



# ***Creating Hope for Women in Recovery: A Web Guide to Planning an FASD Summit***



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
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**SAMHSA**  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

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*“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it’s the only thing that ever has.”*

—Margaret Mead



# INTRODUCTION

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## PURPOSE OF THIS GUIDE

This guide is a reference to help communities conceptualize, plan, facilitate, and convene a successful Women in Recovery summit. Planning a Women in Recovery summit can take up to a year and can require significant time commitment, but the outcomes of a successful summit are well worth the effort. Results may include an increased awareness of fetal alcohol spectrum disorders (FASD) and enhanced FASD prevention and treatment services in your community.

Use the information in this guide as suggestions and guidelines, not as absolutes. This manual synthesizes the experience of planning three successful summits. Planners can modify and tailor these guidelines to the conditions and needs in their particular community.

## OVERVIEW AND OBJECTIVES OF THE GUIDE

The Women in Recovery summit planning web guide has four sections, each of which corresponds to the four objectives of the manual.

<b>1. Background, Framework &amp; Overview</b>	<b>Provides the basis for a focus on FASD and the effects of alcohol on unborn children; provides context for the need to support women in recovery and for the need to educate State and local policymakers</b>
<b>3. Information and Resource List</b>	<b>Provides a list of national, Federal, State, and online resources related to FASD that have valuable information you can use as you consider your goals and desired outcomes</b>



# SECTION 1: BACKGROUND, FRAMEWORK, AND OVERVIEW

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## FETAL ALCOHOL SPECTRUM DISORDERS: WHY THE FOCUS?

Prenatal exposure to alcohol is the most preventable cause of developmental disabilities, yet it affects hundreds of thousands of people in the United States and carries an annual economic cost in the billions.

“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 used as a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

Question	Answer
What causes FASD?	The sole cause of FASD is drinking alcohol while pregnant.
How harmful is drinking alcohol while pregnant?	Of all the substances of abuse—including cocaine, heroin, and marijuana—alcohol causes the most serious neurological damage in a fetus. <sup>1</sup>
How common is drinking while pregnant?	In the United States, more than 1 in 5 women drink alcohol in the first trimester of pregnancy; 1 in 9 pregnant women reports binge drinking in the first trimester. <sup>2</sup>
How often does FASD occur?	In the United States, FASD occurs in about 10 per 1,000 live births, or 40,000 babies per year. <sup>3</sup>
What are the costs of FASD?	For one individual with FAS, the lifetime cost is at least \$2 million. The cost to the nation of FAS alone may be up to \$6 billion each year. <sup>4</sup> Costs of the other conditions across the spectrum are unknown.



## WHY HOLD A WOMEN IN RECOVERY SUMMIT?

The fundamental goal of these summits is simple: greater awareness and knowledge of FASD. While many people are aware that drinking alcohol while pregnant can be harmful, the level of awareness is akin to the awareness of the link between tobacco and cancer in the 1950s. Women know it is probably better not to drink alcohol while carrying a child, but they do not know just how severe the consequences can be.

Hope for Women in Recovery summits introduce women in treatment and their counselors to the issue of FASD. Many of the women have children, some of whom have an FASD. The summits provide a safe, supportive place to learn about FASD and to hear the struggles and successes of other women in recovery. They explore various issues related to parenting children with an FASD and strategies to guide them. Attending these summits, finding a new community, and finding strength in that community can empower women to be advocates for themselves, their children, and for FASD prevention and treatment services in their area.



Equally important, the summits educate policymakers about FASD issues. Policymakers are individuals with the power and influence to develop and change policies and practices in the community. A policymaker with an understanding and a concern about FASD can serve as a catalyst for change.

## HISTORY OF THE HOPE FOR WOMEN IN RECOVERY SUMMITS

To address the problems related to FASD, the United States Congress, under the Children's Health Act of 2000, authorized the Substance Abuse and Mental Health Services Administration (SAMHSA) to establish a center of excellence for FAS and ARBD (now the FASD Center for Excellence). The congressional mandates that guide the FASD Center for Excellence (the Center) include developing innovative techniques to prevent alcohol use among women in childbearing years. The Women in Recovery summits were born from this directive.

In collaboration with the National Organization on Fetal Alcohol Syndrome (NOFAS), the Center convened the first of three Women in Recovery summits in Baltimore, Maryland, in September 2003. Phoenix, Arizona was the site of the second summit in

June 2004. Attendees were primarily Native American women and the summit wove threads of Native culture into the proceedings. NOFAS and the Center convened the third summit in Raleigh, North Carolina in July 2005. Between 150 and 200 people attended each summit.



Women and policymakers who attended each summit gave them high marks and praise. Past summits have proven to be an invaluable means of promoting sustained recovery and effecting policy changes.

The Women in Recovery summits provide a unique model for FASD prevention and education, particularly for women with addictive disorders and their families. This manual is not meant to be all-inclusive. It highlights key considerations for planning and hosting a Women in Recovery summit. The summit model has proven successful in the facilitation of changes in knowledge, attitudes, and increased awareness among women with addictive disorders, policymakers, and State systems.

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<sup>1</sup> Stratton, K; Howe, C; and Battaglia, F., eds. 1996. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*. Institute of Medicine. Washington, DC: National Academy Press.

<sup>2</sup> Office of Applied Studies. 2005. *Results from the 2004 National Survey on Drug Use and Health: National Findings*. Rockville, MD: Substance Abuse and Mental Health Services Administration. [oas.samhsa.gov/nhsda/2k3tabs/LOTsect7pe.htm#TopOfPage](http://oas.samhsa.gov/nhsda/2k3tabs/LOTsect7pe.htm#TopOfPage)

<sup>3</sup> May, P.A., and Gossage, J.P. 2001. Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health* 25(3):159-167. [www.niaaa.nih.gov/publications/arh25-3/159-167.htm](http://www.niaaa.nih.gov/publications/arh25-3/159-167.htm)

<sup>4</sup> Lupton, C.; Burd, L.; and Harwood R. 2004. Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics* 127C (671):42-50.



# OVERVIEW OF THE SUMMIT

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A Women in Recovery summit is held over a 2-day period. Day 1 focuses on educating women of childbearing age in substance abuse treatment, and treatment counselors about the effects of prenatal alcohol exposure and the needs of children with an FASD. Day 2 brings together local, State, and perhaps Federal policymakers and other officials to learn about FASD and the impact FASD has on affected individuals and their families in a particular State or local area.

A town hall meeting, an optional add-on to the summit model, is typically held in the afternoon of Day 1. It is an important component of the summit model because it lays the groundwork for generating State support and legislative activity to develop FASD policies. Town hall meetings are designed for women in recovery, women in addiction treatment, persons with FASD, their families, and health care providers to share their experiences with a panel of local, State, and Federal policymakers. Testimonies have included charges to change policies and practices for improving clinical, educational, behavioral, and social services.

Some communities may choose to exclude this component from their summit due to budget constraints or because they already have achieved similar goals and objectives from another gathering. However, the town hall meeting should be carefully considered due to its potential impact on FASD policies and services in a community or State.

## SUMMIT GOALS

The goals of a summit are twofold:

1. To increase the understanding of FASD among women in recovery from alcohol dependence and substance abuse, women at highest risk for having a child with an FASD, treatment professionals, and policymakers
2. To facilitate the development and enhancement of State systems of care and support services for individuals and families affected by an FASD





## SUMMIT OBJECTIVES

The summit objectives may vary from community to community but include the following as a baseline:

- To enhance understanding about FASD among women in addiction treatment and among treatment professionals
- To allow State policymakers an opportunity to listen to personal stories from women, families, and service providers on issues related to FASD and addiction
- To facilitate understanding about the needs of individuals with an FASD and their families among State policymakers

## TARGET AUDIENCES

A Women in Recovery summit should engage the following target groups:

- Women in recovery who are currently receiving addiction treatment and their partners
- Treatment professionals who work with women in recovery communities
- Policymakers who can effect policy changes in systems that address FASD

Other target audiences may include (but are not limited to):

- Educators
- Public health workers
- Schools of public health students and professionals
- Justice professionals
- Mental health workers
- Maternal and child health workers
- Tribal leaders
- Tribal health staff
- Disabilities professionals
- Vocational/rehabilitation workers
- Legislators
- Medical and nursing programs
- Social service workers



