, including conferences, benefits and briefings
- Technical Assistance consisting of both strategic advice and sample materials on topics such as developing a logic model (goal, objectives, outcomes), securing non-profit status, grassroots advocacy, fundraising and proposal development, public awareness strategies, materials and website development, nonprofit governance and administration, etc.
- Participation in the annual affiliates summit
- Free monthly newsletter and legislative/policy report
- Notification of grant opportunities
- Promotion of your organization and programs
- Featured on NOFAS website, annual report and other organizational materials
- Vote on annual NOFAS honorees
- Members only website featuring affiliate materials
- Opportunity to serve on the NOFAS board of directors
- Enhanced visibility
NOFAS AFFILIATES

NOFAS Alaska
Deb Evesen-Hill, Director
(907) 235-2544
http://www.fasalaska.com
deevesen@alaska.net

California Fetal Alcohol Spectrum Organization (CalFAS)
Amber Kesterson, President
(530)458-2782
http://www.calfas.org
akesterson@calfas.org

NOFAS Connecticut
Stefany Saccente, President
(860)942-4507
http://groups.yahoo.com/group/connfas/
stefany_s_2000@yahoo.com
nofasct@yahoo.com

NOFAS Illinois
Trinity Services Inc.
Kim Shontz, Deputy Director
(815) 485-6197
http://www.trinity-services.org/
kshontz@trinity-services

Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
Joyce Holl, MAPA, Executive Director
(612) 917-2370
http://www.mofas.org
joyce@mofas.org

NOFAS New Jersey
University of Medicine & Dentistry of New Jersey /NJMS
Dr. Susan Adubato
(973) 972-7717
http://www.fasnj.org
adubatsu@umdnj.org

NOFAS New York City
The Fetal Alcohol Syndrome Support Network of NYC & Long Island, Inc.
Susan Rose, President
(718) 279-1173
(718) 886-4076
smrose49@aol.com

NOFAS Upstate New York
National Council on Alcoholism and Drug Dependence - Rochester Area
Depaul Addiction Services
Jennifer Faringer, Director, NCADD-RA
(585) 423-9490
http://www.nydas.org/ncadd.htm
jfairinger@depaul.org

NOFAS North Carolina
Fullerton Genetics Center
Leslie Evans, Genetics Education Coordinator
(828) 213-0022
http://missionhospitals.org/genetics.htm
cgclee@msj.org

NOFAS Ohio
Double ARC
Sr. Linda Falquette, Executive Director
(419) 479-3060
www.doublearc.org
lfalquette@toledosnd.org

NOFAS Oregon
FASCETS Inc. (FAS Consultation, Education and Training Services)
Diane Malbin, Executive Director
(503) 621-1271
http://www.fascets.org
dmalbin@fascets.or

NOFAS South Dakota
Fetal Alcohol Spectrum Disorders Institute, Center for Disabilities
The University of South Dakota School of Medicine and Health Sciences
Judy Struck, Executive Director
(605) 357-1439 or 1-800-658-3080 (Voice/TTY)
http://www.usd.edu/cd/nofassd/
homepage.cfm
jstruck@usd.edu

NOFAS Washington
206-940-2832
Julie Gelo, Executive Director
http://www.nofaswa.org/
FASDSupport@aol.com

NOFAS UK
Susan Fleisher, Executive Director
http://www.nofas-uk.org
susan@midatlantic.co.uk
FOUR CONNECTICUT WOMEN BECOME A NOFAS AFFILIATE AND SECURE THEIR 501(c)(3) IN RECORD TIME

By Cindy Farrow, Prevention Program Coordinator, NOFAS CT

NOFAS Connecticut started two years ago as a group of four adoptive moms determined to increase awareness about Fetal Alcohol Spectrum Disorders in their state. While it sounds overwhelming, the process was actually pretty straightforward. Our first step was to contact NOFAS and apply to become an affiliate member of their program. Using their template, we drafted our bylaws and submitted our application. After acceptance into the affiliate program, we went on the state website for starting a non-profit corporation in Connecticut and downloaded the forms off the internet.

In the span of a few hours, the four of us filled out the forms and sent them in. It took roughly 6 weeks before we became officially “incorporated.” Next we applied for our non-profit/tax exempt status by going on the IRS website and downloading the forms to become a 501(c)(3) non-profit organization. The four of us again met, and spent a total of about 8 hours filling out the application, creating a projected budget and completing the required forms. Nine weeks later, we were an officially recognized 501(c)(3) organization.

We are now in the process of filling out our tax exempt forms for the State of Connecticut to be exempt from paying state sales tax. These forms were also accessed via the Internet, and have not been difficult to complete. This process has cost us $500 thus far. In less than one year, a “group of four moms” grew to an organized non-profit, and a NOFAS affiliate. Not bad!
OBJECTIVES:

- Understand the role of coalitions
- Learn how to request inclusion of FASD on the agendas of existing substance abuse and birth defects coalitions
- Learn the basic steps to create an FASD community coalition
- Learn about creative and effective FASD activities for community coalitions
- Learn about funding resources
- Understand cultural diversity in communities
WHAT IS A COALITION?

A coalition is simply a group of people or organizations that join forces in pursuit of a common goal. Coalitions come in every size and type. They are often comprised of many different types of people and groups, such as local government health department officials, consumer representatives, and national organizations. The composition is irrelevant. The bottom line is that a coalition with defined and consistent objectives will be more effective than a single person or a single organization.

THE ROLE OF COMMUNITY COALITIONS

A community coalition describes a group of community agencies and organizations that work together in order to achieve a shared goal. These groups are invaluable, not only because they bring people and resources together, but because they motivate others to take action. Coalitions allow individuals and groups to contribute their own unique perspectives to address the needs of the entire community. They help to identify community concerns, work together to address problems that arise, and increase productivity and impact through shared responsibility (Advocates for Youth, 1996).

Every community has people or groups already working to contribute to the health and well being of its members. There are a variety of public, private, and civic organizations that can inform, persuade, and mobilize the community that they serve. Many organizations focus on public education to increase awareness about a particular issue and to establish community consensus about supporting prevention and intervention activities.

WORKING WITH EXISTING COALITIONS

Coalitions can be very effective agents of change. However, they can also require a great deal of time, energy, and resources to develop. Therefore, it may be best to tap into existing coalitions with similar missions and objectives—for example, those dedicated to substance abuse prevention and treatment.

The Drug Free Communities (DFC) program provides grants to improve community efforts, and to plan, promote and deliver effective substance abuse prevention strategies. There are over 700 active DFC coalitions across the country. Find DFC Coalitions in your State at: http://drugfreecommunities.samhsa.gov/
PROS AND CONS OF WORKING WITHIN EXISTING COALITIONS

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<td>‣ Have collective experience. Bring knowledge to the table (e.g., relationships with community organizations, lessons learned)</td>
<td>‣ May not be sufficiently interested in taking on the issue of FASD or may have competing priorities</td>
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<tr>
<td>‣ May have already received funding</td>
<td>‣ Offers less influence in selecting members and planning activities</td>
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<td>‣ May include members able to integrate FASD into their everyday work (e.g., social workers, educators, addictions counselors)</td>
<td>‣ May have expectations for members to bring specific skills or resources</td>
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<td></td>
<td>‣ May bring “baggage” of past history (e.g., conflicts between members)</td>
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JOINING AN EXISTING COALITION

All coalitions are different, so there are no clear and fast rules when requesting to join one that already exists. After you are sure the mission and objectives of the coalition are in keeping with your own, contact the appropriate staff person to get information on becoming a member. If no such individual exists, you should contact the lead individual or organization that facilitates the coalition’s membership to request information on how to participate. There may be a cost associated with this, so make sure to ask how much you will have to contribute, if any, in the form of new member dues. Make sure to be receptive to the entire purpose of that coalition so that members do not feel you are trying to take it over, yet be creative enough to integrate your priorities into theirs.

If you are part of a new or existing non-profit organization you can expand your reach by becoming part of an existing coalition. Many coalitions encourage consumer membership. As a family member or caregiver of someone with FASD, you may qualify.

STARTING YOUR OWN FASD COALITION

It is challenging enough to create and maintain your own non-profit organization. As your organization achieves stability your next step may be to start your own coalition. The steps for establishing a community coalition are:

STEP 1: ESTABLISH THE AGENDA
- Define the purpose, potential members and structure
- Establish a few concrete and specific goals
STEP 2: INVOLVE OTHERS

- Begin with a core group of people with experiences and interests in the subject
- Identify groups with whom you have existing relationships
- Identify prospective coalition members already involved in related issues (e.g. March of Dimes, Planned Parenthood)
- Identify organizations that serve your target group
- Recruit community-based organizations

POTENTIAL TARGETS

- Top-level community members that influence the public and increase program credibility
- Neighborhood leaders
- Key health leaders
- Leaders of the most influential organizations or companies
- Leaders of factions and those who act as “go-betweens” or links to several groups
- Leaders of the target population (e.g. Opinion leaders representing women’s or children’s groups)
- Specialists with skills and knowledge relevant to the goals of the program
- Officials who control or support health programs (e.g. Mayor, health director, commissioner)

Do your homework. Know and understand the people you work with (professional background, personal connection to the issue). Know your community—pay attention to the populations represented in your area, what people do in their free time, organizations that work there, and other “market research” that will help guide your activities (CDC, 1998).

STEP 3: HOLD FIRST MEETING

This is the most crucial meeting because it sets the tone for the coalition and establishes a model for the meetings to follow. Participants should leave the meeting:

- understanding the key issues to be addressed and the coalition's goals;
- aware of the potential to address those issues;
- believing that the work of the coalition should be a priority for their organization and for the community;
- understanding what each member (and their respective organization) can or cannot contribute to the work of the coalition;
- feeling that the coalition is well organized.
REACH OUT TO OTHER FASD INITIATIVES IN YOUR COMMUNITY

The field of FASD has developed significantly in the last few years. For example, there are now official FASD Coordinators in 14 States (see listing in Resources Section, pages 84-85).

SAMHSA's State, community, and criminal justice FASD initiatives. In 2004, 10 state, 20 community, and 5 criminal justice subcontracts were funded through SAMHSA's FASD Center for Excellence. All require consumer (e.g., persons with FASD and/or their caregivers, persons in recovery) participation in their planning committees. You may contact them and offer to participate in their efforts. Search these programs at: http://www.fasdcenter.com/initiatives/index.cfm

NOFAS Affiliates Program was established in 2002 to develop formal affiliations with parent and professional groups working in the FASD field. The network is open to all nonprofit organizations that work to prevent, identify, and support FASD through outreach and education. See http://www.nofas.org/about/affiliate.aspx for more information.

FASD ACTIVITIES FOR COMMUNITY COALITIONS

There are many things you can do to raise awareness about FASD. NOFAS recommends the following:

- Center your activities to coincide with nationally recognized commemorative days or events relevant to FASD. Try to “piggy back” on these events by adapting your messages to complement existing FASD activities.
Contact organizers of professional meetings. Propose that sessions on FASD be included in local, regional, and/or national meetings of professionals. Relevant professionals include persons working in public health, substance abuse, mental health, corrections, education, child welfare, etc. Identify upcoming meetings with sufficient lead time to get included in the agenda (usually 6-9 months before the event).

Have a professional FASD trainer/speaker participate in your presentations.

REQUEST PROFESSIONAL FASD TRAINERS/SPEAKERS AT:

- NOFAS (800)66-NOFAS http://www.nofas.org
- The FASD Center for Excellence (877)STOPFAS http://www.fasdcenter.samhsa.gov/

Contact your state’s professional licensing boards to request that questions on FASD be included on their exams for select groups of professionals (e.g., physicians, addiction counselors, teachers, social workers, etc). You can usually find these listed in the Yellow Pages.

Don’t be shy. Many of the websites for the events listed above contain contact information for the organizers. Feel free to contact government officials or other organizers of these events to request inclusion of FASD. If you cannot get FASD included this year you may be able to plant the seed for inclusion in the following year.
- **Contact universities, hospitals, federal employers, schools, churches, corporations** to get dates of upcoming conferences or meetings.

- **Set up FASD information exhibits in public places**, such as parks, health fairs, state capital buildings, and shopping malls. Put together information packets, including brochures, fact sheets, posters, current articles, lists of organizations working on the issue, and alcohol use screening tools. If possible, set up a television or laptop computer and play videos/DVDs on FASD.

Free materials such as posters, fact sheets, video’s, brochures etc. are available through NOFAS at [http://www.nofas.org](http://www.nofas.org) and the FASD Center for Excellence at [http://www.fasdcenter.samhsa.gov/](http://www.fasdcenter.samhsa.gov/).

- **Be prepared for inquiries from women who consumed alcohol during pregnancy.** As you raise awareness of the risks of drinking during pregnancy you may also raise anxiety among women who have used or are currently using alcohol during their pregnancy. Some may ask you about the likely risks of FASD based on their drinking pattern. Unless you have specific training in this area, it is best to leave these answers to professionals. You should recommend that they contact the Organization of Teratology Information Services (OTIS) for information on local medical consultation for prenatal alcohol exposure at 1-866-626-6847 or [http://www.otispregnancy.org](http://www.otispregnancy.org)

- **Post warning signs about risks of drinking during pregnancy** in restaurants, bars, liquor stores and any other places where alcoholic beverages are sold—with permission of course! Tape them on the back of doors in restrooms where the message will definitely be read. You may also post information at grocery stores, bus stops, schools, beauty salons, health clinics, etc.

  Twenty-two states currently have laws on mandatory warnings about drinking during pregnancy at select locations. You may wish to use or adapt the content, language, or presentation used by these states. See:


  - **The FASD Center for Excellence** website section on signage laws at:  [http://www.fasdcenter.samhsa.gov/publications/specialreport.cfm](http://www.fasdcenter.samhsa.gov/publications/specialreport.cfm)

- **Petition to the State Birth Defects Registries for increasing the cutoff point for age of FASD diagnosis.** Currently, more than two-thirds of the states do not record cases of FAS diagnosed beyond the age of 2, well before the average age of diagnosis in the early school years. This contributes to prevalence rates that are far below the national estimates of the CDC.
Enlist the help of volunteers from local organizations, after school programs and student leadership groups, scout organizations, church youth groups, and fraternities and sororities to distribute FASD materials in town and around campuses. Many high schools require that their students perform community service hours for graduation. You may wish to contact the principals or guidance counselors at your local school to inquire about their community service programs.

Conduct opinion polls among your community members on FASD and submit results to local media.

The FAS Knowledge, Attitudes, Beliefs & Behaviors (KABB) Survey has been developed and utilized by the Alaska Department of Health & Social Services, Office of FAS throughout the state among nine targeted audiences: the general public, family physicians, obstetricians/gynecologists, pediatricians, public health nurses, corrections personnel, educators, substance abuse counselors, and social workers. To order a copy, contact the Alaska Office of FAS toll free at: 877-393-2287 or email: fas@health.state.ak.us.

Plan an FASD Town Hall Meeting in your area.

An on-line brochure to help you organize a town hall meeting is available at: http://www.fasdcenter.samhsa.gov/documents/fasd_brochure_final.pdf

A Report on FASD Town Hall Meetings across the country is available at: http://www.fasdcenter.samhsa.gov/initiatives/townhomemeetings.cfm

Conduct outreach to agencies related to substance abuse, maternal child health, adoption, foster care and developmental disabilities by requesting that their websites link to NOFAS and to your local FASD organization’s websites. You may utilize student volunteers to search leading websites for inclusion of FASD information and links to NOFAS or other FASD sites.