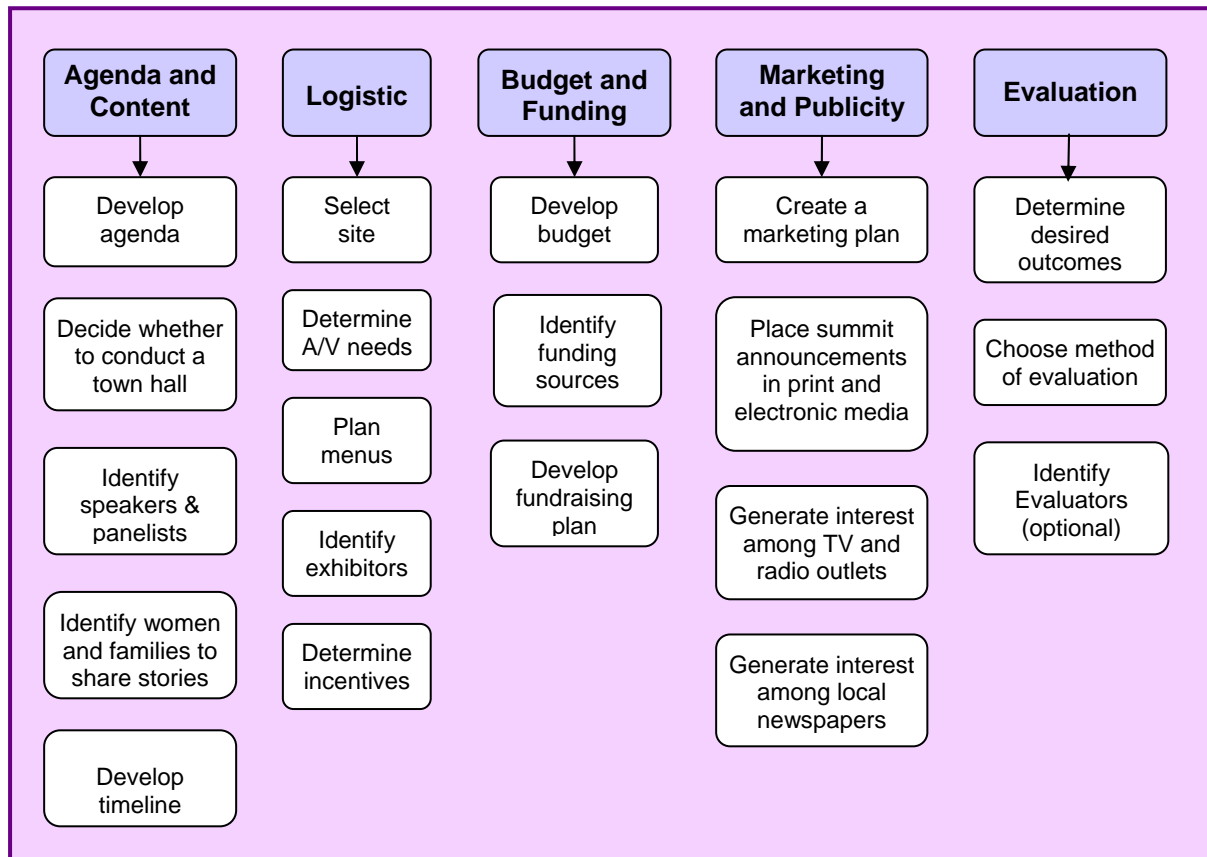
## START YOUR PLANNING!

Preparation to convene a Women in Recovery summit takes as long as a year. This manual provides you with the framework for the summits; information resources; an outline of the summit development steps, including action items and strategies; and a resource kit of sample planning forms, a sample timeline, and other templates.

Remember, this is simply a web guide to planning, and the process of planning is not necessarily linear. For example, some groups may have funding in place or have identified a source at the outset of the process. Others may start raising funds after their first formal planning meeting. Some planners create a draft agenda at the first meeting while others come to the first meeting with a draft already prepared.

Most planners begin their process by identifying planning partners and getting a planning committee up and running. Your first planning meeting will signal the start of actual planning in the key areas shown in exhibit 1 below.

### Exhibit 1. Key Areas of Summit Planning





It is important that you identify at least two key people who will ensure that planners meet all deadlines and that all parties involved in planning the summit are clear on their roles and responsibilities. It is also vital to create a task timeline and convene regular meetings with the planning committee. Include your organization's Board of Directors in the planning process, as their buy-in and support can make a difference. If they cannot participate in scheduled meetings, keep them updated and meet separately with them to assist in identifying key stakeholders, such as politicians, public relations or media representatives, celebrities, and donors to contact for support.

Planning a summit is a great way to effect change for FASD prevention and treatment services in your community. However, the planning can be very challenging and requires a substantial commitment. Therefore, getting organized during the planning phase of the summit will make the process less taxing and help to avoid costly or time-consuming errors.



## SECTION 2: PLANNING AND CONVENING THE SUMMIT

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### IDENTIFY PARTNERS AND ESTABLISH A PLANNING COMMITTEE

During this phase of the planning stage, you will identify partners and establish a planning committee to help guide the development and direction of the summit. Begin by identifying agencies, organizations, coalitions, and civic and service associations that provide services and outreach for women, children, and members of the addiction and recovery communities. It is important that partners have a vested interest in issues specifically related to addictions and maternal and child health. These types of partnerships provide great opportunities to broaden the scope and reach of the summit activities. They also serve to build community support and enhance the credibility of the overall program.

### WHOM SHOULD YOU PARTNER WITH?

Substance abuse counselors, treatment providers, and treatment organizations will be among your most critical partnerships. A summit of this nature needs women in recovery to participate, so you will need the cooperation and involvement of the people who treat and support them. These providers have a vested interest in the success of these summits and will likely be your most active and effective partners.

#### Planning Tip

Don't forget to plan for a pre-summit workshop for treatment center staff a few weeks prior to the summit. Their clients—women in recovery—are a key audience. Not only will this benefit their clients, it will help generate support for the summit and will help you meet your attendance goals.

Here are some considerations when selecting partners from the treatment community:

- Choose treatment centers that are not located too far from the summit site
- Identify inpatient centers that are able to transport clients
- Identify treatment centers that offer special services for women
- Avoid outpatient and methadone centers, which present challenges for determining the number of attendees



Next, seek representatives from State and local agencies and organizations, such as NOFAS, Planned Parenthood, March of Dimes, Al-Anon, and any other regional agency or organization that advocates for women, children, and members of the recovery community.

Forging partnerships with policymakers, including State legislators, elected county officials, or city council members, can produce other invaluable outcomes. Contact them at the State capital or in a local office. In some States, you may reach the policymaker directly; in other States—especially in larger ones—staff people will be the point of contact on health issues. In addition, check out the legislative (State, county, or city) Web site, see who is on the health committees, and contact them. You are well on your way to success if a legislator or a legislative staff person agrees to be on your planning committee. Their presence may also generate interest among funding sources and local media.

Likewise, it is important to contact the Governor’s office, as well as the State or local public health agency and the State agency that handles substance abuse matters. Their input and cooperation is essential as their offices are involved in prioritizing policy and administering funds for programs that concern persons affected by FASD.

Other local planning partners could be:

- Educators
- Schools of public health, both students and professors
- Justice professionals
- Maternal and child health professionals
- Tribal leaders and tribal health staff
- Medical, mental health, and social service professionals

### Planning Tip

A school of public health can be a valuable resource. Use them! Many require that students do an internship, practicum, or thesis. At the outset of planning, contact a local school of public health to find a student who wants to be involved, or a team of students who want to do this as a group project. In addition to being a source of fresh ideas, they can write marketing materials, take notes, and otherwise help out at the meeting, and even take on the evaluation as a topic for credit.



## HOW LARGE SHOULD THE SUMMIT PLANNING COMMITTEE BE?



Your core group of planners should be as large as you need it to be to get the job done. Start with 5 to 10 people and plan to augment that core group with representatives from the community and those listed above. Know that the core group will do most of the work and be required to meet frequently. The other partners, however, will be important for community buy-in, feedback, and other resources you may need.

## WHAT ARE THE ROLES WITHIN THE PLANNING COMMITTEE?

Strong leadership is essential during the planning process. Once you have identified the planning committee, the next step is to establish and assign leadership roles, including the following:

- The **committee chairperson** (and possibly co-chair) leads the committee meetings, assists in the planning tasks, and has primary responsibility for task completion.
- The **committee secretary** takes meeting minutes and distributes them by e-mail and/or hard copy to committee members prior to the next meeting. He or she may also be responsible for reminding committee members of upcoming meetings.
- Other committee members may act as **subcommittee chairs** or take lead roles for specific tasks (e.g., evaluation, incentives, town hall meeting) and may convene their own subcommittee meetings.

## WHAT ARE THE FUNCTIONS AND RESPONSIBILITIES OF THE PLANNING COMMITTEE?

The following tasks are the nuts and bolts of planning a Women in Recovery summit.

- Set the goals for the summit
- Determine the desired outcomes of the summit
- Identify the summit location
- Draft an agenda
- Identify speakers/panelists
- Create a budget and set fundraising goals
- Devise a marketing and publicity plan
- Develop summit materials



- Organizing exhibits
- Identify potential partners/sponsors

Once you have your planning team set, your next task is to select a place and time to hold that all-important first meeting. This initial meeting marks the start of your actual summit planning phase.



# SUMMIT PLANNING MEETINGS

## WHERE SHOULD YOU HOLD YOUR PLANNING MEETINGS?

Your best source of potential planning meeting venues will be the members of the planning committee. Many offices have conference rooms, and a member may be able to secure their space for one or more meetings. Or consider asking a local treatment center to host the initial planning committee meeting. The center may even be willing to host all of the meetings. Be sure to have on hand poster paper, tape, markers, a laptop computer, and, if possible, a projector. Internet access or a wireless connection might also come in handy for on-the-spot research.

### Planning Tip

Send out the agenda for planning meetings at least 1 week prior to the meeting. Call or e-mail members a day or so prior to the meeting to remind them of the meeting's date, time, and location.

## WHAT SHOULD TAKE PLACE AT THE FIRST MEETING?

### **Set leadership, identify partners and key planners**

Establish leadership roles if you have not done so already. If necessary, decide who you want to round out your planning team, either as core members or as adjunct members. Identify at least two key people who will ensure that planners meet all deadlines.

### **Set your goals**

Review the goals set forth in Section 1. You may need to tweak or adapt them to conditions in your State or community.

### **Determine your desired outcomes**

These outcomes, in addition to your goals, will guide your planning. Give each member a chance to share what they think should result from the meeting. Outcomes should be realistic and tailored to the needs in your communities. Examples may include:

- Legislation to facilitate services related to FASD
- Increased resources for FASD



- Policy changes in the education, social service, or justice systems
- A formalized Circle of Hope network of women in recovery (see page 36 for more information)
- A network of persons with an FASD and/or their families

### HOLD AN INITIAL DISCUSSION ABOUT THE BUDGET

It is important to have a discussion about the budget early in the meeting as it will influence where you hold your summit, how many people you will be able to invite, what type of food you will serve (refreshments or meals), and a host of other factors. By meeting's end, you will want to have a ballpark estimate of what the summit will cost and how much money you will need to raise.

#### Some questions to guide your budget discussion

- Will you pay for meeting space?
- Will you have a registration fee for attendees?
- Will you offer scholarships to those who cannot pay?
- Will you pay speakers and panelists?
- Will you pay expenses for speakers or other guests?
- Will you serve lunch or food at breaks?
- Will you hire evaluation specialists?

### DISCUSS POTENTIAL DATES AND LOCATIONS OF THE SUMMIT

If possible, research a list of potential sites before the first meeting to get the discussion rolling. If you do not have a prepared list, brainstorm until you have four or five sites that you can explore for cost, suitability, and availability. While hotels are always a popular meeting site, State universities and colleges often have reasonably priced facilities and meeting planning packages. Hospitals, churches, and synagogues represent other, less expensive alternatives. In addition, many areas have a nonprofit support center that may have a list of conference sites that cater to nonprofits. It is quite possible that a planning member is connected to one of these centers.

Investigate the possibility of holding the summit in conjunction with another community event to boost interest in the summit and lower costs. You may want to plan the summit around International FASD Awareness Day, National Recovery Month, Mothers Day, or another relevant date. However, be sure to avoid scheduling conflicts with other conferences or trainings that may attract a similar audience.

### CREATE A PLANNING SCHEDULE OR TIMELINE

Create a timeline with key dates and responsibilities. See Appendix A for a sample timeline and use that as a starting point.



## DISCUSS AND CREATE SUBCOMMITTEES

Create subcommittees based on meeting planning tasks or meeting segments. Possible subcommittees include:

- Program and agenda (this includes speakers)
- Fundraising (may include grant writing, soliciting donations, and identifying sponsors)
- Logistics (secure the meeting space, decide on food, exhibits, etc.)
- Marketing and publicity (contact media, advertise in newsletters and Web sites)
- Town hall session (coordinate with individuals and families affected by FASD and the policymakers who will attend)
- Evaluation

### First Meeting: Agenda Items

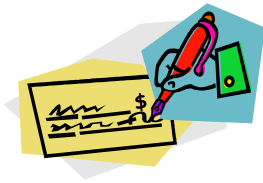
1. Planning committee leadership
2. Who else to involve
3. Summit goals
4. Summit outcomes
5. Budget and funding needs
6. Summit date and location
7. Summit timeline
8. Subcommittees

## HOW LONG AND HOW FREQUENT SHOULD THE MEETINGS BE?

The first meeting should be at least a half-day long, with subsequent meetings lasting 2 to 3 hours. Plan to have the second meeting no more than a week after the first meeting since you are making critical decisions during this phase and it is important that you stay on track with the timeline. To form cohesiveness in your committee, to share the workload, to avoid errors, and to ensure members stay engaged and focused, you should plan for a *minimum* of four subsequent planning meetings and one short wrap-up meeting. Some communities have elected to meet monthly or even biweekly, while others have not found that necessary and have used conference calls and group e-mails to communicate.

## IDENTIFY YOUR FUNDING SOURCES AND SPONSORS

At, or even before, your first planning meeting, you will need to develop a budget and determine how you will pay for the summit. In the event you are starting from scratch and need to raise most of the necessary funds for the summit, you should begin the fundraising process immediately. You may even start to seek funds before the real planning is underway. Funding is available if you are willing to work for it. There are hundreds of foundations that disburse grant funds only in their local area.



- Poll committee members (or potential committee members) and partners to see whether they have knowledge of local foundations or other entities that may be potential sources of seed money.
- Conduct online research to see whether there are foundations or government agencies that may fund small meetings (For instance, conference grants from SAMHSA). Start with a narrow search and broaden it as you go, i.e., start with “FAS” or “FASD” as part of your keyword search, then use more expansive terms like “alcohol prevention,” “community health,” “maternal and child health,” etc. Other keywords might be “small meetings,” “seed money,” “foundations” “name of your State, city, county,” “grants,” etc.
- Check the public library or the closest nonprofit support center to see what resources or information they have about local grant-making organizations.

Regardless of the availability of public funds or other financial resources, minimizing costs wherever possible can enhance the scope of your summit. Even if funding is not a concern, a budget will allow you to track expenses, anticipate cost variances, and seek in-kind support or supplemental funding for specific line items. You might consider the following:

- Explore locations where the summit may be held free of charge or at a reduced cost (e.g., a university conference center, local hospital, church, or synagogue).
- Identify partners, such as a private treatment center, to sponsor one of the meals or cover other specific expenses.
- Tap into a local FASD parent group or FASD organization for assistance or volunteers.
- Identify a local alumni group from a treatment center that may offer assistance.
- Contact a school of public health to find a student or entire class that could adopt the project, conduct the evaluation, and possibly offer other support.
- Ask a local school or college media or film department to volunteer their services to assist in meeting your summit’s audiovisual needs. Note: Some hotels and other host venues may require use of their audiovisual equipment; inquire in advance.

### Planning Tip

Draft an attractive brochure or flyer that contains the details of the summit. You can use this for a variety of purposes: to solicit funds from potential donors, to entice speakers, and to attract attendees.



# BUILD YOUR SUMMIT AGENDA

The summit is designed to include two separate and distinct sessions, with an option for a third component (see a sample agenda in Appendix B):

- **Day 1:** Conference for women in addiction treatment and treatment professionals
- **Day 2:** Conference for State policymakers
- **Town hall meeting (optional; often held on the afternoon of Day 1):** Town hall-style gathering for women, families, community members, and service providers to share personal experiences about addiction and FASD with policymakers and officials

## DAY 1: CONTENT AND AGENDA

The content for Day 1 should include the basic science of FASD, a discussion of issues related to women and alcohol, strategies for parents of children with an FASD, and local referrals for assessment and treatment of FASD. A hopeful tone should be the common thread woven through all of the topics. Design your sessions not only to educate women about FASD but also to inspire them to feel hopeful about their recovery and to assist in reducing the stigma, guilt, and shame that they may experience. Designate treatment staff to be available onsite to provide support to women who may experience powerful emotions after hearing about FASD for the first time.



We suggest that Day 1 begin at 8:30 a.m. thus giving participants enough time to arrive, register, have breakfast, and take their seats. Allow extra time for each presenter so the summit will stay on schedule and conclude on time. An effective and tactful moderator on both days can help make the agenda flow and ensure that time limits for speakers and breaks are adhered to as closely as possible. Plan to end the first day of the summit at approximately 4:30 p.m.

## IDENTIFY YOUR SPEAKERS

It is important to ensure that the speakers you select have current and accurate scientific information. You can identify speakers, materials, PowerPoint presentations, or trainers with



the help of the FASD Center for Excellence ([www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov)) or NOFAS ([www.nofas.org](http://www.nofas.org)).

Birth mothers of children with an FASD will provide much of the content for Day 1. FASD birth mothers offer a unique perspective of hope and are sensitive to the specific needs of women in recovery. For more information, ask NOFAS about the Circle of Hope, a national coalition of birth mothers. It is always best to strive for diversity on panels and to include speakers who are culturally sensitive. Speakers should also be able to relate to and/or reflect the targeted audience. These factors are important for reducing the stigma and guilt associated with alcohol use during pregnancy.

## OPTIONAL COMPONENTS

### *Town Hall Meeting*

The Town Hall meeting is an optional but recommended component of the Women in Recovery summit. It provides a forum for birth mothers in recovery, parents, individuals with an FASD, and their service providers to share their stories with Federal, State, and local policymakers who are agents for change. Town hall meetings are usually held in the afternoon of Day 1. They differ from the panel discussions in that they are less structured. Those who testify simply share their feelings and stories while the policymakers are there to listen. Discussions may ensue, they may not. There are no presentations. Tips for planning the Town Hall session can be found in the Chapter titled Additional and Optional Programs: Town Hall Meeting, on page 38.

### *Opening/Closing Ceremonies*

Including a spiritual opening and/or closing at the summit can empower women in treatment and provide hope for their journey to recovery, but it is important that it be culturally appropriate for your audience. The summit planning committee should identify leaders to deliver the spiritual opening and/or closing, making sure that any materials used are appropriate. For example, the burning and smell of sage can have a trigger effect for some women in treatment.

## DAY 2: CONTENT AND AGENDA

Policymakers from your State or local area are the primary target audience for Day 2. The goal for the second day is to mobilize them—along with the women in recovery or those affected by FASD—into action on FASD-related issues. The agenda should incorporate the following:

- A summary of the science of FASD
- Descriptions of the incidence and costs of FASD in your State



- A description of current State and local FASD services along with a discussion of what is needed and what your State model might look like
- A panel of families impacted by FASD to describe their experience and their needs
- A briefing by a representative from a State that has developed a model system for addressing FASD or has taken successful steps to tackle the issue
- A panel of State agency directors and administrators to discuss their charge to address FASD

That final item is one of the most significant. It can set the stage or even produce a blueprint for future action on FASD in your State or local area. This panel discussion ties back to your desired outcomes, so be clear when inviting and talking to panelists ahead of time about what it is you want to achieve in this discussion. Get a strong facilitator for this session, ideally from the planning committee, to keep the discussion on track.



## IDENTIFY YOUR SPEAKERS

Day 2 speakers might include the following:



- Speakers and experts who can speak to the state of FASD in your State or local area
- Members of Native American tribes in the State who can describe the impact of FASD in their community
- Parents and families who will participate on the family panel
- State agency representatives and a State or local area legislator for the State panel
- An expert who can report on the costs of FASD in the State (to find a cost expert, contact the Lewin Group, as noted in the Resource List)
- A speaker from a State that has developed a model system for addressing FASD

The agenda for Day 2 includes a plenary speaker and a keynote address. These speakers should be well-respected community leaders or public officials with current knowledge of the issues that families and individuals with an FASD face.

### Planning Tip

Develop a speaker information sheet that you can send to panelists and speakers. In addition to the why, where, what, and when information, also include the amount of time they have to speak, how much time you are allotting for Q & A, and a deadline for them to submit their notebook materials and bio to you.