HOW TO OBTAIN FUNDING FOR YOUR COALITION

Unfortunately, getting money usually costs money. After all, your time is money. Developing funding applications can be a very time consuming and expensive process. Fortunately, there are a few resources that can help. Not all are free but they may be very cost effective. When developing your fundraising strategy always begin by seeking money from companies, associations, foundations and individuals in your community.

While the resources listed below are most commonly used by organizations with extensive track records providing services in their community, it is worthwhile to become familiar with the tools of the trade. As your coalition develops and grows, you will want to become prepared to compete for resources in the future.
STEP 1: THINK BIG
FASD is not just about alcohol use during pregnancy. It is connected to multiple social problems and behavioral health issues—violence, mental illness, school failure, teen pregnancy, etc.

Sign up with Join Together. Join Together Online (JTO) supports people working on substance abuse and related issues with free, up to date information on key issues, trends in the field, and funding resources: http://www.jointogether.org/home

STEP 2: DEVELOP A BUDGET
List all your anticipated expenses (e.g. salaries, research and evaluation, program planning, materials development, media outreach, partnership building, temporary help, phones, rent, postage/distribution, duplication, local and long distance travel etc.). Be sure to also include potential funding sources (e.g., in-kind donations, corporate funding, donated media airtime, discounted ad placement, and coalition partners printing/distributing materials).

STEP 3: UTILIZE DEVELOPMENT RESOURCES
A comprehensive development source will have information on a range of funding opportunities and grantmaking resources such as tips for writing proposals. If you are applying for funding for the very first time, it is usually best to start by seeking small grants (i.e. under $10,000).

The Foundation Center. With monthly or annual subscription options (ranging from $95 to $995 per year), the Foundation Directory Online Subscription Service allows you to search databases of up to 80,000 grant makers and more than half a million grants at: http://fconline.fdncenter.org

You may also visit the Center free of charge in any of their locations around the country, as well as any cooperating collection location, listed on their web site: www.fdncenter.org/collections.

STEP 4: LEARN FROM OTHERS
Viewing successful proposals provide a wealth of useful information, examples, and insights such as: effective grant proposal writing, models for designing cutting-edge programs, examples of today’s best practices in the field, evaluation methods and illustrations of how to construct a program budget.

The Grantsmanship Center (TGCI) offers many services and products, including recently funded, top-ranked grant proposals in a wide variety of subject areas. Costs range from $29 for a single proposal to $99 for a CD containing 10 to 15 proposals. See: http://www.tgcigrantproposals.com
STEP 5: APPLY FOR NON-PROFIT STATUS
Apply for non-profit status 501(c)(3) status if you do not already have it.


STEP 6: APPLY FOR WORKPLACE GIVING CAMPAIGNS
Employee giving campaigns exist at the federal, state, and corporate levels. These are programs that allow employees to allocate pretax dollars to charities of their choice. Most government campaigns offer employees a list of prescreened eligible charities, while most corporations allow contributions to any charity that has achieved nonprofit status. Some corporations match contributions made by their employees.

The Federal Government’s Combined Federal Campaign Fund (CFC) is the largest workplace giving program. Find the CFC program operating in your area to apply at: http://www.opm.gov/cfc/Search/Locator.asp

STEP 7: IDENTIFY A COMMUNITY FOUNDATION
Nearly 700 community foundations exist across the country. These foundations support a wide array of social and educational areas. Schedule an appointment with a program officer in your community to discuss grant opportunities.

The Council on Foundations has a comprehensive list of community foundations around the country with contact information. Please see: http://www.cof.org/locator

STEP 8: SHARE THE WORK
Share work load with other organizations to reduce costs. NOFAS and its affiliates usually help each other with tasks and specific projects. For more information on the NOFAS Affiliate Program, please see Section 4, Building FASD Networks by Starting a Non-Profit Organization, pages 25 - 27.

RESPECTING CULTURAL AND COMMUNITY DIFFERENCES

Communities and cultures are different across the world and even within most large cities. They possess different racial, religious, and ethnic backgrounds, and have different ideals and experiences. It is important to understand and respect this diversity for your efforts to be successful.

Strategies for Respecting Cultural and Community Differences:

- **Keep an open mind.** Remember that other individuals may express beliefs that conflict with or challenge your own belief system.

- **Avoid generalizations.** It is also important to understand that each individual may
possess some beliefs that vary from the particular religious or cultural group that they belong to.

- **Pick appropriate venues for conducting your outreach efforts.** For example, if attempting to reach the Hispanic community, hold a health fair in the local barrio where the majority of the population is Latino.

- **Locate presenters, physicians, social workers, etc. that are from the same cultural group** that you are trying to reach. The message will be more effective because this individual is more culturally aware of their local customs and will be better received by the audience (Bridges, 2000).

- **Be culturally sensitive to the types of materials used during activities.** The information given should be consistent with the audience’s spoken language and education level, and materials should be specific to that group whenever possible (Frumin, 1996).

- **Encourage individuals of different ethnic backgrounds to join your coalition.** They will be able to provide insight and suggestions for reaching different populations in your community.

- **Locate a spokesperson to** represent your coalition in the public eye who comes from a background similar to those you are hoping to reach.

- **Conduct a needs assessment** to fully understand the range of needs in your community. Pay special attention to how alcohol consumption is viewed culturally.

- **Look for other organizations in your area that work with the specific group you would like to target.** They should have information available about what works and what doesn’t when addressing different populations.

- **Develop visual formats for relaying information** (ex. Comic books, photo-novellas) are excellent methods to reach people of varying literacy levels and ages (Frumin, 1996). March of Dimes provides several examples of folic acid related fotonovelas and comic books on their Spanish website: [http://www.nacersano.org/acido_folico/9177.asp](http://www.nacersano.org/acido_folico/9177.asp)

- **Review different media channels that serve the specific audiences you would like to reach.** You can learn a lot about different cultures and traditions just by paying attention to the TV shows, radio advertisements, magazines, news sources, etc. that target different populations.
## FASD Resources for Specific Populations

| Spanish speaking | Centers for Disease Control and Prevention (CDC) website in Spanish  
http://www.cdc.gov/ncbddd/Spanish/fas/default.htm |
|------------------|--------------------------------------------------------------------------------------------------|
| Spanish speaking | Little Heroes Comic Books and Parent’s Guide  
http://www.childstudy.org/nti.cgi/lh-101.html |
| Spanish speaking | March of Dimes website  
http://www.nacersano.org/centro/9388_9936.asp |
| Spanish speaking | Medline Plus, National Institutes of Health and the National Library of Medicine Website  
| African Americans and Spanish speaking | Centers for Disease Control and Prevention Learn about the CDC’s targeted media campaigns to enhance current prevention efforts related to fetal alcohol syndrome (FAS).  
http://www.cdc.gov/ncbddd/fas/pubawareness.htm#stlouis |
| African Americans and Spanish speaking | National Organization on Fetal Alcohol Syndrome (NOFAS) 1-800-66-NOFAS, Provides brochures, fact sheets, post cards, posters, parent handbooks and radio and television public service announcements  
http://www.nofas.org |
| Native Americans | *A Practical Native American Guide For Professionals Working With Children, Adolescents, and Adults With Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder* by Robin A LaDue, PhD.  
http://www.nau.edu/ihd/airrtc/R_54/native.html |
| Native Americans | *Twice Toad Tales: Stories of Fetal Alcohol Syndrome* by Robin A LaDue, PhD.  
http://www.nau.edu/ihd/airrtc/R_54/native.html |

## Resources for FASD Coalitions:

**The Community Tool Box.** Promotes community health and development by connecting people, ideas and resources.  
See: http://ctb.ku.edu/index.jsp

**National Association of County and City Health Officials.** Provides access to community mobilization tools.  
See: http://www.naccho.org/index.cfm

**Yellow Pages for Kids with Disabilities.** Provides reliable information and support for each state including resources, government programs, grassroots organizations, and parent support groups.  
See: http://www.yellowpagesforkids.com/
MOTHERS DECIDE TO ADDRESS FASD IN CALIFORNIA

By Eva Carner,
CALFAS Board of Directors

Inspired by her attendance at the 2003 Building State Systems meeting sponsored by the SAMHSA’s FASD Center for Excellence, our founder Diane Kerchner of San Dimas returned determined to join with families throughout the state of California and form a grassroots organization devoted to preventing Fetal Alcohol Spectrum Disorders and assisting those affected. Together with me, Eva Carner of Murrieta, and also Amber Kesterson of Sutter, we three “just moms” formed the California Fetal Alcohol Spectrum Organization or CalFAS in June 2003. We were thrilled when a request to NOFAS to become the California state affiliate was accepted. CalFAS became the second state organization to join with NOFAS to work towards our common goals.

Although Diane Kerchner left the board in June 2004, CalFAS was strengthened by the addition of Carol Echternach of Irvine in January 2004 and in June 2004 with Peggy Combs of San Diego, a current member of the FASD Center for Excellence Steering Committee.

Projects of CalFAS include a state task force, conferences, workshops, presentations, educational materials and displays, a legislative briefing and visits with legislators, and most importantly providing personal support to people with FASD and their families across the state of California. We have discovered that with a little grease on our elbows and a little determination, a few moms can band together and change the future for all of us!
OBJECTIVES:

- Learn valuable resources and strategies for reaching relevant systems of care
  - EDUCATION
  - LEGAL
  - FOSTER CARE/ADOPTION
  - HEALTH CARE
  - ADDICTION TREATMENT
STRATEGIES FOR REACHING SCHOOL SYSTEMS

For most of you this will be your starting point due to necessity. Parents and caregivers have probably already learned that school systems know very little about FASD and they are not familiar with teaching methods for students with FASD. Before you meet with your child’s teacher and other school officials become familiar with the Individuals with Disabilities Education Act (IDEA). If your child requires special education, in most cases, the school system is required to provide a specialized curriculum appropriate to your child’s age and abilities. The provisions of IDEA recognize that children with disabilities are entitled to the same educational experience as their non-disabled peers. IDEA further recognizes that the expenses associated with providing for the special needs of children with disabilities are a public responsibility. To learn more about IDEA and find out if it is relevant to you contact NOFAS.

When you are ready to begin, here are some ways to approach a school or school system:

- **Begin with one classroom.** If you are a parent, talk with the teacher and offer to coordinate an FASD workshop for the faculty at your child’s school. This typically is quite successful and will get the ball rolling.

- **Schedule a meeting with the school principal.** Include other school administrators and your child’s teacher(s) as well. Ask them the best way to reach the school system on a broader level. With their support, it will be much easier to gain access to the right decision makers in your system. This bottom-up approach will ensure greater buy-in from other schools and administrators and legitimize your efforts.

- **Meet with one of your health teachers.** Their curriculum covers a series of topics (alcohol/drug, human development, sexuality) that allow for FASD inclusion. You will find that most educators welcome guest speakers.

- **Visit your local Office of Safe and Drug Free Schools (SDFS) and meet with the director.** SDFS is a federally funded program developed to support training and technical assistance to promote school safety and reduce youth violence. Training and professional development activities provided by the program typically include: an annual conference for Safe and Drug-Free School coordinators, workshops for school administrators, regional workshops on effective safe and drug-free programs. In
addition, the staff provides support to parent and community organizations requesting presentations on safe school and drug prevention efforts. Many SDFS offices offer summer institute programs as well as a comprehensive lending library that includes substance abuse related materials (videos, training packets and materials). Seek to have a FASD workshop added to SDFS activities and/or set up an exhibit at events and disseminate FASD materials.

The Office of Safe and Drug-Free Schools (OSDFS)
http://www.ed.gov/about/offices/list/osdfs

- Identify local Head Start programs and advocate for including FASD and alcohol information in their programs. Offer to provide a workshop for parents. Ask them to include FASD materials in their mailings.

National Head Start Association
Head Start is a school readiness program that provides comprehensive education, health, nutrition, and parent involvement services to low-income children and their families. http://www.nhsa.org

- Contact the Director of the School Board and offer to be a speaker. They appreciate personal stories and will welcome topics such as FASD. Provide them with brochures (electronic and hard copy), posters and fact sheets (be sure to include brochures in all mailings). Request that school boards adopt FASD curricula in their programs. Offer to provide an FASD presentation and FASD materials at Parent Teachers Association (PTA) meetings.

- Bring FASD materials and curricula with you and come armed with them to all of your visits and meetings. Once the schools see that there ARE materials and you have done the hard part for them, it will be a much easier to convince them to include FASD into their existing curriculum.

National School Boards Association's website provides useful information on how to reach the school board effectively. http://www.nsba.org

- A list of FASD curricula is included in the Resources section on pages 44-45.

Do your homework. Understand laws and school policies and requirements for addressing children with disabilities. See the National Dissemination Center for Children with Disabilities at: http://www.nichcy.org/resources/LAWS2.HTM
RESOURCES FOR SCHOOL SYSTEMS

NOFAS K-12 Fetal Alcohol Spectrum Disorders: Education and Prevention Curriculum includes:

K-2 Storybook and Activities
A 25-minute educational lesson designed to increase young students understanding of people with differences and to increase the students respect for others, regardless of their capabilities or disabilities. The curriculum contains an educational storybook entitled, “Karli and the Star of the Week.”

Grade 3-5 Healthy and Harmful Substances Lesson and Activities
A 45-minute lesson designed to educate students in the third to fifth grades about healthy and harmful substances. The educational activities will enable students to reflect on healthy lifestyle habits, understand the impact of prenatal alcohol exposure on pregnancy, and its effects on the developing brain. The lesson also teaches the importance of respect for others, regardless of individual capabilities or disabilities.

Grade 6-8 FASD Education Brain Model
A 45-minute lesson designed to raise awareness about FASD for students in grades six through eight. The lesson has an emphasis on the importance of avoiding all alcohol use during pregnancy. The educational activities elaborate on the physical effects that alcohol has on the brain through the use of a brain model that allows students to compare a brain prenatally exposed to alcohol and a brain that was not exposed.

Grade 9-12 Law and Order Video
A 45-minute lesson that is designed to raise awareness about FASD among high school students. The lesson gives an overview of FASD followed by a 15-minute excerpt from the television program Law & Order: Special Victims Unit. NOFAS consulted on the story and script for the award winning episode featuring alcohol and pregnancy themes. Students will be prompted to discuss the issues involved with drinking during pregnancy and then analyze the internal and external influences that affect the characters’ choices.

Other Curriculum Available:

Kid Quest, a teaching tool that is an interactive web-based program for elementary school teachers and students. http://www.cdc.gov/ncbddd/kids/kfaspage.htm
**Class Action**, an evidence-based, highly interactive, role-playing, 8-10 week (one 45-minute session per week) classroom curriculum in which high school students research and present arguments in hypothetical legal cases involving underage drinking. Published by Hazelden, an internationally recognized leader in addiction treatment, education, and publishing.
http://www.hazelden.org

**Better Safe Than Sorry: Preventing A Tragedy. A Science & Health Curriculum** from the National Institute on Alcohol Abuse and Alcoholism and the University of North Carolina School of Medicine, Bowles Center For Alcohol Studies. This curriculum is designed for middle and high school students to promote independent evaluation and critical thinking to assess the impact of maternal alcohol use on individuals and society as well as strategies for prevention.