# PLAN SUMMIT LOGISTICS

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## SITE SELECTION

Start early! Desirable meeting space fills up quickly, so site selection should be done near the beginning of your planning process. Possible venues include the following (with the last two options being the least expensive):

- Hotels
- Colleges and universities
- Conference or retreat centers
- Church or synagogue meeting rooms
- Hospitals

Questions to ask when choosing a location for the summit:

- How safe is the neighborhood surrounding the venue?
- What are the transportation and parking options?
- If participants require overnight accommodations, how many rooms are open? What are the characteristics of the minimum-grade room available?
- Does the venue comply with the American for Disabilities Act (ADA) requirements?

## BREAKS AND FOOD

If at all possible, feed your audience well. On Day 1, provide breakfast, lunch, and food for at least two additional breaks. Day 2 should include lunch and at least one additional food break.

If you want to provide your own food or food from another source, find out whether your hotel or host venue requires use of their caterer. Many do, so be sure to ask first. Ask the hotel or venue about special arrangements, such as buy-one-get-one-free deals. Consider asking a meeting partner, community group, or local business to sponsor the refreshments as in-kind donations.

Consider diet preferences and restrictions when planning menus. Provide space on the summit registration form to allow participants to note any dietary requirements.



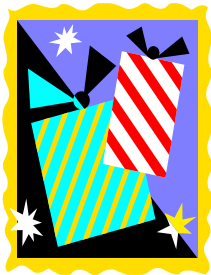


display and exhibit areas. Participants should be made aware of the display/exhibit area (if it is not immediately obvious) and encouraged to visit it.

When speaking with individuals or organizations that wish to exhibit at the summit, encourage them to do so on both Day 1 and Day 2. To retain exhibitors through both days, you may want to show them a list of confirmed Day 2 participants, explain to them how beneficial their continued participation would be, and have the moderator remind participants to visit the display/exhibition area.

## INCENTIVES

If possible, provide gift bags to participants as a thank-you for attending the summit. They can serve as an incentive to complete the evaluations (distribute the gift bags when collecting the completed evaluations). Identify potential donors for gift bag items and other summit incentives (e.g., door prizes) early in the planning process.



At past summits, planners collected gift bag items from local or national companies by writing letters to request in-kind donations (see Appendix D) or by requesting donations through company Web sites. Complete letters and requests at least 6 to 9 months before the event.

The planning committee should also consider the following when discussing incentives:

- Providing speakers with small tokens of appreciation
- Giving door prizes throughout the conference to keep participants engaged and interested
- Making sure that incentives meet the standards of participating treatment centers and are appropriate for women in treatment (e.g., no products with alcohol or caffeine)



# MARKETING THE SUMMIT

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## MARKETING FOR PARTICIPANTS

Establish a targeted number of attendees for all components of the summit and then determine whether you will need to market the event to reach your goal. Some communities have had such a great response from the summit planning committee that marketing was not needed. Some successful marketing strategies include:

- Working with treatment centers to gain the participation of women receiving addiction treatment.
- Placing announcements on Web sites and in newsletters of participating agencies and organizations.
- Identifying publications appropriate to your audience that feature a “Calendar of Events.”
- Identifying TV and radio stations that broadcast community calendars of events in your area. In some smaller markets, National Public Radio stations provide this service.
- Getting a mention in the Alcoholics Anonymous publication “The Grapevine.”
- Being showcased in State health and human service agencies via e-mails or listservs.
- Generating word of mouth.

### Planning Tip

One of the more daunting challenges you may encounter will be getting women in recovery to attend. A strong alliance with area treatment centers will be key in addressing this hurdle. Planners of past summits worked closely with the treatment centers; many counselors drove their clients to the summit.

## MARKETING FOR PUBLICITY

Attracting press and media attention is another way to successfully market the summit. While media attention is likely to be beneficial to your endeavors, the potential also exists for negative coverage. Hence, it is best to be prepared. Early on, designate a planning committee member—such as the person who chairs the marketing subcommittee—to be the media liaison. It will be the task of the marketing or publicity subcommittee to craft a marketing plan for your Women in Recovery summit.

### Planning Tip

Including a local celebrity or politician on the agenda may make the summit more newsworthy and give you a better chance of attracting media attention.



## NEWSPAPERS/PRINT MEDIA

Newspapers should be your primary target as they remain a popular source of local information. In addition, papers offer the potential for in-depth coverage. Some community and special interest newspapers will print whatever you send them; others may even send a reporter to your event.

Press releases should be faxed to local newspapers 2 weeks prior to the summit and again during the week of the summit. A sample press release is included in Appendix F. Points to consider include:

- Find out who the editors of the paper are and address the release to them by name.
- Use any media contacts you or other planners have to make personal calls to request that the story be covered.
- Be concise but clear about FASD as an issue, highlight any well-known speakers, and include audience numbers, location, dates, and times.
- Consider targeting specific columnists, editorial writers, or journalists and send them story angles with suggestions of people who are willing to be interviewed. (Obviously, you will have obtained permission from any potential interview subjects!)
- Use your organization's newsletter, or a newsletter from a planning partner, to convey information to media outlets, both before and after the event.

## ELECTRONIC MEDIA

The principles of marketing to TV and radio outlets are similar to those of print media. Strategies to consider:

- Identify local TV and radio stations that air announcements of local events. Some may help you record an announcement. Many will announce your summit as part of a calendar of events. Contact the station's public affairs director.
- Look for outlets that reach small targeted audiences, such as public access cable TV stations and college radio stations.



- Use the public access channels available from your cable television provider. They often cover community events or produce talk shows that discuss local happenings or issues. This is a great way to get a televised feature story about FASD.

### Planning Tip

Identify individuals affected by FASD, along with one or two planners, who are willing to do interviews. Coach them. Radio and TV interviewers love articulate and prepared local spokespersons.



# EVALUATING THE SUMMIT

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Evaluation can be a very valuable component of the summit. A decision about whether or not to conduct an evaluation will depend on your needs and resources, as well as funder requirements. If you choose to conduct an evaluation, you should identify someone early on to be responsible for this task.

An evaluation provides information to improve future summits or similar meetings and to achieve intended outcomes. Depending on the circumstances, you might explore evaluators from evaluating agencies or contact a social service agency or a school of public health. Some schools have classes or students that have to conduct a credible, supervised evaluation as a class assignment and will often do so free of charge. No matter what you decide, it is important that your evaluators are active in the initial planning phases of the summit. Keeping the summit goals in mind will help you identify the best evaluation methods for your needs and conduct a successful evaluation.

## EVALUATION TOOLS

Planners of past Hope for Women in Recovery summits have administered pre- and posttests to gauge the amount of knowledge about FASD gained during the event. This manual includes that tool (see Appendix C), which you can copy or modify. Another form of evaluation might be a structured, post-summit debrief of the planning group. Together, these assessments can provide information on what should be done to change or improve the intended outcomes when you decide to host another summit or similar event.

## MAXIMIZING EVALUATION COLLECTION

Collecting completed evaluations can be challenging, especially when working with large numbers of participants. To encourage participants to complete the evaluations, incentives such as gift bags can be distributed when the participant returns a completed evaluation form.



# FOLLOWUP

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After the summit ends, start your post-summit activities by taking care of the followup tasks that are important after any meeting. In the days immediately following the summit:

- Conduct a planning committee debrief to discuss what went well and what could have been improved.
- Send thank-you letters to all presenters, panelists, and to the treatment centers
- Compile a database of contacts.
- Send packets of information to community leaders and VIPs who could not attend.
- Plan a post-summit press release.
- Compile evaluations.

## STIMULATING CHANGE

The next steps can lead to real change. Your successful summit has likely generated policy recommendations and highlighted needs in your community. Capitalize on the summit momentum by immediately scheduling sit-down appointments with key legislators and policymakers to discuss next steps. Maintain contact with them to keep them apprised of needs and progress. They are critical to the success of future efforts. If they were not able to attend the summit, you will need to educate them on FASD and issues related to FASD. Prepare talking points prior to your meetings and let them know about policy changes that would be helpful. (See Appendix I for tips on meeting with policymakers.)

One concrete step that States and local areas can take is to marshal support and organize an FASD task force, which can facilitate long-term changes in FASD policies and funding. Whether the task force is Statewide or local, the objectives are the same: determine the extent of the problem and recommend a response to address it.

### *Local or Community Task Force*

Effective community task forces involve a wide range of participants, including:

- Parents of children with an FASD
- Educators
- Behavioral health providers, including addiction professionals



- Public health providers
- Students
- Local or State legislators
- Community leaders or tribal elders
- Representatives from criminal justice, child welfare, and vocational training

Once a task force forms, it can:

- Educate the community about FASD and the consequences of drinking alcohol while pregnant through speaking engagements, public forums, public service announcements, distribution of materials available through NCADI, the Arc, NOFAS, CDC, and the March of Dimes.
- Identify and share information on effective evidence-based methods of preventing FASD and alcohol-exposed pregnancies and working with people with an FASD.
- Identify and share information on policies that have helped other states and localities reduce their rates of FASD.
- Conduct FASD training in the community (in health care clinics, schools, early childhood centers, etc.) on evidence-based treatment and prevention practices.
- Create or increase support services for those affected by FASD.
- Foster the development of diagnostic teams, which can involve more community members and make significant changes in attitudes.

### **State Task Forces**

A Statewide task force can assess the current level of FASD services and measure the gap between those services and identified needs. It can determine what the State's response should be and make recommendations on how to achieve that response. Like the community task force, State task forces involve a wide range of participants, including:

- State agencies, including social services, public health, corrections, and education
- State Board of Education
- FASD service providers
- Parents and advocates
- State legislators
- Local chapters of the March of Dimes, the American Academy of Pediatrics, and the American College of Obstetrics and Gynecology



Some activities and goals that State task forces could pursue include:

- Conduct outreach efforts aimed at pregnant women and women of childbearing age.
- Provide training on FASD for health care professionals working with at-risk women.
- Ensure that providers have access to FASD materials for their staff and patients.
- Identify and implement evidence-based screening and diagnostic practices that will increase the numbers of people identified and diagnosed as having an FASD.
- Create and increase access to multidisciplinary systems of care for those diagnosed.
- Train educators to identify and better serve students who may have an FASD.
- Train corrections officials on how to address the needs of inmates with an FASD.
- Develop education campaigns about the dangers of drinking alcohol while pregnant.
- Establish an FASD coordinator position within a State public health or social services agency.

The Resource List in this guide has links to information about several State and local FASD task forces. These task forces are at different stages of development but all are examples of successful State and local efforts to address FASD.

## **CIRCLE OF HOPE NETWORK FOR WOMEN IN RECOVERY**

One of your desired outcomes from the summit may be the creation of a network of “Warrior Moms.” These are women recovering or trying to recover from an addictive disorder. The term “Warrior Moms” is a salute to and acknowledgement of their incredible strength.

The Circle of Hope is a birth mother network of women in recovery from alcohol and drug addiction who used alcohol during pregnancy and may have children with FAS/FASD. Circle of Hope is evolving into a national network of women united in a circle of support and understanding. Circle of Hope provides mentoring, family support, and educational resources for its members and their families.

To generate interest, work with the local treatment centers before the summit to get the word out about the Circle of Hope. Mention the network during the summit and hand out “Warrior Moms” network forms. Ask interested attendees to complete and hand in the form before they leave or set up a table for sign-up. Order “Warrior Mom” T-shirts from NOFAS and hand them out to people who sign up.

Contact NOFAS (see Resource List) for more information and advice on how to establish and grow a Circle of Hope network.



# ADDITIONAL AND OPTIONAL PROGRAMS: THE TOWN HALL MEETING

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## THE TOWN HALL MEETING

The Town hall meeting is an event within an event. If you choose to incorporate a town hall meeting into your summit, here are the decision points you will encounter:

- Manpower
- Budget
- Moderator
- Panelists
- Testifiers
- Town hall location and time (usually late afternoon or evening of Day 1)
- Scheduling of testimonies
- A/V needs
- Recording (tape or writer)
- Press and media
- Confidentiality
- Barriers to testifying (times, child care, etc.) and solutions for women in treatment

## LOGISTICAL CONSIDERATIONS

- Make sure that the summit site has enough space for the town hall meeting.
- Have the room set up at least 1 hour before the town hall meeting starts (see Appendix F).
- Schedule the town hall meeting for no longer than 2 to 3 hours.
- Limit testimonies to 3 to 5 minutes (depending on the numbers of oral testimonies).
- Have a moderator keep the official clock and identify appropriate moments to interrupt testimonies if necessary.



- Include all participants on the agenda.
- Allow individuals who do not wish to testify in person to provide written testimony; have a designated person read it for them.
- Ask participants to sign release and informed consent forms during registration (see Appendix E).
- Secure additional private space for participants who may need to talk in confidence or submit private testimonies.
- Plan for A/V equipment.
- Plan for attendees with special needs (e.g., wheelchair access, sign language interpreters).
- Provide free parking or parking passes for panel members and testifiers.
- Include water on the panelist table and refresh as needed.
- Provide at least water and hard candies for all participants.

### **ASSEMBLING A TEAM OF TOWN HALL PLANNERS**

It is important to have a good team for a successful town hall meeting. Team members should be able to:

- Identify and call the potential moderator, panelists, and testifiers.
- Develop and maintain an active database of invitees and attendees.
- Create registration forms, release forms, and consent documents.
- Staff the registration table(s).
- Develop information packets for panel members.
- Conduct media outreach.
- Develop event-related materials.
- Complete followup tasks.
- Solidify partnerships and working relationships.
- Assist in facilitating the town hall meeting.

### **RECRUITING TOWN HALL PARTICIPANTS**

The planning committee should be responsible for developing the initial list of candidates to serve as moderator, panelists, and testifiers. The moderator for the summit may also agree to serve as the moderator for the town hall. The list of potential panelists should include at least 20 names, because many of the invitees will decline.



If a committee member has a personal relationship with a potential panelist, he or she should make the first contact—by phone, e-mail, letter, or in-person visit. The chair of the committee can follow up immediately with a letter and phone call.

Once you have set your summit date and location, send out formal letters from the Chair announcing the summit and inviting the recipients to participate on the town hall meeting panel. Once a panelist has accepted the invitation, send a confirmation letter 1 month and again 1 week prior to the event.

Planners also need to recruit individuals to provide personal testimony. Potential testifiers include participants in the Women in Recovery summit, women in treatment, and/or their counselors. The target number of testifiers will depend on the amount of time allotted for the town hall meeting.

## MODERATING THE TOWN HALL

The moderator is responsible for maintaining the order and focus of the town hall meeting. Specific tasks include:

- Opening the meeting
- Welcoming participants and introducing panelists
- Calling on testifiers
- Acting as the timekeeper
- Thanking testifiers
- Opening the floor for panelist responses
- Providing comments and feedback and posing questions

The moderator should have the following qualities:

- Knowledge of issues relating to FASD and women and addiction
- Good communication skills
- Organization
- Confidence
- Professionalism
- Ability to manage the flow of discussion



## PANELISTS

The role of a panelist is to listen to personal testimonies related to FASD, women and addiction, and related services. Give panelists the opportunity to respond with comments or questions after each individual testimony. Encourage them to analyze and use the information they learn and to share it with their colleagues to promote changes in practice and policy within their respective arenas. There should be about 12 panelists. The following groups can be good sources of potential panelists:

- Mental and behavioral health professionals
- Addiction professionals
- Allied health professionals
- Physicians
- Tribal councils
- Federal, State, and local officials
- Justice and juvenile justice professionals
- Parole and probation officers
- Social workers
- School systems
- Managed care organizations
- Medicaid representatives
- Social services and disability agencies
- Legislators

## TESTIFIERS

Anyone who can describe a real-life personal experience with addiction and FASD may provide testimony. The list of potential testifiers includes:

- Women in addiction treatment
- Women who used alcohol during pregnancy
- Individuals with an FASD
- Families affected by an FASD
- Physicians and other health professionals who work in addiction or FASD
- Other addiction professionals
- Justice/juvenile justice professionals



- Tribal justice/court professionals
- Tribal law enforcement professionals
- Teachers
- Social workers
- Disabilities service providers

Topics addressed in the personal testimony may include, but are not limited to:

- Barriers and challenges to navigating health and social services
- Educational needs
- Lack of knowledge among physicians, allied health professionals, and other professionals
- Federal, State, and local policies and practices
- Lack of resources for improved quality of life
- Transition services
- Job services



## PREPARATION TIPS FOR TESTIFIERS

Planners and facilitators can discuss and distribute the following tips to persons who agree to testify. For many testifiers, this may be their first public speaking experience. For most, these are difficult and emotional issues. Helping them prepare will ease their anxiety and make this a truly positive experience.

- There is no right or wrong thing to say or way to feel. The key is to talk about how you feel and how you see the situation now. Your story may change from one day to the next. You may feel frightened, tearful, angry, or proud. You can turn grief and anger into constructive energy.
- You are the expert in the care of your child with special needs. Family stories are important to both parents and professionals. They help parents know they are not alone and they provide insight for professionals and providers. The information can help service providers create new and effective programs.
- Share your story when you feel comfortable. You can provide written testimony if you prefer.
- Issues to address can include medication, finances, emotions, education, dependency, fears, dreams, and impact on marriages. Share positive and negative experiences.



- Open with name, partner, where you live, and number of children.
- Relax. Take a few deep breaths and look for a friendly or familiar face, project (use the microphone), and speak calmly and slowly. It helps to write your story down when you have only a specified time to talk.
- Make eye contact, look at friendly faces, and look around so that everyone feels included.
- Humor is fine but not sarcasm or teasing. Also, it is okay to say “I don’t know” or “I don’t want to answer that.” If you cry, take some deep breaths and take a moment to compose yourself. You might want to hold on to something to help you relax, such as a pen or a stress ball.
- You are not alone. You are the expert. Strength and power come from accepting, sharing, and change.

You can also obtain a brochure on planning a town hall meeting from the FASD Center for Excellence Web site ([www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov)).



# ADDITIONAL PROGRAM: PRE-SUMMIT WORKSHOPS FOR TREATMENT CENTER STAFF

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## PRE-SUMMIT WORKSHOPS FOR TREATMENT CENTER STAFF

Pre-summit workshops can help generate support for the summit and present its goals and logistics. Even more importantly, they can help treatment staff understand FASD and incorporate that knowledge into their approach to treatment. Educating treatment staff about FASD prior to the summit also will benefit their clients, who may need extra support after learning about FASD at the summit.

It is important to conduct a pre-summit workshop for treatment professionals from each invited treatment center. This task is easily accomplished if you are working with a coalition of women in treatment. If not, see whether you can present a 30- to 60-minute workshop at a regularly scheduled meeting of the treatment centers, or conduct individual workshops at each center.

Clients of the treatment centers attending the summit should not be invited to the pre-summit workshop. Too much exposure to information about alcohol, pregnancy, and FASD prior to the summit may taint evaluation results and limit your ability to measure increases in knowledge.