**Fantastic Antone Succeeds! Experiences in Educating Children with Fetal Alcohol Syndrome** by Judith Kleinfeld and Siobhan Wescott, 1993.
www.nofas.org/estore

**CDC Curricula for parents and school staff** available from four websites.
www.cdc.gov/ncbddd/fas/awareness.htm

**Students Taking Academics Responsibly (S.T.A.R.)** A school based program for kids with FASD. NW Regional Educational Laboratory, 2002.
http://www.nwrel.org/nwedu/08-03/calm.asp
Trevor missed 60% of his classroom instructional time in 5th grade due to his inappropriate behavior. His frustrated teachers blamed Trevor. I remember a meeting between the parents, teachers, counselors and administrators, where tempers flared:

- “Nothing works. I have given up trying!”
- “Trevor doesn’t even care!”
- “He acts out for no reason.”
- “His behavior doesn’t make any sense.”
- “What is going on at home that he acts this way?”
- “I don’t think Trevor can be educated in the public school system.”
- “I thought I was a good teacher, but after this year I want to quit.”

In a heart-to-heart conversation with his tearful parents after the meeting, I learned that Trevor had just been diagnosed with a FASD. Diagnosis opened the door to understanding and the path to success with this very challenging student. As both parents and teachers learned and understood how the brain works differently in individuals with FASD, they tried new approaches. Trevor blossomed.

Years later when Trevor ran for student body class president, he walked up on the stage and flawlessly delivered a speech he had written himself. At the completion of his speech, the entire student-body and faculty rose to their feet in a unanimous standing ovation. One of the teachers turned to her friend and said, “This may be the biggest moment of my entire teaching career.”

Learning about FASD will make your job and life easier. As human beings who care about each other, we can deal with anything if we just understand it. Working together we can and are making a difference!
STRATEGIES FOR REACHING THE JUSTICE SYSTEM

- Contact State Bar Associations and request to present a FASD training as part of their mandatory continuing legal education requirement programs. Currently forty states have mandatory continuing legal education requirements. Even in states without them, certain divisions of local courts have continuing legal education requirements for court appointed practitioners (e.g., public defenders). Most states also have voluntary bar associations based on practice areas. Voluntary association practice areas that are relevant to FASD are child abuse and neglect, juvenile justice, and criminal law, among others.

  Search for your state bar associations at:

- Locate your state contacts from the Office of Juvenile Justice and Delinquency Program (OJJDP). An office within the US Department of Justice, OJJDP supports states, local communities, and tribal jurisdictions in their efforts to develop and implement effective programs for juveniles. Offer to arrange a FASD in-service or workshop.

  Find State juvenile justice contacts at:
  http://ojjdp.ncjrs.org/statecontacts/resourcelist.asp

  Locate FASD Juvenile Court Initiatives in your area at:
  http://www.fasdcenter.com/juvcourt/index.cfm

- Contact drug court professionals and inquire about potential opportunities to conduct FASD training. While drug courts deal with illicit substances, most drug users who would be charged in drug courts are also likely to abuse alcohol.

  The National Association of Drug Court Professionals (NADCP) seeks to reduce substance abuse, crime and recidivism through drug courts and providing for collection and dissemination of information, technical assistance, and mutual support to association members. See: http://www.nadcp.org/about/
MEDICAL INFORMATION CARD HOPED TO ALLEVIATE MISCONCEPTIONS OF FASD AMONG LAW ENFORCEMENT

Kathryn Ann Kelly, University of Washington, Fetal Alcohol and Drug Unit

In 1996, at Dr. Ann Streissguth’s Secondary Disability Conference in Seattle, Washington, Eric Schnapper of the University of Washington School of Law and I, then a mitigation specialist at the Office of the Federal Public Defender in Los Angeles, invited conference participants interested in legal issues associated with FASD, to meet on the auditorium stage over the lunch hour. To our great surprise, the stage was filled with more than forty people, including Michael Dorris, Julianne Conroy of the University of British Columbia, and her co-author of FAS and the Criminal Justice System, Diane Fast, parents Vicky McKinney, Marcie Ten Eyck, and Jim Fox, Audrey Salalub of the Asante FAS Diagnostic Clinic in British Columbia, and many others. We were astonished by the diverse FASD legal issues with which these families and professionals were dealing.

One of the most significant issues raised was the concern over what took place when individuals with FASD came into contact with the police. If interviewed by police without a parent, advocate or attorney, individuals with FASD often admitted to offenses they had not committed, offenses for which others were primarily responsible, or offenses that had not even occurred. These families were searching for a way to prevent such unguarded and unreliable interviews from occurring. They were at their wit’s end.

When we later set up the FAS/FAE Legal Issues Resource Center, one of the first things we attempted to do was to find a practical solution to this problem. My colleague at the University of Washington Fetal Alcohol and Drug Unit, Dr. Kieran O’Malley, gave us a card that he, together with a parent of a patient with FASD, had developed for the young man to show to strangers. The card stated that the young man had FASD, and asked that his mother be contacted regarding medical, financial or legal issues.
It occurred to us that a new card could be developed specifically to address the particular legal issues that arise under American law when an individual is dealing with the police. The card—“Medical Information for the Police”—notifies the police that the individual is not competent to waive his or her legal rights, and that any interview should not be conducted until police have first notified the parents of or an advocate for the individual. We put a downloadable copy of the card on our Web site, together with suggestions for its use. NOFAS did the same. We hope this response to the heartfelt concerns of many parents and professionals proves helpful.

Front of Card:

MEDICAL INFORMATION FOR POLICE

I have the birth defect Fetal Alcohol Syndrome/Fetal Alcohol Effects, which causes brain damage. If I need assistance, or if you need my cooperation, you should contact the person listed on the back of this card.

Because of this birth defect, I do not understand abstract concepts like legal rights. I could be persuaded to admit to acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my Miranda rights.

Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting with an attorney. I do not consent to any search of my person or property.

Back of Card:

For information or assistance regarding:

Please contact:

Doctor or diagnostician:
RESOURCES FOR THE JUSTICE SYSTEM

FAS/FAE Legal Issues Resource Center’s Website: Includes articles on legal issues confronted by individuals with FASD.
http://depts.washington.edu/fadu/legalissuesfaslaw.html

Tools for Success: Working with Youth with Fetal Alcohol Syndrome and Effects in the Juvenile Justice System prepared by the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
http://www.mofas.org/tools_for_success.htm

FAS Community Resource Center Links to documents that are helpful to parents, lawyers, probation officers, and judges to be shared with court system professionals.
http://come-over.to/FAS/Court/

Curriculum developed by National Indian Justice Center
http://www.nijc.org/FAS.htm
STRATEGIES FOR REACHING FOSTER CARE/ADOPTION

Surprisingly, FASD may not be well received as a topic for discussion in foster care and adoption agencies. Many agencies fear that admitting the possibility of FASD may deter parents or families from wanting to foster or adopt children. Often, there is a lack of education surrounding the impact and permanency of FASD in these systems, which may create a notion that a “loving environment” given by a foster or adoptive family will help to address and “cure” developmental delays or other issues in affected children. It is important to keep this in mind when approaching these systems. After all, their motives are great! They simply want to place children in loving homes. This is why educating these agencies is so important. Through FASD education, we can reduce the stigma and the fears that are associated with raising a child with FASD.

- Contact foster care and adoption agencies and inquire how they are addressing the issue of FASD. Parents are required to attend educational sessions. Offer to present one of the sessions or locate an FASD speaker. Deliver materials to the agencies and ask them about their needs. You may be more successful in getting them to include FASD if it is done in a way that is not threatening, such as by focusing on successful strategies for helping someone with FASD reach their potential.

- Provide foster and adoption agencies with referral information to knowledgeable physicians in their area for available FASD diagnostic and therapeutic services.

  The National Adoption Information Clearinghouse offers a comprehensive directory. Select your state to identify all agencies, specialists, and adoption information sources in the area at:
  http://naic.acf.hhs.gov/database/nadd/naddsearch.cfm or call toll free 888-251-0075.

  The NOFAS website provides a National and State Resource Directory of physicians familiar with FASD: wwwnofas.org/resource/directory.aspx

  The National Adoption Information Clearinghouse provides a list of medical doctors across the nation available to conduct a developmental evaluation of internationally adopted children upon their arrival in the United States at:
  http://naic.acf.hhs.gov/pubs/r_devev.cfm

- Meet with agencies involved in international adoptions about local diagnostic clinics for FASD.
JOYS AND REALITIES OF MOTHERHOOD
by Julie Gelo,
Foster & Adoptive Parent
of 7 children with FASD

The last 13 years have been the most challenging, frustrating, difficult, painful, discouraging, heartbreaking, heart wrenching years of my life. Not because of the children but rather from the interactions with the systems of care and agencies whose lives my children touch. Our children have given us more joy and unconditional love than we have ever experienced in our lives. Out of need and necessity I have learned about Special Education, the IDEA, the ADA and 504 accommodation plans, adoption support, the state laws around foster care and adoption. I have also learned about tribal governments, the Indian Child Welfare Act, Special Olympics, the Multi-Ethnic Placement Act, cultural sensitivity and relevancy, grief and loss, the essential connections of human beings, and the importance of self-esteem.

My children have taught me about modifications of the environment, natural and logical consequences, reflective listening, I-messages, social communication, sensory integration, and effective questioning, and less about time outs. I have learned about termination of parental rights, open adoption, and the court process. I have seen the possibilities of birth families and adoptive families working together for the children and the blending and merging of those two units when safe and appropriate. My daughter Faith was diagnosed at the age of 25 with FAS and I had to accept the truth of being a birth Mom as well as a Foster/Adoptive Mom of children with FASD. Through all this I have been given the opportunity to be part of the lives of wonderful children who are upstanding citizens and contributing members to society and who fill my life with joy.
RESOURCES FOR THE FOSTER CARE/ADOPTION SYSTEM


National Resource Center for Special Needs Adoption
http://www.nrcadoption.org/index.htm

Families for Russian and Ukrainian Adoption
http://www.frua.org/index.html

Foster Parent Network http://www.fosterparentnet.org/

AdoptFASD2 Mail List This group supports people who have adopted children with FASD
http://groups.yahoo.com/group/AdoptFASD2/
Healthcare professionals are a key target audience for FASD awareness activities. If they have not been educated on FASD in school or in training, it is likely they are not identifying FASD in their patients. If FASD is not identified, it simply does not exist in a community. Maybe even more disturbing are the mixed messages women still receive from their physicians about drinking during pregnancy. Prevention, identification and treatment services can be enhanced through some very simple efforts. FASD awareness efforts need to target both healthcare students and practicing clinicians.

- **Participate in hospital or health department health fairs or alcohol awareness events.** Meet with directors of the health communications and/or public relations offices, and community outreach personnel of local hospitals and clinics. Inquire about possible health fairs or other events where you could exhibit FASD materials with a display booth, or provide FASD materials for dissemination.

- **Organize a Grand Rounds Presentation or FASD in-service for physicians or other health care providers.** Meet with directors of the health education office, or the medical/nursing education department to discuss in-service trainings or Grand Round presentations for physicians and other health care providers. Grand Rounds are scheduled educational sessions provided for physicians in most hospitals. Typically, the medical education department will provide continuing medical education (CME’s). The presenter may be required to be a physician or a licensed professional. In busy hospital units (i.e. Labor and Delivery) they often welcome in-service training on the unit (you must be flexible with their unpredictable schedule). (Sample topics: FASD through the lifespan, the stages of addictive disease, identifying substance abusing women, patient referral for addiction assessments and treatment).

- **Deliver brochures and posters to hospitals, physicians’ offices, Health Maintenance Organizations (HMOs), mobile clinics, family planning clinics and community health clinics.** NOFAS has developed a short FASD “loop” tape that can be featured in the lobby areas of all of these health settings. NOFAS can provide you with free or low-cost posters, brochures, fact sheets or links on where to locate other free FASD materials to disseminate. Offer to provide an in-service training or to speak at other regularly scheduled or planned workshops.

- **Visit with your local Healthy Start Program.** Offer to provide trainings and bring FASD materials to distribute and display. Healthy Start is a free health insurance program for pregnant, uninsured low-income women offering early prenatal care, postpartum care, family planning services, counseling and referrals.
Meet with universities and colleges in your state that offer medical and other allied health programs. Ask them how they are addressing FASD in their coursework. If FASD is not being included as an elective course or integrated within their coursework suggest it as a possibility. Bring literature that supports the importance of FASD education and give examples of universities that are addressing FASD. Contact NOFAS to provide you with listing of schools that offer FASD curriculum and assistance on how to create change in the university setting.

Contact the Dean’s Office of your local medical and allied health programs. Ask them to post messages through the student email list serve about FASD awareness volunteer opportunities. Many medical schools require mandatory participation in community service projects in order to graduate. Students are often looking for meaningful, health related projects in the community such as staffing tables or exhibits at health fairs, and conducting screenings.

Visit with the Executive Director of your State’s Medical Board and discuss ideas for educating physicians on FASD. Ask them to feature FASD in their newsletter or other publication or to include it in planned conferences, and inquire about including FASD fact sheets and brochures in mailings to physicians.

Fact sheet on the limited guidance on abstinence from alcohol during pregnancy in obstetrical textbooks at: http://www.cesar.umd.edu/cesar/cesarfax/vol11/11-38.PDF

Information on schools that have developed medical school curriculum:
CDC Regional Centers for the Education and Training of Medical and Allied Health Students http://www.cdc.gov/ncbdd/fas/regional.htm

Search for medical schools at: http://services.aamc.org/memberlistings/index.cfm

Search for the Healthy Start representative in your State at: http://www.healthystartassoc.org/
Medical school is often compared to running a marathon. What seems like an infinite journey is best handled by clear-headed discipline and focus. However, like a marathon, the greatest challenge is not losing site of the finish line. There is so much to learn that my classmates and I often lose sight of why we entered medical school in the first place: to care for those individuals in need. That is why taking the course, “Fetal Alcohol Syndrome: A Comprehensive View,” sponsored by NOFAS, was a breath of fresh air. The course allowed my classmates and I to look beyond the basic science of FASD and use the bio/pyscho/social model of the disorder to learn about the effects of prenatal alcohol exposure on the individual, the family, the support network, and the nation as a whole. NOFAS empowered us to use our burgeoning knowledge of medicine as advocates, inviting us to participate in Hill Day Activities, and providing us with the resources to educate individuals at Washington DC’s Annual Walker Jones Health Fair. I was so used to feeling overwhelmed by the mountain of details and skills that I have not yet mastered, that I failed to reflect on and use those that I have!