The pre-summit workshop agenda should include:

- Goals and objectives of the summit (and town hall meeting)
- Brief background information on FASD
- Impact of FASD on clients, children, and communities
- FASD in the clinical setting
- Spiritual healing (if appropriate for your community)
- Summit and town hall meeting logistics (e.g., transportation, agenda, and lunch)
- Tips to encourage clients to share their stories (have women write their stories in advance)
- The importance of the evaluation process



- The pre-registration, registration, and departure process
- The need for adequate staffing from treatment centers with clients in attendance
- Resources, such as training materials and trainer contacts, are available through NOFAS and the FASD Center for Excellence to help ensure that essential content about FASD is covered (see [www.nofas.org](http://www.nofas.org) and [www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov))



## SECTION 3: INFORMATION AND RESOURCE LIST

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### FEDERAL AGENCIES

#### **Centers for Disease Control and Prevention (CDC)**

[www.cdc.gov/ncbddd/fas](http://www.cdc.gov/ncbddd/fas)

800-311-3435 or 404-639-3534

CDC addresses FAS through the activities of its FAS program, which focuses on prevention. CDC also hosts the National Task Force on FAS/Fetal Alcohol Effect. In addition, diagnostic guidelines are now available online in PDF format.

#### **Indian Health Service (IHS)**

[www.ihs.gov](http://www.ihs.gov)

301-443-3024

The Indian Health Service Behavioral Health Program strives to eliminate alcoholism and other drug dependencies and improve the health care of American Indians and Alaska Natives.

#### **Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS)**

[www.niaaa.nih.gov/AboutNIAAA/Interagency](http://www.niaaa.nih.gov/AboutNIAAA/Interagency)

ICCFAS is hosted by the National Institute on Alcohol Abuse and Alcoholism. It includes representatives from various branches of the Department of Health and Human Services and the Departments of Education and Justice. ICCFAS members work to exchange information and coordinate Federal FAS strategies and programs.

#### **National Institute on Alcohol Abuse and Alcoholism (NIAAA)**

[www.niaaa.nih.gov](http://www.niaaa.nih.gov)

301-443-3860

NIAAA supports research to improve diagnosis and assessment of impairment and disability and to develop tools to enhance academic and daily living skills. Areas of research include screening, diagnosis, and treatment of FASD.

#### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

[www.samhsa.gov](http://www.samhsa.gov)

(Contact numbers available at <http://www.samhsa.gov/aboutsamhsa/contacts.aspx>)



SAMHSA's mission focuses on building resilience and facilitating recovery for people with or at risk for mental or substance use disorders. The Web site offers resources for help, information on current programs and campaigns, and a feature that allows browsing by topic (including FASD).

**SAMHSA FASD Center for Excellence**

[www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov)  
866-STOPFAS

The SAMHSA FASD Center for Excellence is a Federal initiative devoted to preventing and treating FASD. The Web site provides information and resources about FASD. It also provides materials that can be used to raise awareness about FASD.

**National Clearinghouse for Alcohol and Drug Information (NCADI)**

<http://ncadi.samhsa.gov>  
800-729-6686

NCADI is operated by SAMHSA. It has one of the largest repositories of alcohol and drug information in the world and offers access to current literature, research reports, and educational resources. Their online catalog includes an FASD page.

**NATIONAL ORGANIZATIONS**

**March of Dimes**

[www.marchofdimes.com](http://www.marchofdimes.com)  
888-663-4637

March of Dimes researchers, volunteers, educators, outreach workers, and advocates work together to address prematurity, birth defects, and low birthweight.

**National Organization on Fetal Alcohol Syndrome (NOFAS)**

[www.nofas.org](http://www.nofas.org)  
800-66NOFAS

A co-sponsor of the Hope for Women in Recovery summits, NOFAS is dedicated to eliminating alcohol-related birth defects and improving the quality of life for individuals with FASD and their families. Its Web site is an invaluable resource for any State or local group wanting to convene a Women in Recovery Summit or start up an FASD group. It contains a State-by-State list of FASD activities and resources, FASD advocacy materials, and a community advocacy guide.

**The Arc of the United States**

[www.thearc.org](http://www.thearc.org)  
301-565-3842



The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. The Arc has a [fetal alcohol syndrome](#) page.

## STATE FASD PROGRAMS, TASK FORCES, AND INITIATIVES

### **Alaska Office of Fetal Alcohol Syndrome**

<http://www.hss.state.ak.us/fas/>

907-334-2424

Alaska's FAS project is a comprehensive, integrated effort encompassing FASD prevention, screening, diagnosis, and services.

### **California Fetal Alcohol Spectrum Organization (CalFAS)**

<http://www.calfas.org/>

877-FASD-411

The mission of CalFAS is to prevent FASD and to intervene and provide assistance to those who are living with FASD.

### **Colorado Fetal Alcohol Syndrome Prevention Program**

<http://www.uchsc.edu/ahec/fas/>

1-888-724-FASD (3273)

The Fetal Alcohol Syndrome/Alcohol Tobacco and Other Drug Prevention Outreach Project (POP) is a collaborative effort involving numerous community sectors and health, education, social service, law enforcement, and community groups.

### **Illinois FASD Task Force**

<http://www.prevention.org/Initiatives/FASDTaskForce.asp>

800-252-8951 TDD 217-793-7355

The Illinois FASD Task Force is determining the extent to which prenatal alcohol exposure is a problem in Illinois and will recommend appropriate state responses for preventing, diagnosing, treating and ameliorating the effects of FASD.

### **Maryland FASD Coalition**

[http://www.fha.state.md.us/mch/fasd/html/md\\_fasd.cfm](http://www.fha.state.md.us/mch/fasd/html/md_fasd.cfm)

410-767-6713

The Maryland FASD Coalition came into existence after a September 2003 "Hope for Women in Recovery Summit" in Baltimore. Many key policymakers, including several Maryland legislators, attended the Summit and an FASD Work Group was convened in July 2004 by DHMH and the Governor's Office on Crime Control and Prevention.



**Michigan Department of Community Health Fetal Alcohol Syndrome Program**

<http://fascenter.samhsa.gov/links/links.cfm#3>

517-373-3740 TDD 517-373-35-73

The goals of the fetal alcohol syndrome (FAS) program are to reduce cases of FAS, provide timely diagnosis, and assist with needed support services. Services are provided through Centers of Excellence, community outreach and education projects, and training and consultation.

**Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)**

[www.mofas.org](http://www.mofas.org)

866-90MOFAS

MOFAS is a nonprofit organization dedicated to eliminating alcohol-related birth defects and improving the quality of life for individuals with FASD and their families. MOFAS is the first State affiliate of the National Organization on Fetal Alcohol Syndrome.

**New Jersey Regional FASD Diagnostic Centers**

[http://www.fasnj.org/content/english/nj\\_initiative.html](http://www.fasnj.org/content/english/nj_initiative.html)

973- 972-8930

The New Jersey Regional Fetal Alcohol Spectrum Disorders (FASD) Diagnostic Centers created this Web site to provide information to the families of children for whom prenatal exposure to alcohol may be a diagnostic concern, and for the allied professionals responsible for providing services to them.

**New York FASD Initiative**

<http://www.oasas.state.ny.us/fasd/oasasinitiative.cfm>

518-485-1768

**Texas Office for Prevention of Developmental Disabilities (TOPDD) Fetal Alcohol Syndrome Consortium**

<http://topdd.state.tx.us/fasdprevention.html>

512-206-4544

TOPDD coordinates activity among the many State and private agencies that work to prevent developmental disabilities. The Fetal Alcohol Syndrome Consortium addresses public awareness and education about fetal alcohol syndrome.

**NOFAS Washington**

<http://www.nofaswa.org/>

206-940-2832

The mission of NOFAS Washington is to provide support, education, advocacy, and training on FASD through the cooperation and collaboration of families, caregivers, community providers, professionals, and individuals affected by prenatal alcohol exposure.



### **Washington State FAS Interagency Workgroup (FASIAWG)**

<http://depts.washington.edu/fasdwa/>

800-999-3429 or 253-531-2878

FASIAWG was established in 1995 to coordinate and enhance Washington State FASD screening, diagnosis, intervention, prevention, surveillance, and training programs.

### **The University of Washington Fetal Alcohol and Drug Unit**

<http://depts.washington.edu/fadu>

206-543-7155

The Fetal Alcohol and Drug Unit is a research unit dedicated to the prevention, intervention and treatment of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Their main goals are to conduct research on fetal alcohol and drug effects across the life span, to disseminate information on fetal alcohol and drug effects, to provide consultation for persons of any age thought to be affected by prenatal exposure to alcohol, and to provide training in human behavioral teratology.

### **The University of Washington FAS Diagnostic & Prevention Network**

<http://depts.washington.edu/fasdpn/>

The Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FAS DPN) is a network of five WA State community-based clinics linked by the core clinical/research/training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, WA. The website features a synopsis of successful FASD prevention efforts in Washington State.

## **OTHER FASD RESOURCES AND REPORTS**

### **FASlink**

[www.acbr.com/fas](http://www.acbr.com/fas)

FASlink maintains an active listserv of families and providers affected by, and interested in, FASD.

### **FAS/FAE Legal Issues Resource Center**

<http://depts.washington.edu/fadu/legalissues>

206-543-7155

Sponsored by the University of Washington School of Law and the UW Fetal Alcohol and Drug Unit, the FAS/FAE Web site contains a State-by-State listing of FASD resources, including community-based groups and prevention programs.



### **Fetal Alcohol Spectrum Disorder: Several State Initiatives**

<http://projectforum.org/docs/FetalAlcoholSpectrumDisorder-SeveralStateInitiatives.pdf>

This report by Project Forum describes the characteristics of FASD, identifies several federal-level initiatives that emphasize education and describes four state-level FASD initiatives that involve state education agencies (SEAs).

### **Report on State Approaches to FASD**

[http://www.nofas.org/resource/State\\_Report.htm](http://www.nofas.org/resource/State_Report.htm)

This NOFAS report describes the various approaches States have undertaken to address FASD.

### **Economic Costs of Fetal Alcohol Spectrum Disorders**

<http://fasdcenter.samhsa.gov/documents/UpdatedCostPresentation.ppt>

This report by the Lewin Group details the costs of FASD. Contact the Lewin Group at 703.269.5500 for information on the cost of FASD in your State or to find a cost expert.



# APPENDIX A

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*Summit Planning Checklist*

## APPENDIX A: SUMMIT PLANNING CHECKLIST

This checklist covers many of the planning details. You will find many are discussed in the manual but the list also includes many that are not. Again, use this as a guide and adjust it to your own planning needs and schedule.

### 12-10 Months Prior

- Identify your summit partners
- Hold first planning meeting
  - Set leadership roles
  - Set goals and desired outcomes
  - Discuss proposed summit agenda
  - Define committee members' roles and expectations
  - Review budget and funding sources
  - Review location, date, and time
  - Discuss evaluation
  - Discuss marketing needs and plan
  - Determine next steps and assign tasks
  - Determine planning committee meeting schedule
- Contact the State governor's office and State division of drug and alcohol council to discuss collaborations and ask for feedback on assembling a State panel for Day 2
- Contact State policymakers and politicians with a special interest in women's health issues, substance abuse, etc., and ask for feedback on assembling a State panel for Day 2

### 9-7 Months Prior

- Finalize the summit budget, date, and location
- Send letters inviting speakers and panelists to participate
- Follow up on invitation letters with phone calls
- Review updates on agendas and speakers for all components of the summit
- Review updates on potential panel members for the summit and town hall
- Review updates on women, families, and individuals with an FASD to participate in panels and other elements of the summit
- Identify local speakers and FASD experts
- Identify parents and family members to participate in the family panel
- Identify State agency representatives to participate in the State panel
- Identify local agencies to disseminate information at display tables

- Identify expert that can report on the costs of FASD in the State
- Identify local community members to provide spiritual or cultural remarks or testimony
- Identify community contacts that may be willing to donate items for gift bags
- Draft a brochure or a flyer that gives details on the summit (you will need this for contacting donors and speakers)
- Draft letters to potential donors requesting sponsorship funding or gift bag items
- Continue to monitor all tasks and address logistical barriers

#### **6-4 Months Prior**

- Continue pursuing presenters for both days of the summit:
  - Identify possibilities for a spiritual opening and/or closing
  - Identify possible keynote speakers for both Day 1 and Day 2 (Be flexible in pursuing VIPs; offer morning opening, lunchtime, and closing as possibilities )
- Discuss gift bag ideas with the planning committee and use their contacts for donations
- Revise agenda if necessary to accommodate presenters
- Contact the State licensing counseling board to provide continuing education units (CEUs) for participating counselors (if applicable)
- Create a one-page summary and an “at a glance” document that easily communicates the goals, agenda, and purpose of the summit—to be faxed, e-mailed, and mailed in outreach efforts
- Continue refining the evaluation tool (if used) with the help of the evaluating agency
- Begin collecting resources and materials to be distributed at the summit
- Send letters of request for in-kind donations to targeted companies and organizations
- Create a “presenter information form” to send to all presenters:
  - Collect information on presentation goals, abstracts, A/V needs, and handouts for distribution
- Send an invitation letter to the keynote speaker
- Create a system for collecting all pre- and posttests and evaluations

#### **3-2 Months Prior:**

- Continue corresponding with all involved parties and pursuing speakers and panelists
- Continue outreach for in-kind donations
- Generate mailing list of contacts to receive a “Save the Date” mailing and other summit materials
- Contact NOFAS to order “Warrior Mom” shirts (if planned)

- Create a “Save the Date” mailing and send to all contacts on the mailing list (all materials should include summit logo, if you are using one)
- Contact local organizations to set up display/exhibit tables for both days of the summit
- Send presenter information forms to confirmed presenters and provide a deadline for submitting their PowerPoint presentations
- Send final invitation letters to potential State panelists
- Create drafts of brochures and folder materials to be distributed at the event
- Draft a press release and compile a contact list of local newspapers radio/TV stations
- Complete all CEU paperwork and submit it to licensing boards
- Create registration form and make it available online if possible
- Conduct followup calls with all contacts on mailing lists
- Send invitations letters to all health officers to attend the summit
- Finalize agenda
- Schedule dates to visit treatment centers for pre-summit workshop

### **1 Month Prior**

- Review the agenda and make any last-minute changes
- Confirm all presenters, keynote speaker, spiritual closing, State panelists, and individuals to testify at the town hall (if you are planning one)
- Collect estimates of numbers of attendees
- Confirm that all of the speakers have submitted their presentations
- Have a committee review all of the slides and check for accuracy and redundancy; ask speakers to modify presentations if necessary
- Prepare handouts of presentations and other materials for duplication
- Continue recruitment and outreach efforts to potential participants through followup calls and the dissemination of summit materials
- Confirm agencies that will provide exhibit/display tables
- Finalize transportation needs
- Develop the design and text for all signage necessary for summit
- Finalize press release and media package to send to contacts
- Ask the Governor’s office to create a governor’s citation to be read by a representative of the office to open the summit (if applicable)
- If summit coincides with International FASD Awareness Day, look for a local church that will participate in bell ringing
- Finalize brochure and folder materials

- Mail brochures to key invitees
- Finalize evaluation
- Send confirmation letters to all presenters and panelists
- Create “Warrior Mom Network” forms (if planned)
- Finalize gift bag contents; have volunteers prepare gift bags
- Make copies of all needed materials, handouts, sign-in sheets, evaluations, and instruments
- Print nametags and table tents for participants, speakers, panelists, and resource tables
- Locate local families that are willing to provide media interviews
- Contact treatment centers for a head count and collect registration forms

### **10 Days Prior**

- Distribute media packages containing press releases to all newspaper, radio, and TV contacts
- Inform media that planners, speakers, or families are available for interviews
- Assign remaining onsite roles
- Create a checklist of all materials needed for the event
- Continue correspondence with funding agency
- Continue outreach and followup activities
- Review system for registration and evaluation
- Prepare folders
- Conduct final meeting with host site, and conduct a final run through of room setup, A/V needs, food issues, and agenda
- Continue to monitor all participating treatment centers to collect registration forms

### **1 Day Prior**

- Transport all materials to summit location
- Display all signage
- Set up all exhibit/display tables
- Set up registration table:
  - Folders for participants
  - Evaluation instruments
  - Gift bags for participants (to remain concealed until the end of the summit)
  - Sign-in sheets

### **Followup**

- Immediately schedule appointments with key legislators and policymakers to discuss next steps
  - Present a proposal asking for the changes you want in your community
  - Request support in organizing an FASD task force in your State
- Hold a brief wrapup meeting with planning committee members
- Send thank-you letters to all presenters and panelists
- Compile a database of contacts
- Send packets of information to community leaders and VIPs that were unable to attend
- Begin to organize the Circle of Hope network (if planned)
- Compile evaluations



# APPENDIX B

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*Sample Agenda*

## APPENDIX B: SAMPLE AGENDA

### SAMPLE DAY 1 AGENDA

**7:30 a.m. Registration/Breakfast/Evaluation**

**8:30 a.m. Welcome**

**8:45 a.m. Summit Overview**

**9:00 a.m. Alcohol and Women: What You Need To Know**

Questions and Answers

1. Understand the gender-specific challenges to recovery.
2. Describe the biochemical effects that alcohol can have on women.
3. Understand the issues that contribute to relapse.

**9:30 a.m. Alcohol and Pregnancy: Owning Your Warrior**

Questions and Answers

1. Recognize that it is never too late to change behaviors.
2. Experience motivation to remain sober.
3. Experience motivation and understanding on the importance of having children assessed.
4. Understand the Circle of Hope (COH) and feel encouraged to join.

**10:10 a.m. Break**

**10:25 a.m. Alcohol and Pregnancy: Effects on the Fetus**

Questions and Answers

1. Understand the difference that alcohol has on the fetus
2. Describe the stages of fetal development and how the timing and amount of alcohol can have a spectrum of effects.
3. Experience how a birth mom manages her son and the grief that she has overcome.

**11:15 a.m. If the Eyes Have No Tears, the Soul Has No Rainbow**

Questions and Answers

1. Identify characteristics of FASD in children.
2. Understand the developmental milestones in children with FASD.

**12:00 noon Networking Lunch and Door Prizes [Optional]**

**1:00 p.m. Strategies That Help Individuals With an FASD**

Questions and Answers

1. Describe systemic strategies.
2. Understand how to reframe interpretations of behaviors associated with FASD.
3. Understand the connection between brain function and behaviors to increase understanding, reduce frustration, and contribute to successful behavioral outcomes.

- 1:30 p.m. Stories of Recovery and Hope: Surviving the Grief**  
**Moderator**  
**Panel Members (Birth Mothers)**  
Questions and Answers
1. Recognize that grief can be overcome with a support system.
  2. Understand that feelings of shame can be released.
  3. Describe techniques for overcoming grief.
- 2:15 p.m. Break**
- 2:30 p.m. Circle of Hope: Warrior Moms Unite**  
**Moderator**  
Questions and Answers
1. Understand that it is possible to work through the guilt of having a child with an FASD.
  2. Experience other women's stories and their process of acceptance.
- 3:15 p.m. Evaluations**
- 3:30 p.m. Spiritual Closing**
- 4:00 p.m. Breakout Sessions Viewing of "Recovering Hope"**  
**Sponsored by SAMHSA's FASD Center for Excellence**
- (For testifiers only) Preparation for Testimonies: An Overview
1. Explain to testifiers the procedure for presenting their case/story.
  2. Provide examples of past testimonies.
  3. Explain the purpose of a town hall meeting.
- Town Hall Gathering
1. Light refreshments may be served.
- 4:30 p.m. Town Hall Meeting**

## **SAMPLE DAY 2 AGENDA**

**8:00 a.m. Registration/Breakfast/Evaluation**

**8:30 a.m. Welcome**

**8:50 a.m. Why a Summit on Fetal Alcohol Spectrum Disorders (FASD)?**

1. Recognize that women with addictive diseases are at very high risk for having children with an FASD.
2. Understand that women who drank during one pregnancy are likely to drink during all pregnancies.
3. Understand the importance of screening women for alcohol use and addiction disorders.
4. Understand that early identification of children with an FASD can reduce secondary disabilities and improve outcomes for future success.
5. Recognize the importance of FASD prevention, intervention, and education in all systems of care.