I took my passion for advocacy a step further. NOFAS was kind enough to allow me to complete a summer fellowship as a public health and legislative affairs associate. In this capacity, I used my science foundation to write papers, create educational materials, and advocate on Capitol Hill. Finding a passion for FASD truly helped me gain a tremendous amount of perspective. Remembering the human side of medicine will ultimately make me a better physician and keep me focused on the long road that lies ahead.
EXTRA RESOURCES:


Online Clinic. This site features Dr. Larry Burd’s research and publications on FAS. The site also describes how to refer patients, access seminars, and order FAS related materials. http://www.online-clinic.com/Content/index/articles.asp

Health Professional Students for Substance Abuse Training (HPSSAT). This web site provides health care professionals with information on addiction including, resources on curriculum development, training tools, and educational opportunities. http://www.hpssat.org


NOFAS FASD Loop-tape Video for Waiting Area’s. Ideal for settings such as doctor’s offices, conferences, clinics, health fairs, schools, etc. Available from NOFAS at www.nofas.org/estore. Please specify loop tape when ordering.
STRATEGIES FOR REACHING THE ADDICTION TREATMENT SYSTEM

In order to prevent FASD we must target efforts to the highest risk group for giving birth to children with FASD—women who suffer with addictive diseases. Addiction treatment in most communities is woefully behind in offering education to their clients on FASD. There are several reasons for this. FASD is not typically offered as a topic in most programs that certify or license addiction counselors, and historically FASD educational materials have not been affordable or accessible to treatment centers. Also, many addiction professionals are in recovery from addiction themselves and may have emotional barriers to receiving the information. These are important factors to consider when you are meeting with this system of care.

Contact the addiction treatment facilities in your community. Start by reaching out to the director(s) and the clinical director. Ask to have a time-slot to address the clinical team at their next staff meeting. Share SAMHSA’s, “Recovering Hope” video, the NOFAS fact sheet for addiction treatment, posters and other materials. Be prepared to make your points in 10 minutes, and “close” the talk with a scheduled activity. If they are open to allow you to provide a FASD in-service, include a birth mother to give a personal testimony. NOFAS can assist you in locating an available birth mother from the NOFAS Circle of Hope (see below).

Locate treatment centers in your community at: http://dasis3.samhsa.gov/
You can search for programs that specifically provide services to pregnant/postpartum women at: http://dasis3.samhsa.gov/PrxInput.aspx?detail=1

Recovering Hope: Mothers Speak out About Fetal Alcohol Spectrum Disorders – Video. Features a series of women who tell poignant and memorable stories about alcohol use during pregnancy and its effect on their children. Their experiences are supported by expert clinicians and researchers who talk about disabilities associated with FASD and evaluation and intervention services. Order copies at: http://store.health.org/catalog/ProductDetails.aspx?ProductID=16955.

Circle of Hope. The Circle of Hope (COH) is a confidential network of women who used alcohol during pregnancy and have or may have children with FASD. COH provides mentoring, family support and educational resources for its members and their families. NOFAS can forward your request to locate an available birth mother in your area. http://www.nofas.org/coh
Contact your local Alcohol and Drug Advisory Boards. Many communities have Alcohol and Drug Advisory Boards consisting of appointed representatives from relevant professional groups (e.g., law enforcement, counselors) and community members with a vested interest (e.g., persons in recovery). Advisory Boards elicit input from the community and make policy recommendations to local branches of government. Most Alcohol and Drug Advisory Board meetings are open to the public.

Subscribe to your local Department of Health newsletter. They often provide useful information concerning local programs and activities. You can advertise upcoming FASD trainings or find out about future addiction related conferences to disseminate information.

Contact your State Substance Abuse Agency. Inquire about opportunities to participate in your statewide Substance Abuse Treatment and Prevention (SAPT) Block Grant State Plan.

Locate the Substance Abuse Agency in your state at: http://findtreatment.samhsa.gov/ufds/abusedirectors
FROM VICTIM TO WARRIOR MOM: A FASD PREVENTION MODEL
By Kathleen Tavenner Mitchell, MHS, LCADC
Vice President and National Spokesperson
NOFAS

After completing a series of FASD town hall forums, the meeting planners were surprised that so few birth families came out to share their stories. As a birth mom, I believed that I had the answer. Certainly stigma alone might prevent birth families from public testimony, but I actually believe the more prevalent problem is that birth moms do not know and are not being told that the problems or difficulties that their children are experiencing are related to their alcohol use during pregnancy. Since alcohol dependence is a chronic, progressive condition in some cases we see women giving birth to several children with alcohol-related effects. Their children are not identified with FAS, so the mothers remain ignorant of both the effects of their alcohol consumption on their offspring and the lifelong consequences of those effects. Typically, physicians, therapists, addiction professionals and other health care providers simply address the child’s symptoms and relate them to their environment (which can certainly compound the problem; but is not the cause).

I am a licensed clinical chemical dependency counselor (LCADC), and worked in treatment for many years before becoming a FASD advocate and activist. The way to reach birth moms is to reach the women in addiction treatment. This was the beginning of the birthing process of the NOFAS/SAMHSA, “Hope for Women in Recovery Summits.”

There have been three successful summits thus far, and a Summit Replication Manual is available (contact NOFAS). The Summits were designed to reach two important audiences:

- women in recovery and their counselors
- state policy makers

The two-day summits proved to be a successful way to reach the highest risk women for having children with FASD and the systems of care that serve them. The summit, designed as a community based model, allows for
planning input from a community advisory panel. The summit brought together women from treatment centers, counseling staff, and state policy makers. The women were invited to participate on panels and attend planning sessions. Women had an opportunity to hear from systems of care on how they planned to improve services for their families. Each summit featured a town hall meeting where agency representatives listened to the stories from women and families. All participants learned from each other and were inspired to do a better job with prevention and services for individuals with FASD and their families.

All women in treatment need to learn about FASD, primarily FASD prevention. Women come into treatment and they share their stories. They tell us of the problems they are having with their children. By having counselors able to recognize the signs of FASD they will know to refer the children to screening and assessment. The truly loving thing to do for women with addictions is to educate them on FASD. This not only prevents future exposures but will assist in their children obtaining the services they need. We walk with them through the grief into acceptance. We strengthen their recovery and a “Warrior Mom” is born - a true FASD advocate!

**EXTRA RESOURCES**

NOFAS and SAMHSA’s FASD Center for Excellence curriculum for addictions professionals (coming soon)

NOFAS *Hope for Women in Recovery Summit: Women’s Summit Replication Manual* (coming soon)
SECTION OBJECTIVES:

- Learn about valuable resources and strategies for reaching your community:
  - YOUTH
  - BUSINESS
  - FAITH BASED GROUPS
STRATEGIES FOR REACHING YOUTH

Schools and school systems nationwide should be educating our youth about alcohol and pregnancy by including information in health or science class curricula. Fortunately, education materials have been developed by NOFAS and others for Kindergarten through 12th grades students. Another effective way to reach youth is through peer to peer education. The venues and opportunities to reach youth with information on FASD are limitless. Efforts may require a focus on some of the broader issues of FASD such as underage drinking, binge drinking and alcohol’s effects on the body.

After school programs, student leadership groups, SADD (Students Against Drunk Driving) groups, scout organizations and church youth groups are good sources to recruit interested young people. Many high schools require students to complete community service hours for graduation. Youth groups are often seeking issues to address and will welcome an outside mentor to “guide” a project. FASD is a unique topic and one that will generate enthusiasm.

WHEN TARGETING YOUTH BE SURE TO:

- Include young people in the decision making process and take advantage of their expertise. No one knows youth and how to reach them better than young people themselves.
- Be honest about your expectations and how they can lead and contribute to a project.
- Help build their skills to be more effective and more involved. Provide opportunities for learning about FASD, public speaking, and working with others.
- Offer incentives, awards, and recognition for the work that they do for your organization.
- Schedule meetings at times and locations that are accessible to them.

Developing projects for youth are limitless. Here are a few to get you started:

**Host a teen Town Hall meeting on FASD**

- Identify a school or youth group that may have an interest in focusing on alcohol related issues.
- Develop a “core group” to serve as peer mentors. Work with the group to identify the when, where and how the meeting will be planned.
- Once you have identified the date and location invite VIPs to participate (i.e. local sports figures, musicians, media, radio personalities, politicians, etc.).
› Identify local radio personality to emcee the meeting. Ask the radio station to broadcast live from the meeting. Many stations have promotional vans and will provide free CDs and other giveaways.
› Have students contact local businesses for donations of venue, food and beverages, raffle prizes and other resources needed for meeting.
› Working in small groups allow students to work on various aspects of the meeting such as creating a PowerPoint presentation, play, skit, rap tunes, etc.

› **Start an FASD peer education program.** These are just a few of the many successful peer to peer projects:

**NOFAS Project REaCH**
(Reducing FASD through Education, Advocacy and Community Health) NOFAS educators work with a core group of youth that serve as peer mentors and educators. The youth facilitate teen town meetings, participate in community health fairs, develop skits, presentations, plays, songs, and host art contests and music contests, such as “battle of the bands”, to teach other youth about FASD.

**NineZero Project’s FASTRAC Curriculum**
This training module for use in high schools delivers the message about the potential consequences of drinking during pregnancy. High school upperclassman present the multimedia educational lessons to younger students. [http://www.ninezero.org](http://www.ninezero.org)

**The University of New Mexico, Center for Alcohol, Substance Abuse, and Addictions (CASAA) GRADS (Graduation, Reality and Dual-role Skills)**
GRADS students are trained to develop and make presentations designed to reduce alcohol and substance abuse-related birth defects. [http://www.nmgrads.org](http://www.nmgrads.org)

› **Create a skit, play or song on FASD.** Tie the performance to commemorative events such as alcohol awareness week.

› **Encourage students to write letters to the editor or informational articles to their school newsletters or magazines that interest their age group.**

› **Survey classmates to determine their ideas about drinking and pregnancy or have students survey members of their own communities.** This is a great way to get media interested in the topic of the students’ project, particularly if they can connect it to another related event.
Contact your local movie theatre and ask them to include an FASD-related slide in their pre-movie slide presentation.

NOFAS has a cinema slide on FASD. Please contact NOFAS to receive a copy

Have students contact retail stores, restaurants, nail and hair salons, day spas, liquor stores, etc. to inquire about putting up posters with FASD information.

Select FASD as a topic for health/science project.

Free Posters and other related FASD information are available at:
http://www.nofas.org
http://www.fasdcenter.samhsa.gov/

Hold a poster or art contest. This is not only a fun project for students; it is an easy way to attract media attention to the cause. You'll need to identify the grades and school districts you'll want to target. If you open it to all K-12, you will collect a wonderful spectrum of art and messages!

- A good way to promote the contest is through your school board. The board can contact all of the art teachers in your target districts.
- Invite local community members to serve as judges.
- Host an event and invite local politicians and media to present awards to the winning artists. Contact local businesses to donate scholarships for winning entries. Be sure to obtain releases so that you will have use of the artwork.

Create a public service announcement (PSA) through the media department at your school. Have students meet with television, cable and radio stations to encourage them to run PSAs and broadcast interviews with students working on the issue.

NOFAS has several PSAs. Please contact NOFAS to receive copies. To view the new PSA produced by Women in Film, please visit:

Search through dozens of FASD PSAs at:
http://www.fasdcenter.samhsa.gov/grabgo/publicservice/cfm
Contact your local Girls Scouts Council and request that they consider offering merit badges for conducting FASD activities. The Girl Scout program has greatly expanded from its original mission and now addresses various social issues. Today the Girl Scouts have numerous progressive programs, including those set in prisons, detention centers and public housing projects.

Locate a Girl Scout Council near you at: http://www.girlscouts.org/councilfinder

Use the latest “cool” stuff. These days, plastic commemorative bracelets are a must have item for many kids. Started by cyclist and cancer survivor Lance Armstrong to raise funds for cancer research, the bracelets have been adopted for many other causes, including FASD.

NOFAS Washington State has produced bracelets to create awareness on FASD. To order the NOFAS WA bracelet, please contact http://www.nofaswa.org/

The Nine Zero Campaign was started by high school students to promote abstinence from alcohol during pregnancy. Order your nine zero bracelets at: http://www.ninezero.org/ or Call 888-818-6298.

EXTRA RESOURCES FOR REACHING YOUTH

American Medical Association, Reducing Underage Drinking Through Coalitions

The Cool Spot. Online service of the National Institute on Alcohol Abuse and Alcoholism that is just for teens. Addresses the facts about underage drinking. http://www.thecoolspot.org/

Substance Abuse and Mental Health Service Administration. Website to support parents and other caring adults to promote mental health and prevent the use of alcohol, tobacco, and illegal drugs among 7-18 year olds. http://www.family.samhsa.gov/talk/

FAS Community Resource Center. Provides class presentations, handout ideas, and sample quizzes to help students educate their peers on FASD. http://www.come-over.to/FAS/Classroom5minute.htm

Students Against Destructive Decisions (SADD)
http://www.saddonline.com/
I work as a peer educator on the Navajo Nation. I was trained through the NOFAS REACH project to spread FASD awareness among youth on the Navajo land.

On our reservation there are many who still live the traditional Navajo ways. When educating them on FASD, we use taboos and old teachings that have been told to us from the elders. In our culture, when a woman is pregnant she is to remain in harmony. She cannot tie things such as string, yarn and rope because this can disrupt the development and delivery of the child. She has to have an open mind to all beautiful things and must avoid cutting raw meat and attending certain healing ceremonies or funeral services. It is also said that the way a woman acts when she is pregnant is how her child will act when she or he grows up. Many years ago my grandparents were told if you drink crazy water then you will have a crazy child.

Using the traditional Navajo ways to educate is really important because many peers carry these messages to families and friends. The only way to reach more people is to have others take away and spread the message. A good education is good medicine among families.

Over the past year we did many presentations in my home town, of Kayenta, Arizona, at schools, the Chapter House, and Township meetings. We also presented at summer camps at the Shonto school and other neighboring communities. We have reached over 1,500 students through the REACH project. Through our media outreach we have reached 68,000 listeners on the largest Navajo Nation owned radio station, KTNN.

It is great than we can educate youth about the dangers of drinking during pregnancy and also about waiting, thinking and planning their future before getting pregnant. Alcoholic beverages have recently become illegal on the Navajo Nation. This is a great accomplishment for our people. So, remember, there is no safe amount of alcohol during pregnancy and remember, FAS is 100% preventable.
STRATEGIES FOR REACHING BUSINESS

Local businesses can assist your efforts by providing you with both resources and access to the community. Ask them for both. Whenever you meet with someone from the business community, be sure to ask them for names of individuals (either internal or external) that may have interest in FASD prevention. Be sure to keep a contact list of everyone you meet—you never know when you’ll need a past contact. Networking is the key to successful advocacy. To reach your business community start by visiting the office of economic development and obtain a list of the top 10-20 employers in your community.

- Contact companies that have an Employee Assistance Program (EAP). Most larger companies have EAP’s. The EAP may be in-house or subcontracted to outside agencies. Contact the director of the EAP and inquire about ways to reach employees, management, and other EAPs with FASD information. The following is a list of activities you may want to pursue:

  - Provide FASD presentations (or locale speaker) at a lunchtime “brown bag” session.
  - Inquire about annual health fairs and set up an FASD display table.
  - Provide EAP with FASD materials and ask them to display information in their offices.
  - Attend a local Employee Assistance Practitioners Association (EAPA) meeting and bring FASD materials to disseminate; inquire about getting on the agenda for future meetings to provide FASD trainings.
  - Ask about meeting space if you need a location to hold support group meetings.

Search for EAP service providers in your State at:

- Target smaller local businesses and schedule meetings with owner. Ask them to participate in FASD awareness day or other alcohol related commemorative days or events and include FASD. Be prepared to give them several ideas of how they might consider participating, such as:

  - Providing tables to disseminate materials to employees.
  - Posting FASD messages in rest rooms.
  - Hanging FASD notes on clothing tags (maternity stores).
Post FASD posters in small business establishments, such as:

- Nail Salons
- Cosmetic Shops
- Beauty Salons
- Maternity Stores
- Day Spas
- Childcare facilities
- Clothing, shoe, or jewelry stores

Contact local civic organizations to get their members involved. Civic organizations or clubs host local meetings and welcome guest speakers. Attend a meeting and network with the members. Ask about getting on the agenda and once you get a date come prepared with a “menu” of FASD projects that they may want to take on.

**Kiwanis Clubs** are made up of active or retired business and professional men and women. Kiwanis’ continuing service emphasis is called “Young Children: Priority One,” which focuses on the special needs of children from prenatal development to age five. Search for Kiwanis clubs in your area at: [http://www.kiwanis.org/clubloc/](http://www.kiwanis.org/clubloc/)

Members of a **Rotary club** are part of a diverse group of professional leaders working to address various community service needs and to promote peace and understanding throughout the world. Rotary International has a wide variety of youth outreach programs. [http://www.rotary.org/](http://www.rotary.org/)

**The Lions Club International** has programs that are dedicated to improving the lives of our youth. Contact a club near you to see what types of programs an FASD education program would fit with. [http://www.lionsclubs.org/EN/content/youth_index.shtml](http://www.lionsclubs.org/EN/content/youth_index.shtml)
Contact your local restaurant association and arrange to attend a meeting in your area. Inquire about having alcohol use and pregnancy included in educational objectives for bartenders. Ask them to participate in a Pregnant Pause event (below) or create a special event that addresses alcohol use and pregnancy. Local print or radio station involvement will entice participation. Great ideas include:

- Create table-tents and put out for FASD Awareness Day, Mothers Day, etc.
- Create placemats or napkins with an FASD message.
- Ask bars/restaurants to allow you to post FASD posters, messages in bathroom stalls.

Search for your state restaurant association through the National Restaurant Association’s (NRA) website:
http://www.restaurant.org/states/index.cfm?CFID=17968897&CFTOKEN=93078265

Pregnant Pause Events are “celebrations” that encourage alcohol-serving establishments to offer non-alcoholic drinks in an effort to reduce FASD. Radio, television and print media will often help promote an event like this. Mixologists (bartenders) from local restaurants compete for cash prizes in contests to create the best non-alcoholic drinks. Expectant Moms serve as judges and prizes are awarded to the teams that create the winning drinks.

See how Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) organized a pregnant pause event: http://www.mofas.org/pregnantpause.htm

Also contact the Epilepsy Foundation of New Jersey for additional information about planning a Pregnancy Pause Event http://www.efnj.com/programs/pregnant.shtml (609) 392- 4900 or e-mail: efnj@efnj.com.

Meet with the public relations or community affairs director from local sports clubs. Discuss ways that they may be willing to assist you in your prevention efforts. Among ideas you may want to consider are:

- Have teams show the NOFAS PSA on arena or stadium video screens.
- Have them pay to print cups or napkins with a FASD prevention message.
- Ask them to donate signed balls, shirts, or other giveaways for you to use in youth programs, or to raffle.
- Ask for a commitment from them to send team members to one or more of your community events.
On Thursday, September 9, 2004, DC area Fuddruckers Restaurants celebrated International FASD Awareness Day by donating 15% of their proceeds from the purchases of individuals presenting an FASD Awareness flyer at participating restaurants (see left). NOFAS hosted this charity event at the Fuddruckers Restaurants in Rockville, Maryland, Alexandria, Virginia and the District of Columbia. The money raised was used for FAS prevention and awareness activities.

The goal of the event was to raise awareness about the dangers of alcohol use during pregnancy. To gain visibility, local radio stations promoted the event. NOFAS Staff was on hand to answer FASD-related questions. To encourage participation, NOFAS handed out free gifts to pregnant mothers and provided educational materials to all that attended.

**RESOURCES FOR BUSINESS**

*Life Skills for Vocational Success* is a curriculum that contains training materials in the typical areas of life skill training such as social skills, money management, employability, and health. [http://www.workshopsinc.com/manual/TOC.html](http://www.workshopsinc.com/manual/TOC.html)

*What Works for John’s Employment Program*, by Teresa Kellerman, provides information on job coaches, employment programs, and more. [http://www.come-over.to/FAS/WhatWorksForJohn.htm](http://www.come-over.to/FAS/WhatWorksForJohn.htm)

*The National Small Business Association* has several state affiliates. You can reach your local small business association at: [http://www.nsba.biz/welcome/affiliates/](http://www.nsba.biz/welcome/affiliates/)
My niece, Karli Schrider, is pretty well known in the FAS world. She is a doll and to know her is to love her. Karli was not diagnosed until she was 16 years old. Our family was shocked to discover that she had FAS. After we understood what had caused Karli’s problems I had this internal nudge to make a difference. I own my own business and work lots of hours, but I do allow myself time to enjoy my passion: cycling. One day, while out on a glorious 10 mile ride through the countryside- it came to me – “I would take some time off from work and would ride my bike for Karli. This way I could combine something that I loved doing and help support NOFAS.”

I began my 6 week, 3500 mile journey, across the United States in July 2001 from the coast of Oregon. NOFAS supported my journey by charting my travels across the United States on their website and organizing FAS groups across the country to coordinate events with my stops. The FAS groups held gatherings, prepared media interviews, and had supporters waving flags and greeting me with fruit, Gatorade, hugs and well-wishes! After riding about 110 miles a day I made my arrival on August 4, 2001 at the Atlantic Ocean in Henlopen, Delaware. It was an incredible journey and it gave me the satisfaction of knowing that I had really made a difference. I met incredible people along the way, raised over $20,000 for NOFAS, heightened awareness about the issue through media attention, and got in the best physical shape of my life! This was an incredible life experience and I am grateful to have been able to make the trip!
STRATEGIES FOR REACHING FAITH BASED GROUPS

Many religious and faith based organizations now address community health issues. These issues can include counseling for individuals, couples, and families. Some offer workshops, health fairs, and a variety of other wellness related activities. There are numerous ways to have faith based organizations participate in FASD prevention.

- Stay on top of activities that the faith community conducts in your area. Be aware of any health fairs or other events where FASD information may be disseminated or discussed.
- Offer a workshop on FASD. Include broader issues such as how alcohol use affects families and communities or underage drinking.
- Encourage FASD as an interesting topic for a weekly sermon. See the “Real World FASD Public Awareness in Faith Communities” section for an example.
- Highlight a family in your community living with FASD in the weekly church bulletin.
- Invite a person with FASD or a family affected by FASD to share their experiences.
- Suggest FASD as a topic a youth group can focus on. Assist youth groups to develop and/or stage a play to present for members of your faith based community (i.e. church, synagogue, temple, etc.) The theme may focus around acceptance of individuals with disabilities.

Contact the State of Alaska, Office of Fetal Alcohol Syndrome to order plays about FASD - “Wakanyeja: Children are Sacred” and “Crossing the Street.” http://www.hss.state.ak.us/fas/Resources/lendinglibrary/books.

- Create a mentoring program through the faith community for teenagers. Enlist active members of the congregation to help. Initiate conversations with youth about values and relationships in an informal gathering. Combine your efforts with a local Boys and Girls Club (http://www.bgca.org/) or other youth oriented organizations.
- Recruit volunteers from faith based organizations. Respite Services and Mentoring for individuals about FASD are ways in which you can reach out to members of faith based groups.

Faith in Action, a project of the Robert Wood Johnson Foundation, involves hundreds of programs offering free interfaith volunteer caregiving services nationwide. To find out if free services or volunteer opportunities are available in your area, enter your state or zip code at: http://www.fiavolunteers.org/programs/index.cfm
“Last week a friend gave me a book about a young woman named Liz with fetal alcohol syndrome. Fetal alcohol syndrome is something that happens when a woman drinks during pregnancy, and the developing fetus is affected. As I was reading this book I was reminded of people who have tested my patience as Liz tested her parents. I was also aware that at much lower levels of testing, I am likely to have my patience wear thin. I am likely to want to turn away, or give up. It is easy to lose sight of what might be in someone else, and walk away. And that is where the story hits our lesson from James. James is a very practical book in the Bible that is concerned with how we act. James teaches that faith is shown in who we are in day-to-day life. Liz’s parents saw that something inside of Liz. She came to their home as a baby of five months who was expected to die. She was a screaming tense little bundle who wouldn’t make eye contact and was ready to leave this painful world. She wasn’t gaining weight, and she wasn’t developing. Her little body had enough. But Liz’s parents saw a light inside. And they decided to work toward that light. They saw that God had given Liz some good gifts that could be claimed, and that the light of God in her could save her. Sometimes we don’t notice, or realize, the majesty and mystery of what God has placed right here, right in front of us when we look in the mirror. Right in you and right in me, and right in Liz.”
RESOURCES FOR REACHING FAITH-BASED COMMUNITIES

**Pathways to Prevention:** Guiding Youth to Wise Decisions. A Prevention Guide for Youth Leaders in Faith Communities.  
http://www.mediacampaign.org/faith/preventionguide.pdf

**Core Competencies for Clergy and Other Pastoral Ministers** in Addressing Alcohol and Drug Dependence and the Impact on Family Members.  
http://alt.samhsa.gov/grants/competency/css/menu.htm

**The Faith Partners Journal** is both an instructional guide with practical how-to tips on how congregations can be more effective in the early recognition and treatment of addiction disease.  
http://www.Rushcenter.org

“**Faith Community Involvement in Substance Abuse Prevention**” and “**Leap of Faith: Bringing Faith-Based Programs into Your Community Coalition**” are two videos which highlight the current faith-based and community initiatives movement. To order, call SAMHSA at 1-800-729-6686.
SECTION OBJECTIVES:

- Learn about valuable resources and strategies for reaching the media
STRATEGIES FOR REACHING THE MEDIA

The easiest and fastest way to reach a community with FASD prevention messages is through the media. While planning any effort to prevent FASD, consider how you might attract media attention. Develop relationships with your local newspaper writers and local television broadcasters. Remember that involving VIPs will go a long way to attracting attention and focus to your efforts.

- **Develop a media list and keep it current.** Your media list should include newspapers, magazines, health professional print materials, local radio and TV stations, local cable channels, and public broadcasting stations (CDC 2000).

  - **Use the NOFAS Capwiz site.** Capwiz is a subscription service that NOFAS makes available free of charge to our constituents. It offers direct links to legislative committees at the federal, state, and local levels. It also hosts a large media contact database. See Section 9: Resources, pages 86 - 87 on how to search for media contacts. [http://capwiz.com/nofas/home/](http://capwiz.com/nofas/home/)

  - **You can also create lists by using your local library’s reference books on local and national media.**

- **Contact your state health information officer.** They have established relationships with key media contacts in your state and can help you make these connections.

  - **To find who this person is in your state visit the National Public Health Information Coalition web site at [http://www.nphic.org](http://www.nphic.org) and go to the Membership link to enter your criteria.**

- **After you identify the right contacts, develop a “pitch” or story idea(s) that you think should be covered. Story ideas could be for news, feature or editorial coverage.**

  - **To entice the media, you will need a “pitch”—a current event or personal story. See a sample pitch in Section 9: Resources, page 97.**

- **If you have a community event, develop a press kit and send it to local media.** A press kit contains some or all of the following components:

  - Press release - a brief description of the basic story angle
  - Media alert - who, what, when, where, and why of your event
  - Backgrounder - an overview of the event, campaign or coalition
  - Fact sheet - relates the basic information on FASD, including statistics, etc.
Meet with your local cable and broadcast television and radio stations and ask about available air time to run Public Service Announcements (PSA) on FASD. Most television and radio networks do not charge any fee to air PSAs, however, they may only be willing to run them in late evening or early morning hours. When contacting the stations, try to meet or speak with the community affairs person first. You might have to speak or meet with several people at each station until you find the right person.


See samples of a PSA pitch letter and PSA in Section 9: Resources, pages 97 - 98.

Contact local cable networks and radio stations and suggest FASD as a possible “community spotlight” program. Many local television and radio stations are required to host community service segments that feature non-profit organizations, health issues, and other special interest topics.

Write an Opinion-Editorial (Op-Ed) piece expressing your personal views to your local paper, community newsletter, community talk radio shows or magazines. You will be eligible for free postings if you are a non-profit.

TIPS FOR WORKING WITH THE MEDIA

- **Start with smaller media outlets.** Smaller stations and newspapers are more approachable; larger stations often receive an abundance of requests.

- **Use a personal touch.** Send your information to specific people, not general positions (i.e. editor, health reporter, etc.). Check with reporters to see how they wish to receive press releases and other materials (i.e., by mail, email, or fax). Try to establish an on-going relationship with your contact. Hand delivering is the best way to ensure that your message has been received. Don’t be afraid to follow-up.

- **Keep it simple.** Keep the pitch concise and to the point. Practice it several times first.

- **Use personal stories in the community.** Local stories have more success with reaching producers, reporters, and editors. Personal stories of individuals and/or families living with FASD, birth mothers of persons with FASD, or active community members or health care providers make for good stories. Then connect these stories to the larger problem of FASD in the state or country. For example, use Dr. Larry Burd’s Online FASD Prevalence and Cost Calculator to calculate the estimated number of births affected by alcohol exposure during pregnancy for your state at [http://www.onlineclinic.com/Content/Materials/calculator.asp](http://www.onlineclinic.com/Content/Materials/calculator.asp). Presenting statistics and making the issue relevant to the media outlets, readers, viewers or listeners will make more of an impact.

- **Keep records.** Always keep a log of with whom you speak, how they prefer to be contacted (email, phone, etc.), and when to follow up.

- **Be proactive.** Call the assignment editor a week before an event, the day before the event, and then follow up after the event has taken place.

- **Always ask for donated space or time.** Most media venues have discounts or free airtime for non-profit organizations. If you are organizing any type of community event, enter it in the Calendar of Events section of your local newspaper; it’s free! You can also look into advertising on your community-access television channels. These are cost-effective alternatives to larger media outlets.
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<th>CHARACTERISTICS OF MASS MEDIA CHANNELS</th>
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WASHINGTON – Fetal Alcohol Spectrum Disorders (FASD) took center stage at the Capitol Hill premiere of the Prism Awards with Law and Order: Special Victims Unit winning an award in the category of Drama Series Episode for Television. The award-winning episode, “Choice,” first aired on November 4, 2004. The storyline followed an expectant mother after an attack going from victim to accused when her husband charged that she endangered her child by drinking alcohol excessively.

“We are delighted that the episode of Law and Order: Special Victims Unit highlighting FASD, was chosen as a Prism award winner,” said Tom Donaldson, President of the National Organization on Fetal Alcohol Syndrome. “NOFAS salutes the program and Executive Producer Dr. Neal Baer on this achievement and the Prism Awards for recognizing programming that is not only entertaining, but is also a realistic portrayal of substance abuse and addiction.” The Prism Awards Capitol Hill premiere attracted top policy makers from across Washington and leaders from social and health issue organizations. The awards are presented annually and recognize the accurate depiction of drug, alcohol and tobacco use in entertainment programming. As a result of this episode, millions of people became educated about FASD and thousands visited the NOFAS website for more information.
RESOURCES FOR THE MEDIA

http://www.beststart.org/resources/alc_reduction/keys.pdf

Media Campaign Implementation Kit. Centers for Disease Control and Prevention.
http://www.cdc.gov/ncbddd/folicacid/documents/MediaCampaignKit.pdf

The National Association of Broadcasters Stations Target Alcohol Abuse Reduction (STAR) campaign is the largest, longest running public awareness project ever undertaken by the broadcast industry.
http://www.nab.org/publicservice/STAR.asp

http://health.hss.state.ak.us/fas/Resources/media.htm

CDC Tip Sheets for TV writers include information on “Alcohol Use and Pregnancy” and “Fetal Alcohol Syndrome”.
www.cdc.gov/communication/entertainment_resources.htm
<table>
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<th>WHERE TO FIND FREE FASD MATERIALS</th>
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<tr>
<td><strong>NOFAS</strong></td>
</tr>
<tr>
<td>900 17th Street, NW</td>
</tr>
<tr>
<td>Suite 910</td>
</tr>
<tr>
<td>Washington, DC 20006</td>
</tr>
<tr>
<td>1-800-66-NOFAS</td>
</tr>
<tr>
<td><a href="http://www.nofas.org">www.nofas.org</a></td>
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<tr>
<td><strong>Centers for Disease Control</strong></td>
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<tr>
<td>and Prevention</td>
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<tr>
<td>NCBDDD, CDC</td>
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<tr>
<td>Mail-Stop E-86</td>
</tr>
<tr>
<td>1600 Clifton Road</td>
</tr>
<tr>
<td>Atlanta, GA 30333</td>
</tr>
<tr>
<td>(404) 498-3947</td>
</tr>
<tr>
<td><a href="http://www.cdc.gov/ncbddd/fas/">http://www.cdc.gov/ncbddd/fas/</a></td>
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<tr>
<td><strong>University of Washington School</strong></td>
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<tr>
<td>of Medicine Fetal Alcohol and Drug</td>
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<tr>
<td>Unit</td>
</tr>
<tr>
<td>180 Nickerson St., Suite 309</td>
</tr>
<tr>
<td>Seattle, WA 98109</td>
</tr>
<tr>
<td>(206) 543-7155</td>
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<tr>
<td><a href="http://www.depts.washington.edu">www.depts.washington.edu</a></td>
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<td><strong>SAMHSA FASD Center for Excellence</strong></td>
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<td><strong>FAS Community Resource Center</strong></td>
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<td><strong>Canadian Centre on Substance</strong></td>
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2006 DIRECTORY OF THE NATIONAL ASSOCIATION OF FASD STATE COORDINATORS

This is a group of state administrators identified by the SAMHSA FASD Center for Excellence to plan FASD specific activities and programs in their respective states. They meet annually to discuss progress, measures, and to plan activities.

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LOCATE LOCAL MEDIA IN YOUR COMMUNITY

HOW TO SEARCH FOR MEDIA CONTACTS
Example: Washington, DC

STEP ONE:
Go to the NOFAS website at:
www.nofas.org

STEP TWO:
Click on the Advocacy Tab.

STEP THREE:
Scroll down to the “Action Alert” section. Locate “Guide to the Media” and enter your zip code. Click the “GO” button.
**STEP FOUR:**
The results for your specific zip code will display. You will find:
- Newspapers
- Political Publications
- Online services
- Columnists
- Magazines
- Television Networks
- Television Stations
- Radio
- News Services

Find the organization you are interested in and click on the name.

**STEP FIVE:**
The contact information for the organization will appear. Find the name of the person you want to contact and click on their name.

TIP: If possible, look for someone who works with health issues.

**STEP SIX:**
The contact information for the person will appear.
SAMPLE SPEECH TO THE SCHOOL BOARD

Good evening.

I am here to emphasize the importance of teaching our students about the leading known cause of mental retardation, birth defects and learning disabilities—Fetal Alcohol Spectrum Disorders (FASD).

Each year in the United States as many as one in 100 newborn babies will suffer some type of lifelong damage because of maternal alcohol consumption during pregnancy. Children that are affected could have an array of learning and behavioral difficulties. The problems could be subtle and they might not be identified until adolescence or later. Often it is not understood that prenatal alcohol exposure caused these issues. Children with persistent difficulties may be given a diagnosis such as attention deficit hyperactivity disorder (ADHD), learning disabilities (LD), conduct disorder, or a host of other psychiatric illnesses.

I know all to well about this disorder. Let me tell you about my son/daughter: (personal stories will be your best teaching technique)

There are K-12 educational materials available to our teachers. Our children need to have this information presented to them in the early phases of education and reinforced throughout their school years. After all, the effects on infants are lifelong. Fortunately, the appropriate education methods can greatly improve performance and outcomes for students with FASD. FASD needs to be prioritized in our educational system.

Our teachers need to receive training on FASD as well. They are at the front lines for recognizing these symptoms and taking action so that we can ultimately improve the quality of our children's lives. Currently, many affected children are not being identified. As a result they may not have success in school and may be viewed as being “willfully disobedient” or children that “could do better if they just tried harder,” rather than children with neuro-cognitive issues. So, the school system can help identify children facing difficulties and it has an obligation to help them succeed.

I am asking that we all do our part to insure that our children reach their full potential.

Thank you.
SAMPLE LETTER TO SCHOOL PRINCIPAL

Date

Name
Title
School
Mailing Address
City, State  Zip

Dear Principal (insert name):

My name is (insert name) and I am concerned about the lack of knowledge by our educators on Fetal Alcohol Spectrum Disorders (FASD). (If you have a personal story, include it here—keep it to 2-3 sentences).

I am writing to request your support and help in the prevention of FASD. FASD is the number one cause of mental retardation in the United States, yet it is 100% preventable. A child that is prenatally exposed to alcohol may have subtle to profound learning disabilities and behavioral problems. Education is the key to prevention of this disability that has a lifelong effect on both the affected individual and their family.

There are many things that your school can do to help prevent this disability. The following can be easily implemented:

- Offer an in-service training on FASD to school personnel.
- Incorporate FASD prevention in health sciences classes.
- Propose a poster, art or essay contest on alcohol and pregnancy for teachers to conduct with students.
- Facilitate dialogue about the ethical issues that arise with FASD through a student debate.
- Set up an FASD information booth at a school health fair.

I would like to schedule a time to meet with you personally so that I can provide you with additional resources and contacts to help you with the above-mentioned activities.

I will follow-up with you shortly. Thank you in advance for your support.

Sincerely,

(insert name)
SAMPLE LETTER TO BUSINESSES

Date
Name
Title
Division Name
Company Name
Mailing address
City, State, Zip

Dear (insert name):

Fetal Alcohol Syndrome (FAS) is a major public health problem, affecting as many as 12,000 infants in the United States each year. Characterized by a distinctive facial appearance, growth deficiency, and neurological damage it is a lifelong yet completely preventable condition. The Center for Disease Control and Prevention estimates that 0.2 to 1.5 of 1,000 live births in this country are born with FAS, making it more prevalent than down syndrome, cerebral palsy, or spina bifida. At least three times this number of children are adversely affected by prenatal alcohol exposure, although they lack the facial characteristics to receive a FAS diagnosis.

As a leading publisher of health sciences textbooks, you are in a unique position to educate significant portions of the population on this preventable birth defect. Your audience is an ideal one for prevention education—young and engaged in learning. I am writing to ask that you include current, accurate information on prenatal alcohol exposure in your health sciences text books.

I continue to be alarmed by the lack of information on the full range of problems related to prenatal alcohol exposure in educational texts. Even when the topic is addressed, the vast majority of textbooks do not reflect public health recommendations, and in some instances, even contradict them.

I would like to enlist your support in meeting our nation’s public health objectives by providing accurate information on this preventable and unnecessarily prevalent birth defect. I encourage you to use any of the attached information, including the images, which are in the public domain. I also encourage you to utilize the ETOH database located http://etoh.niaaa.nih.gov/ for further reference.

FAS is a major public health problem that fortunately is entirely preventable. I hope that you can assist your authors in making this a part of any new textbook or revision. If you have any questions or would like additional information, please feel free to contact me. I would be happy to work with you or your authors to assist in this effort.

Sincerely,

(insert name)
SAMPLE PRE/POST-TEST FOR EVALUATION OF PROGRAM ACTIVITY

1. Most individuals who have been affected by their mother’s use of alcohol during pregnancy receive a correct diagnosis.
   ___ I don’t have enough information to decide if this statement is true or not true.
   ___ I am certain this statement is true.
   ___ I think this statement is probably true.
   ___ I think this statement is probably not true.

2. Alcohol use is harmful only during the first month of pregnancy.
   ___ I don’t have enough information to decide if this statement is true or not true.
   ___ I am certain this statement is true.
   ___ I think this statement is probably true.
   ___ I think this statement is probably not true.

3. Drinking beer or wine is safer than drinking distilled spirits (hard liquor) while pregnant.
   ___ I don’t have enough information to decide if this statement is true or not true.
   ___ I am certain this statement is true.
   ___ I think this statement is probably true.
   ___ I think this statement is probably not true.

4. Most children affected by Fetal Alcohol Spectrum Disorders (FASD) will “grow out” of their problems as an adult.
   ___ I don’t have enough information to decide if this statement is true or not true.
   ___ I am certain this statement is true.
   ___ I think this statement is probably true.
   ___ I think this statement is probably not true.

5. Drinking alcohol during pregnancy is less harmful than using crack cocaine, marijuana or other illicit drugs during pregnancy.
   ___ I don’t have enough information to decide if this statement is true or not true.
   ___ I am certain this statement is true.
   ___ I think this statement is probably true.
   ___ I think this statement is probably not true.
Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of developmental disabilities and birth defects that occurs among children born of mothers who consumed alcohol during pregnancy.

FASD is the leading known preventable cause of mental retardation, learning disabilities and birth defects.

As many as 40,000 newborns every year—one in 100—are affected by prenatal exposure to alcohol.

American Indians and Alaska Natives may have a FASD incidence rate that is up to seven-fold higher than the general population.

FASD is more prevalent than other commonly known health conditions such as down syndrome, cystic fibrosis, spina bifida, cerebral palsy, sudden infant death syndrome (SIDS) and muscular dystrophy.

FASD is 100% preventable!

FAS costs society $5.6 billion per year in direct and indirect costs. This does not include the costs of other disorders associated with FASD.

FASD is a permanent disorder requiring care throughout the lifespan.

FASD is widely under diagnosed, misdiagnosed or not diagnosed at all.

In 2005, U.S. Surgeon General Richard H. Carmona reissued an advisory warning pregnant women and women who may become pregnant to abstain from alcohol consumption due to the risk of birth defects.

Alcohol is a known teratogen, a substance that is toxic to human development like lead or mercury. Alcohol crosses the placenta into the blood supply of the embryo or fetus.

There is no known safe amount of alcohol use during pregnancy; why play Russian roulette with the health of your baby?

Alcohol is far more dangerous to a pregnancy than illicit drugs such as heroin, cocaine and marijuana.

Individuals with FASD may succeed academically and in society, but only with appropriate health, social and educational resources.
SAMPLE COMMUNITY CALENDAR LISTING:  
(ADAPTED FROM THE POINTS OF LIGHT FOUNDATION, 2002)

(Name of Coalition) Will Host a Community Health Fair to (Goal of Project)

On (day, month, time) coalition members will join with other organizations from (city, county, neighborhood, etc.) to gather at (project site) and raise awareness about the dangers of drinking during pregnancy and other pregnancy related health issues.

Volunteers are encouraged to join this project and help us build healthier communities to make a difference in the lives of our children.

For additional information, please call the project coordinator, (name), at (your number).

SAMPLE OP-ED LETTER:

Dear Editor,

As a mother of a child with Fetal Alcohol Syndrome (FAS), I was dismayed that the article titled “The Nine Months of Living Anxiously” did not treat the subject of drinking alcohol while pregnant more seriously.

The dangers of drinking while pregnant are very real, and to put it in a laundry list of concerns for pregnant women alongside bikini waxes diminishes the seriousness of this issue. There is a spectrum of disorders and disabilities called Fetal Alcohol Spectrum Disorders (FASD) that can result from prenatal drinking, and the statistics are staggering.

Every year, as many as 40,000 babies are born with preventable disabilities resulting from prenatal alcohol consumption. These disabilities may include mental retardation, learning disabilities, physical defects and behavioral disorders. Furthermore, this amounts to roughly 1 out of every 100 births in the U.S., making Fetal Alcohol Spectrum Disorders more prevalent than spina bifida, down syndrome, cerebral palsy and cystic Fibrosis combined.

The good news is that these birth defects are completely preventable; the bad news is that unless we as a society begin to address the reality that alcohol – in any amount – and pregnancy don't mix, we will continue to jeopardize the health of future generations.

Concerned,

(insert name)
1. SAMPLE PRESS RELEASE

FOR IMMEDIATE RELEASE: Contact: Kathy Mitchell
202-785-4585
February 27, 2002

The National Organization on Fetal Alcohol Syndrome Announces Partnership with National Institute on Alcohol Abuse and Alcoholism, Unveils Educational Campaign

(Washington, D.C.) — The National Organization on Fetal Alcohol Syndrome (NOFAS) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) is launching a campaign to raise awareness on drinking during pregnancy, the leading cause of preventable birth defects and learning difficulties. The campaign will target African-American women of childbearing age in Washington, D.C. and will serve as a prototype for campaigns in other cities.

To kick off the program, NOFAS and NIAAA are holding a press conference on Tuesday, March 5, at Union Station’s Columbus Club beginning at 11:00 a.m. Expected attendees include Mayor Anthony Williams and members of Congress. Debra Terry of the WPGC Radio Donnie Simpson Show will preside over the conference.

NOFAS and NIAAA are working together to raise awareness on the harmful effects of drinking alcohol during pregnancy, including fetal alcohol syndrome. According to the March of Dimes, more than 40,000 infants each year are born with some degree of alcohol-related effects. These effects include learning disabilities, behavioral problems, and in severe cases can result in mental retardation. Alcohol-related effects on a fetus occur more frequently than Down syndrome, cerebral palsy, cystic fibrosis, spina bifida, and sudden infant death syndrome combined, according to NOFAS.

“Our goal is to raise awareness about the dangers of drinking during pregnancy,” said Tom Donaldson, Executive Director of NOFAS. “If women can abstain from drinking alcohol during pregnancy, fetal alcohol spectrum disorders and other problems are 100 percent preventable. That is the message we are sending.”

The pilot program in D.C. will send the message “Play It Smart. Alcohol and Pregnancy Don’t Mix” through transit advertising, public service announcements, and grassroots approaches. The campaign will also include partnerships with community groups, local health organizations, and retail establishments.

“After we have assessed the success of this pilot program, we hope to launch the campaign in other cities across the country,” said Raynard S. Kington, M.D., Ph.D.,
acting Director of NIAAA. “But first we need to reach women right here in the nation’s capital.”

NIAAA, a component of the National Institutes of Health, U.S. Department of Health and Human Services, conducts and supports approximately 90 percent of U.S research on the causes, consequences, prevention, and treatment of alcohol abuse, alcoholism, and alcohol problems, and disseminates research findings to science, practitioner, policy making, and general audiences.

NOFAS, a nonprofit organization founded in 1990, is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected. NOFAS, the only national organization focused solely on FASD, pilots its programs among diverse populations nationwide, and takes a multicultural approach to prevention and healing. NOFAS is committed to raising public awareness of FASD—the leading known cause of mental impairment and birth defects—and to developing and implementing innovative ideas in prevention, intervention, education, and advocacy in communities throughout the nation.

2. SAMPLE MEDIA ALERT
(Points of Life Foundation, 2002):

FOR IMMEDIATE RELEASE:

Contact: Name of contact for any media questions, include a phone number and/or email address.

Project Title-Bold and all CAPS
(Subtitle of Project- Bold)

WHAT: Write a description of the project, including: number of volunteers, purpose of the project, link to other projects, and community issue being addressed.

WHO: List any VIPS attending or participating in the project and the groups your volunteers come from, families or local residents involved, etc.

WHEN: Date and time for the media to attend

WHERE: Physical address of the activity

WHY: Explain the purpose of your activity and/or the anticipated impact of the project in the local community, and link it to your group’s mission statement goals or community objectives. Include mission statements or message points form other participation organization or partners.
3. SAMPLE FAQs (FREQUENTLY ASKED QUESTIONS):

What is FASD and how many individuals does it affect?
Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. FASD is estimated to affect as many as 1 in 100 live births or as many as 40,000 infants each year in the United States.

Fetal Alcohol Syndrome (FAS) is the most serious set of birth defects associated with alcohol use during pregnancy. FAS is characterized by 1) brain damage, 2) facial dysmorphology and 3) growth deficiency.

Can I drink alcohol when I am pregnant or planning to get pregnant?
No. Do not drink alcohol when you are pregnant. When you drink alcohol, such as beer, wine, or distilled spirits (mixed drinks or hard liquor) so does your baby. Alcohol is a substance known to be harmful to human development. When it reaches the blood supply of the embryo or fetus, it can cause permanent defects to the major organs and central nervous system.

Is there any kind of alcohol that is safe to drink during pregnancy?
No. Drinking any kind of alcohol can interfere with healthy development of your baby. Alcoholic drinks can include beer, wine, wine coolers, or distilled spirits (mixed drinks or hard liquor).

What if I am pregnant and have been drinking?
If you drank alcohol before you knew you were pregnant, stop drinking now. Anytime a pregnant woman stops drinking, she decreases the risk of harm to the baby. If you are trying to get pregnant, do not drink alcohol. You may not know you are pregnant right away, so if you could be pregnant don’t drink alcohol.

What if I drank during my last pregnancy and my baby was fine?
Every pregnancy is different. Drinking alcohol may hurt one baby more than another. You could have one child that is born healthy and another child that is born with problems. Some of the issues related to drinking alcohol during pregnancy can be subtle and are not identified until the child is an adolescent or adult.

What if a friend, partner, spouse, or family member is drinking while pregnant?
Many women are unaware of the consequences of drinking during pregnancy. Some women are not aware that wine or beer is alcohol. In some cases, a woman may have an alcohol dependence. She may need to know what effects alcohol can have on the baby or be screened for an alcohol problem. Contact NOFAS for more information.
4. SAMPLE PITCH

Hello, my name is _______ and I am with the organization ________. Is this a good time for you? I am calling to share some information about the issue of fetal alcohol spectrum disorders (FASD) which is extremely important for your readers (viewers, listeners). You may already know that as many as 40,000 children are born each year with this disorder that can result in physical, mental, and behavioral problems. I frequently read (watch/listen) your column (program) and thought you might be interested in this story…

5. SAMPLE PSA PITCH LETTER

Date

Address

Dear (insert name):

The National Organization on Fetal Alcohol Syndrome promotes healthy choices by encouraging women who are pregnant or even thinking of becoming pregnant to abstain from alcohol use. In honor of Mother’s Day NOFAS will release a brand new Public Service Announcement which informs women about the risks and consequences of alcohol use during pregnancy. Mother’s Day brings families together and is a time to celebrate the mother-child relationship. NOFAS feels this is a perfect opportunity to send this message to women when their thoughts and feelings surround motherhood.

Drinking during pregnancy is the leading known cause of mental retardation as well as a leading cause of learning disabilities and birth defects. As many as 12,000 infants are born annually with Fetal Alcohol Syndrome and as many as 40,000 are born with some degree of alcohol-related problems.

Enclosed please find a copy of our 30 second PSA for your review. We hope that you will support us in our efforts to educate women and their families about the dangers of drinking alcohol during pregnancy. NOFAS staff will follow up with you in the coming weeks.

Sincerely,

(insert name)
6. NOFAS RADIO PUBLIC SERVICE ANNOUNCEMENTS

**MYTH:** Drinking alcohol is no big deal if you’re pregnant.

**FACT:** Staying alcohol-free from the very start is the only safe choice. If you drink while pregnant, your baby’s at risk for learning disabilities and birth defects. Problems that last a lifetime. So when it comes time to have a baby – or even think about it—stay clear of alcohol—that means beer and wine too. To learn more, call 1-800-66-NOFAS. Play it Smart. Alcohol and Pregnancy Don’t Mix. A public service of NIAAA and the National Organization on Fetal Alcohol Syndrome.

Speak up. If you know someone who is pregnant—or even thinking about it—tell her to steer clear of alcohol. Tell her that drinking during pregnancy can cause lifelong problems like learning disabilities, mental retardation, and birth defects. Tell her all forms of alcohol are dangerous—including beer and wine. Tell her to stop drinking now. To learn more, call 1-800-66-NOFAS. Play it Smart. Alcohol and Pregnancy Don’t Mix. A public service of NIAAA and the National Organization on Fetal Alcohol Syndrome.

If you drink, think twice before getting pregnant. Because you’re going to have a lot more to think about than your most recent hangover. Like learning disabilities and birth defects. Alcohol can harm your baby’s brain at any time during pregnancy, and that means lifelong problems for you and your child. To learn more, call 1-800-66-NOFAS. Play it Smart. Alcohol and Pregnancy Don’t Mix. A public service of NIAAA and the National Organization on Fetal Alcohol Syndrome.
National Organization on Fetal Alcohol Syndrome
Helping children & families by advocating for the prevention and intervention of Fetal Alcohol Spectrum Disorders, the leading known cause of mental retardation & birth defects.

**FASD: WHAT EVERYONE SHOULD KNOW**

Alcohol use during pregnancy is the leading known preventable cause of mental retardation and birth defects in the United States.

![Estimated Cases Each Year](chart)

FASD affects an estimated 40,000 infants each year - more than Spina Bifida, Down Syndrome and Muscular Dystrophy combined.

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

FASD includes conditions such as:

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (PFAS)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)
- Fetal alcohol effects (FAE) *obsolete terminology*

**What Are the Effects of FASD?**
The effects of FASD vary among affected individuals. Outcomes associated with FASD can include:

- Specific facial characteristics
- Growth deficits
- Mental Retardation
- Heart, lung, and kidney defects
- Hyperactivity & behavior problems
- Attention & memory problems
- Poor coordination or motor skill delays
- Difficulty with judgment and reasoning
- Learning disabilities

"Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

*Institute of Medicine, 1996.*

![Normal Brain vs Severe FAS-Affected Brain](image)

- **FASD also takes an enormous financial toll on affected families and society as a whole.** Fetal Alcohol Syndrome (FAS), the most severe and least common effect under the FASD umbrella, costs the United States $5.4 billion annually in direct and indirect costs. This is only a small portion of the total societal costs associated with FASD.

**How Can FASD Be Prevented?**
While there is no cure for FASD, it is 100 percent preventable when pregnant women abstain from alcohol. Good reproductive care before knowledge of pregnancy would also assist in prevention of FASD to a great extent.
FASD PREVENTION

While there is no cure for Fetal Alcohol Spectrum Disorders (FASD), they are 100 percent preventable when pregnant women abstain from alcohol.

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. FASD affects an estimated 40,000 infants each year.

"We do not know what, if any, amount of alcohol is safe. ... Therefore, it’s in the child’s best interest for a pregnant woman to simply not drink alcohol."

U.S. Surgeon General Richard H. Carmona
February 21, 2005

Challenges for FASD Prevention

- An estimated 5.3 million women in the United States drink in a way that threatens their health, safety, and general well-being.
- Nearly half of all pregnancies are unplanned.
- Many women do not know they are pregnant for several weeks (or even months) during which time they may drink alcohol.
- Health and social service professionals that provide services for women of childbearing age lack knowledge of, or training on, FASD.
- Alcohol screening of patients are not routine in health care settings.
- Many health professionals still advise women that ‘moderate’ alcohol use during pregnancy is safe.

Strategies for Reducing Alcohol Use During Pregnancy

Public Education and Awareness

- Public service announcements and other mass media approaches;
- U.S. Surgeon General’s Advisory;
- Official awareness days and proclamations;
- Alcohol warning labels and posters; and
- Signage at all points of sale of alcohol.

Professional Training and Education

- FASD Curricula for medical/nursing students;
- Education and training on FASD and chemical dependency for social service professionals; and
- Mandatory education for professional licensure.

General Prevention Programs

- Routine, prenatal screening for alcohol use;
- FASD curricula for school children;
- Workplace health promotion programs; and
- Information dissemination through healthcare professionals and insurance providers.

Targeted Prevention for High-Risk Women

- Routine education about FASD and assessment of children of women in addiction treatment
- FASD education for pregnant teens attending prenatal clinics;
- Science-based clinical interventions, such as motivational interviewing by physicians and trained healthcare providers.
- FASD education for persons in jails, prisons and those in shelters.
National Organization on Fetal Alcohol Syndrome
Helping children & families by advocating for the prevention and intervention of Fetal Alcohol Spectrum Disorders, the leading known cause of mental retardation & birth defects.

FASD IDENTIFICATION

Recognizing Fetal Alcohol Spectrum Disorders (FASD) can be difficult. Early and accurate identification is key to receiving appropriate educational and medical support.

Fetal Alcohol Syndrome (FAS), a diagnosable condition, is just the tip of the iceberg. Other FASD may be more difficult to distinguish, particularly when the mother's exposure to alcohol is unknown. Many of the problems and behaviors that lead to an assessment for FASD cannot be identified at birth but become more recognizable with age and time.

The FASD Iceberg

- FAS
  Fetal Alcohol Syndrome
- PFAS
  Partial Fetal Alcohol Syndrome
- ARND
  Alcohol Related Neuro-Developmental Disorder
- ARBD
  Alcohol related Birth Defects

FAS diagnosis requires all three of the following:
- Documented presence of discriminating facial characteristics,
- Documented growth deficits; and
- Documented central nervous system (CNS) abnormalities.

Confirmed prenatal alcohol exposure strengthens the case for clinical diagnosis of FAS, but is not necessary if the three requirements above are met.

Health professionals are often reluctant to identify prenatal alcohol exposure because of the stigma attached to alcoholism and the perception that a diagnosis may not lead to effective treatment options.

Individuals should be referred for a FAS diagnostic evaluation if:
- There is known prenatal alcohol exposure;
- There is concern of the caregiver that the individual may have FAS; or
- The individual has all characteristic facial features of FAS or some of the facial features with accompanying growth deficits and/or CNS abnormalities.

See CDC’s 2004 publication “Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis” for more information.

To increase FASD identification, routine screenings are recommended for:
- Children of women with a history of substance abuse; and
- Those in the foster care, juvenile justice, or adult criminal justice system (where individuals with FASD are overrepresented).
Fetal Alcohol Spectrum Disorders (FASD) have lifelong implications.

FASD Throughout the Lifespan

- **Infants**: low birth weight; irritability; sensitivity to light, noises and touch; poor sucking; slow development; poor sleep-wake cycles; increased ear infections.
- **Toddlers**: poor memory capability, hyperactivity, lack of fear, no sense of boundaries, need for excessive physical contact.
- **Grade-school years**: short attention span, poor coordination, difficulty with both fine and gross motor skills.
- **Older children**: trouble keeping up with school, low self-esteem from recognizing they are different from their peers. Problems understanding cause-effect relationship.
- **Teenagers**: poor impulse control, cannot distinguish between public and private behaviors, may need constant reminding.

Each individual with FASD will have unique physical, educational, social and medical needs.

Teachers, social workers, physicians and childcare providers are just some of the professionals that will need to use adapted strategies when assisting individuals with FASD. These professional should be educated about the effects of FASD and possible interventions.

Strategies for Living

Individuals with FASD can benefit from:

- Consistent routines;
- Limited stimulation;
- Concrete language and examples;
- Multi-sensory learning (visual, auditory and tactile);
- Realistic expectations;
- Consistency at home, school and other settings;
- Supportive environments; and
- Supervision.

There is still limited knowledge about the effectiveness of FASD interventions. Interventions currently being evaluated include:

- Individualized, supportive, behavioral consultations for parents and school staff (working with children ages 5 to 11);
- A school-based social communication intervention (for ages 8 to 12);
- Behavioral Regulation Training (for ages 3 to 9);
- Parent Child Interaction Therapy (for ages 2 to 7); and
- Parent-assisted social skills training (for ages 6 to 8)


Pharmaceutical Intervention

Medication maybe necessary and should be considered when developing a treatment plan. Medication may be able to mitigate some symptoms of FASD, including impulsivity, hyperactivity, oppositional behavior, and sleep disorders.

Parent Support

Individuals with FASD and the families who care for them depend on social networks as a source of support and encouragement. NOFAS maintains listings of parents, parent support groups and FASD professionals who can help families caring for individuals with FASD at [www.nofas.org](http://www.nofas.org)
National Organization on Fetal Alcohol Syndrome
Helping children & families by advocating for the prevention and intervention of
Fetal Alcohol Spectrum Disorders, the leading known cause of mental retardation & birth defects.

FASD: What School Systems Should Know About Prevention

Schools exercise a powerful influence over young people, making them ideal settings to educate about the dangers of underage drinking and sexual activity.

Despite laws in every state that make it illegal for anyone under the age of 21 to purchase or possess alcohol, young people report that alcohol is easy to obtain.

- Alcohol is by far the most commonly abused substance by female adolescents with 36.5% (4.5 million) of girls ages 12 to 17 reporting alcohol use within the past year.
- Nearly 74% of adults report that they began drinking alcohol before the current legal drinking age of 21.
- A nationwide study indicates that 60% of adolescents ages 12 to 17 who drink are binge drinkers (5 or more drinks in a row).

Drinking predisposes young adults to risky sexual behaviors.

- A study of adolescent drinkers found that problem drinkers are more likely than other drinkers to be sexually active, to have a greater number of partners, and to initiate sexual activity at younger ages.
- Among the reported 34% of currently sexually active students nationwide, 25% had drunk alcohol or used drugs before their last sexual intercourse.

"Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."
Institute of Medicine, 1996.

Unplanned pregnancies pose one of the greatest challenges for prevention of Fetal Alcohol Spectrum Disorders (FASD).

- Roughly a million American teenagers become pregnant each year. The majority of those pregnancies (an estimated 78%) are unintended.
- Nearly one quarter of sexually active teens and young adults report having unprotected sex (using no form of contraception) because of alcohol or drug use.

School Systems can help prevent FASD by:

- Including information about FASD in health and/or human development course curricula;
- Providing alcohol-free recreation and entertainment opportunities for young adults;
- Supporting FASD peer-education programs; and
- Encouraging student participation in FASD or substance abuse-related community coalitions to meet required community service hours for graduation.
What School Systems Should Know About Students with FASD

Students with Fetal Alcohol Spectrum Disorders (FASD) have special learning needs and a wide range of behavioral challenges.

How does FASD affect learning and behavior?

Students with FASD have problems receiving and processing information. They often cannot store what they learn or lack the mental capacity to use new information they have been given.

While students with FASD have IQ scores that range from 29 to 140, their overall level of adaptive functioning (i.e. ability to perform daily life skills) is often much lower than would be expected.

Educators can play a critical role in determining whether children with FASD reach their maximum potential.

Successful strategies for educating children with FASD include:

- Using concrete, hands-on learning methods
- Establishing structured routines
- Keeping instructions short and simple
- Providing consistent and specific directions
- Repeating tasks again and again
- Providing constant supervision

Recognizing FASD can be a challenging task

Most students with FASD are unidentified or go misdiagnosed as most people with FASD do not have the characteristic features associated with fetal alcohol syndrome. The majority of students with FASD are not mentally retarded, and they can be articulate and skilled at performing specific tasks.

Students with FASD may exhibit behavior or learning problems. Such students should be referred for psychoeducational testing to identify possible damage to central nervous system damage.

School Systems can prepare for students with FASD by:

- Providing in-service training for teachers on recognizing the characteristics of FASD and strategies for educating students with FASD
- Providing access to special education in and out of school for those with learning disabilities that are associated with FASD.

Common challenges for educators who teach students with FASD include:

- Poor Executive Functioning and Organization
- Hyperactivity and Impulsivity
- Attention and/or Memory Deficits
- Inability to complete tasks, disruptiveness
- Poor social skills
FASD: What the Justice System Should Know

Alcohol abuse and pregnancy are common among women in the criminal justice system.

- An estimated 70 to 85 percent of inmates need substance abuse treatment.
- Approximately one in four women is either pregnant or postpartum when she enters prison.

The Justice System can help to prevent Fetal Alcohol Spectrum Disorders (FASD) among the incarcerated population by offering educational workshops on FASD and addiction counseling for women inmates.

Many individuals with FASD will never socially mature beyond the level of 6 year-old child.

People with FASD end up in Justice system as victims of crimes

Other factors that may place persons with FASD at risk for involvement with the criminal justice system include:

- Difficulties in impulse control;
- Intellectual deficits;
- Poor judgment skills; and
- A history of abuse and/or neglect.

Problems individuals with FASD may encounter when dealing with police include:

- Being persuaded by the police (even inadvertently) to admit to crimes which they did not commit;

Victimization of FASD within the legal system

- Taking responsibility for crimes committed by others in order to win the favor of more sophisticated companions or to please the police;
- Consenting to searches of themselves or their possessions in circumstances in which non-disabled sophisticated individuals would not;
- Panicking during encounters with the police, running away or resisting arrest;
- Saying that they understand their legal rights when in fact they do not; and
- Making potentially incriminating statements about how serious any misconduct may have been.

The Justice System can help FASD-affected individuals by:

- Educating judges, police officers, lawyers and parole officers about the characteristics and behaviors of persons with FASD;
- Establishing screening, analysis, and treatment procedures for those with FASD who enter the juvenile justice or adult criminal justice system;
- Establishing/utilizing alternative sentencing programs for persons with FASD who have committed non-violent offenses; and
- Screening referral information for the children of incarcerated women who may have been prenatally exposed to alcohol.
- Providing appropriate support to reduce the incidence of victimization of people with FASD.
FASD: What the Foster Care System Should Know

The majority of children with Fetal Alcohol Spectrum Disorders (FASD) are not raised by their birth parents.

- It is reported that up to 80% of children with FASD do not stay with their birth families due to the high needs of parents and children.
- Studies suggest that a rise in alcohol and drug use by women has resulted in 60% more children coming into state care since 1986.

The incidence rate of FASD is unusually high among the U.S. foster care population.

- It is estimated that almost 70% of the children in foster care are affected by prenatal alcohol exposure in varying degrees.
- Children from substance abusing households are more likely to spend longer periods of time in foster care than other children (median of 11 months versus 5 months for others in foster care).

Many children with FASD go unidentified or are misdiagnosed. Often, behavioral problems caused by brain damage due to prenatal alcohol exposure are mistakenly thought to be solely a result of difficulties in the child’s previous home environment.

Secondary behavioral disorders associated with FASD can further complicate a child’s transition into and out of foster care homes.

Children with FASD often have difficulty:

- translating body language and expressions;
- understanding boundaries;
- focusing their attention; and
- understanding cause and effect.

Children with FASD can be easily frustrated and require a stable, structured home and school environment. Adjusting to a new home, a new family, and a new school can be particularly difficult.

Children with FASD can benefit from:

- Consistent routines;
- Limited stimulation;
- Concrete language and examples;
- Multi-sensory learning (visual, auditory and tactile);
- Realistic expectations;
- Supportive environments; and
- Supervision.

The foster care system can help prepare for children with FASD by:

- Providing training to foster care/adoption personnel to help recognize the disorder’s characteristics in order to seek diagnoses for suspected cases and ensure appropriate placements;
- Providing education to parents entering the foster care system, as well as for families who already have foster children, in order to help recognize the disorder’s characteristics, seek a diagnosis, and appropriately respond to the unique needs of the child; and
- Developing and/or enforcing policies on obtaining and disclosing information on birth mothers’ history of drinking during pregnancy.
FASD: What the Addiction Treatment System Should Know

The majority of children with Fetal Alcohol Spectrum Disorders (FASD) are born to alcohol-abusing or alcoholic women.

- Treatment programs are an ideal place to educate high-risk women about the dangers of drinking during pregnancy.

- About half of all pregnancies in the United States are unplanned.

- In 2002, 15,300 U.S. women of child-bearing age (15-44) were pregnant at the time of admission for substance abuse treatment.

- Women may enter treatment centers not knowing they are pregnant or may become pregnant during treatment.

- The greatest predictor of giving birth to a child with FASD is already having done so.

"Alcohol and drug abuse by pregnant women is a public health problem and ... laws, regulations and policies that treat chemical dependency primarily as a criminal justice matter requiring punitive sanctions are inappropriate."

American Psychological Association, 1991

Breaking the cycle of addiction is key to preventing FASD and ensuring affected children get the care and services they need.

- Women are less likely than men to seek treatment – women make up 30% (4.6 million) of alcohol-abusing or -dependent individuals in the U.S. but only 24.5% of clients in treatment centers.

- Evidence from health care providers suggests that fear of prosecution and loss of their children may deter women from seeking substance abuse treatment.

Women in recovery who have children with unidentified FASD may also be at high risk for relapse due to the challenging behavior of their children.

The substance abuse treatment system can help prevent and identify FASD by:

- Providing routine screening for pregnancy among new or returning clients;

- Providing education on the effects of alcohol on the developing fetus using resources developed specifically for women in recovery;

- Encouraging the use of contraception for sexually active clients; and

- Provide screening and referral for children of women in recovery who may have been exposed to alcohol during pregnancy.

"Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

Institute of Medicine, 1996

The majority of persons in substance abuse treatment use multiple substances. Pregnant drug addicts (e.g., heroin, cocaine) often quit illicit drug use but continue to drink, incorrectly believing that alcohol is less harmful to the fetus.
Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

FASD is 100% preventable if women abstain from drinking during pregnancy.

Young People and Drinking

Despite laws in every state that make it illegal for anyone under the age of 21 to purchase or possess alcohol, young people report that alcohol is easy to obtain:

- Alcohol is by far the most commonly abused substance by female adolescents with 36.3% of girls ages 12 to 17 reporting alcohol use.
- Underage binge drinking has become a social norm in the United States, with more than 7.1 million youth, ages 12 to 20, participating in this type of drinking pattern. Binge drinking was defined in this survey as five or more alcohol drinks in a row.
- Standard drink sizes are defined as 1.5 oz. of 80 proof liquor, 12 oz. of regular beer, or 5 oz. of table wine. Many cocktails may contain more than 1.5 oz. of liquor, combining several shots of liquor.

“Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

Institute of Medicine, 1996

Young People and Pregnancy

Unplanned pregnancy poses one of the greatest challenges to preventing FASD. Alcohol is a major factor in unprotected sex among youth, increasing their risk of unplanned pregnancies:

- The rates of teen pregnancy are noticeably high in the United States, estimated at one million per year, 88% of which are unplanned.
- Nearly one quarter of sexually active teens and young adults report having unprotected sex (using no form of contraception) because of alcohol or drug use.

Young women who are sexually active, not using contraception, and drinking alcohol are at risk for having a child with FASD.

Young people can help to prevent FASD by:

- Abstaining from alcohol use; abstaining from sexual intercourse;
- Volunteering with local FASD or substance abuse prevention coalition;
- Organizing an FASD presentation for their school or other youth organization;
- Creating a peer education program to teach others about the consequences of drinking while pregnant;
- Writing letters to the editor or informational articles to their school newsletters or magazines that interest their age group;
- Select FASD as a topic for a school project;
- Encourage school/teachers to include FASD in their curriculum.
Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects, which also include fetal alcohol syndrome (FAS), the least common yet most severe and most recognizable effect under the FASD umbrella, can include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

FASD takes an enormous financial toll on affected families and society as a whole.

- Fetal Alcohol Syndrome (FAS), the most severe and least common effect under the FASD umbrella, costs the United States $5.4 billion annually in direct and indirect costs;
- An individual with full-blown FAS incurs an average lifetime health cost of $860,000, although costs can be as high as $4.2 million;

FASD is 100% preventable if women abstain from drinking during pregnancy.

- Potential savings from preventing 1 case of FAS would result in a $300,000 reduction in medical costs alone.

FASD may affect an individual's ability to live independently throughout their lifetime.

- Nearly 80% of adults with FASD do not live independently;
- 80% of adults with FASD have problems with employment.

The business community can help individuals with FASD by:

- Providing productive work with structure and routine to help them stay focused and increase their self-esteem;
- Emphasizing life skills through pre-employment vocational skills programs;
- Providing highly structured, part-time jobs;
- Providing on-going job coaching and minor adjustments in work hours and demands.

The business community can help prevent FASD and support affected individuals and families by:

- Hiring individuals with FASD and other disabilities;
- Including FASD in their health fairs;
- Providing information to employees about the risks of drinking during pregnancy;
- Contacting Employee Assistance Program programs to request training on FASD for their counselors;
- Participating in alcohol-related commemorative days/events (e.g. National Alcohol Awareness Week) and including FASD;
- Supporting FASD support groups or community coalitions through in-kind donations of meeting space or staff assistance;
- Supporting non-profit organizations dedicated to prevented FASD through workplace giving campaigns.
National Organization on Fetal Alcohol Syndrome
Helping children & families by advocating for the prevention and intervention of Fetal Alcohol Spectrum Disorders, the leading known cause of mental retardation & birth defects.

FASD: What the Faith Community Should Know

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

FASD is 100% preventable if women abstain from drinking during pregnancy.

Faith communities offer a unique and underutilized conduit for delivering information to help people make healthy life choices.

Faith communities:

- Have access to important populations for FASD prevention including youth and parents;
- Are service oriented and could be a good source of volunteers;
- Focus on values and social responsibility; and
- Have strong credibility within the greater community.

The majority of children with FASD are born to alcohol abusing or alcoholic women.

- Alcoholism is a disease. People who have the disease have lost control over their drinking and are not able to stop without help.
- Approximately 14 million Americans – 7.4 percent of the population – meet the diagnostic criteria for alcohol abuse or alcoholism.
- Approximately one in four children under 18 years of age in the United States is exposed to alcohol abuse or alcohol dependence in the family.

Individuals with FASD and the families who care for them depend on social networks as a source of support and encouragement.

Spirituality can help individuals with FASD, regardless of their level of understanding or ability to function:

Involvement in a faith community can provide:
- Help in seeking inner forgiveness of the birth mother;
- Basis for accepting self as a good person, "child of God";
- Healthy role models;
- Healthy social environment for nurturing friendships;
- Support when problems occur;
- Inclusion in regular groups that are not focused on disabilities; and
- Encouragement of healthy lifestyles and behaviors.

The faith community can help prevent FASD and support affected families by:

- Incorporating FASD into a weekly sermon;
- Highlighting a family in the community living with FASD in the weekly bulletin;
- Inviting an FASD trainer to a youth group meeting; and
- Sponsoring workshops for parents about how to talk with their children about sensitive subjects, such as alcohol use and sexual activity.
Mass media plays a significant role in the daily lives of women and children, making it an invaluable platform for disseminating messages about preventing Fetal Alcohol Spectrum Disorders (FASD).

- The average American youth spends one-third of each day with various forms of mass media, mostly without parental oversight.

- More than 50% of regular drama viewers report that they have learned something about a disease or how to prevent it from a TV show. Nearly one-third of viewers report that they took some action after hearing about a health issue or disease on a TV show.

Mass media campaigns can create awareness, change attitudes, and motivate individuals and communities to engage in healthy behaviors.

- A CDC-led review of the research literature revealed that mass media campaigns can be effective in preventing alcohol-impaired driving, with a median decrease of 13% in total alcohol-related crashes.

- Studies evaluating the effectiveness of mass media campaigns in reducing tobacco use (as measured by statewide cigarette sales) found a median decrease of 15 packs per person per year.

A review of national network evening news broadcasts between 1977 and 1996 found that alcohol and pregnancy was a topic in only 36 of the newscasts.

The most effective media campaigns target specific audiences while taking into account the audiences unique preferences and needs.

Media campaigns currently being evaluated for FASD prevention include:

- A campaign targeting African-American women, ages 18 through 55 years, at risk for pregnancy (St. Louis, MO);

- A campaign using a “narrowcasting approach” targeted to White, Hispanic and African-American women ages 18 to 30 (Los Angeles, CA);

- A campaign aimed at reducing prenatal alcohol use in rural areas, targeting women enrolled in the Women, Infants, and Children (WIC) program (Iowa City, IA).

More information available at www.cdc.gov/nchddddd/fas/faspubnews.htm

The Media can help prevent FASD by:

- Including stories on the dangers of drinking while pregnant in health and community-related sections of print media and broadcasts;

- Incorporating audience-specific FASD prevention public service announcements in programming targeted to youth or women of childbearing age;

- Reporting on alcohol-related commemorative events, such as Alcohol Awareness Week or International FASD Awareness Day (September 9);

- Depicting responsible behavior, such as abstaining from alcohol during pregnancy, FASD prevention messages and addition treatment, in television programming and cinema;

- Participating in FASD or substance abuse-related community coalitions.
www.advocacy.org/definition

http://www.agi-usa.org/pubs/archives/abortww_nr.html

http://www.archrespite.org/index.htm


http://www.dca.gov.uk/family/fla/section6.htm


http://www.cdc.gov/doc.do/id/0900f3ec8001946c

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http://preventionpartners.samhsa.gov/resources_glossary_p2.asp


http://www.cdc.gov/ncbddd/folicacid/prev_guide.htm


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