**9:00 a.m. Drinking and Pregnancy: Effects on the Fetus Last a Lifetime**

Questions and Answers

1. Understand how drinking alcohol during pregnancy affects the fetus.
2. Gain knowledge of the process that takes place during the exchange of alcohol to the fetus.
3. Understand that FASD is 100 percent preventable.
4. Understand that there is no cure for FASD.

**9:45 a.m. Addressing FASD in New York: Developing a Statewide Initiative**

Discuss the New York model for addressing FASD.

Discuss the importance of collaboration and coalition building as an effective strategy to bring about change in systems of care.

**10:15 a.m. Break**

**10:30 a.m. Costs of FASD in North Carolina**

Questions and Answers

1. Understand the economic impact of FASD in the Nation and in North Carolina.
2. Recognize that prevention is less expensive than long-term health care for individuals who are affected by an FASD.

- 11:15 a.m. FASD: Effects on the Family**  
**Moderator**  
Panel of families from throughout the State  
Questions and Answers
1. Recognize the obstacles faced by families of individuals who are affected by FASD.
  2. Understand services needed by families.
- 12:30 p.m. Lunch**  
**Keynote Address**
- 1:30 p.m. Where To Go for Diagnostic and Other Services for FASD in North Carolina**  
Questions and Answers
1. Explain the approach to FAS diagnosis.
  2. Identify main clinical criteria for FAS diagnosis and what occurs at a clinical genetics evaluation.
  3. Recognize the limitations in making an FAS diagnosis.
  4. Learn how to refer patients for FAS evaluation.
  5. Identify local resources for FASD.
  6. Understand the information gap between physicians and treatment centers.
- 2:00 p.m. FASD in North Carolina: Where We Are and Where We Are Going**  
**Moderator** (State health representative)  
**Panel Members** (State health officials, legislators, State policymakers, and other individuals who have an impact on improving health in the State)  
Questions and Answers
1. Identify systems of care in North Carolina that serve families with an FASD.
  2. Learn updates on future plans to better address FASD in systems of care in North Carolina.
  3. Learn how to access up-to-date information on FASD in North Carolina.
- 3:00 p.m. Evaluations and Closing**



# APPENDIX C

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*Sample Pre and Posttest  
(Days 1 and 2)*

## APPENDIX C: SAMPLE PRE AND POSTTEST (DAYS 1 AND 2)

### Day 1 Evaluation

Registration # \_\_\_\_\_

1. The whole family benefits when a child is given a clear diagnosis of fetal alcohol syndrome (FAS) instead of a more general diagnosis of “disability.”  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
2. Women in recovery from alcohol are more likely to stay sober when they know how drinking may have affected their child’s development.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
3. Most individuals who have been affected by their mother’s use of alcohol during pregnancy receive a correct diagnosis of their problem.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
4. Alcohol use is dangerous only during the first month of pregnancy.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
5. Drinking beer or wine is safer than using hard liquor while pregnant.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
6. Most children affected by an FASD will “grow out” of their problems as an adult.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.
7. There is a national network of support for mothers whose drinking may have harmed their child.  
 I am certain this statement is true.  
 I think this statement is probably true.  
 I think this statement is probably not true.  
 I don’t have enough information to decide whether this statement is true or not true.

**Day 2 Evaluation**

**Registration # \_\_\_\_\_**

1. The State government of North Carolina spends more than \$10 million per year on health, education, and legal costs resulting directly from prenatal exposure to alcohol (i.e., fetal alcohol spectrum disorders or FASD).  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.
2. A child with learning disorders benefits from securing a formal diagnosis of an FASD because family members can use the diagnosis to reduce the risk of related disabilities.  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.
3. In North Carolina, most children of mothers who drink alcohol during pregnancy now are tested for an FASD.  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.
4. Most children with symptoms of FASD "grow out" of those symptoms during adolescence.  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.
5. An FASD diagnosis in North Carolina is largely a subjective judgment; clinicians do not perform evaluations identically.  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.
6. Successful statewide efforts to prevent FASD usually are developed within a professional association, such as groups of pediatricians or social workers, with little input from other professions.  
 I am certain this statement is accurate.  
 I think this statement is probably accurate.  
 I think this statement is probably not accurate.  
 I don't have enough information to decide whether this statement is true or not true.

7. Most scientists estimate that two-thirds of all cases of FAS—the most recognizable form of FASD—could be prevented by changes in the behavior of women of childbearing age, while one-third would occur because of genetic heredity, regardless of the behavior of the mother.
- I am certain these statements are accurate.
  - I think these statements are probably accurate.
  - I think these statements are probably not accurate.
  - I don't have enough information to decide whether these statements are true or not true.



# APPENDIX D

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*Sample Letters*

## APPENDIX D: SAMPLE LETTERS

Dear XXXXX:

I write to invite you to participate as a panelist in the Fetal Alcohol Spectrum Disorders (FASD) Town Hall Meeting, to be held in collaboration with “Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure” at the Wyndham-Baltimore Inner Harbor Hotel on September 8, 2003. The summit is hosted by the National Organization on Fetal Alcohol Syndrome (NOFAS) and the FASD Center for Excellence, a project of the Federal Substance Abuse and Mental Health Services Administration (SAMSHA).

Your participation will come on the first day of a 2-day conference directed to women who are currently receiving addiction treatment and who have either used alcohol during past or current pregnancies or are at high risk for using alcohol while pregnant. The goal of the project is to educate high-risk women about alcohol-related birth effects, prepare a report of their collective experiences, and use this information to develop a plan for the State of Maryland to better serve individuals and families impacted by this very important issue. The summit is Maryland’s response to National Recovery Month and is also a pilot project that will become the first in a national effort to combat FASD.

The first day of the summit will focus on women in Maryland substance abuse treatment centers. There will be a panel of birth mothers of FASD children and presentations by such experts as Dr. Ed Riley, a leading researcher from San Diego State University and the Chairman of the National Task Force on FAS/FAE; Dr. Faye Calhoun, Associate Director of NIAAA; and Dr. Paula Lockhart, from Maryland’s Kennedy Krieger Institute. The afternoon portion of the summit will be an FASD Town Hall Meeting with testimony presented by women in attendance. The town hall meeting is one in a series of national meetings to hear from individuals and families affected by prenatal alcohol use. The second day, which coincides with International FASD Awareness Day, will focus on developing an FASD strategic plan in Maryland. Dr. Deborah Stone of SAMSHA and Dr. Deborah Cohen of the New Jersey Department of Human Services, among others, will be discussing the state of FASD in Maryland, New Jersey, and internationally.

Sincerely,

XXXXX

To Ben & Jerry's Royal Bakery Donations Director:

On July 20 and 21, 2005, the National Organization on Fetal Alcohol Syndrome (NOFAS) is hosting a women's summit in Raleigh entitled "Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure." The summit is sponsored by the Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence, a division of the Substance Abuse and Mental Health Services Administration (SAMHSA). North Carolina is the third and final State to be involved in this pilot project that will possibly lead to a nationwide program in following years.

The primary goal of the summit is to educate women at highest risk for having a child with an FASD. A secondary goal of the summit is to educate policymakers for the purpose of facilitating the creation and enhancement of State systems of care and support services for families affected by FASD. Because fetal alcohol syndrome is the known number-one cause of mental retardation, we find it necessary for all individuals to know the risk of mixing alcohol with pregnancy.

We believe that Ben & Jerry's, through its community involvement program, may be able to help us by donating gift certificates or ice cream for the women and children attending the summit. The certificates would be given either as door prizes or as part of the women's and children's gift bags. NOFAS would be delighted to have Ben & Jerry's gift certificates or ice cream to show our appreciation for the women's attendance and willingness to learn about the harmful affects that drinking alcohol during pregnancy can cause.

NOFAS is a 501 (c) (3) nonprofit organization (EIN 46-0412365), and the value of all contributions is tax-deductible to the fullest extent permitted by law. Please contact me at 202-785-4585 if you need additional information, and thank you in advance for your consideration.

Sincerely,

XXXXXX



# APPENDIX E

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*Sample Release Forms*

## APPENDIX E-1: SAMPLE VIDEOTAPE RELEASE FORM

### Videotape Release Form Town Hall Meeting on FASD

I, \_\_\_\_\_, give my consent to allow my testimony to be videotaped at the town hall meeting on FASD in Washington, DC, on June 18, 2003.

I understand my testimony may be used by the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence to develop summary reports on the town hall meetings for the general public, the Federal Government, and Congress.

I also understand that my testimony may be used by key Federal agencies to aid in the development and coordination of strategies to further advance the field.

I hereby release from liability SAMHSA, the FASD Center for Excellence, and their subcontractors.

I further understand that if the SAMHSA FASD Center for Excellence identifies a need to use my testimony for any reason other than the above-stated purposes, I will be contacted for additional consent.

Signature \_\_\_\_\_ Date \_\_\_\_\_

#### **Please print:**

Name \_\_\_\_\_

Street Address \_\_\_\_\_

City, State, ZIP \_\_\_\_\_

Phone \_\_\_\_\_

## APPENDIX E-2: SAMPLE PHOTO RELEASE FORM

### PHOTO RELEASE FORM

I, \_\_\_\_\_, give my permission to the FASD Center for Excellence to use my photographs for educational purposes only. I understand that the image(s) will be used in Web-based materials on the 2006 Building FASD State Systems meeting. I understand that the photo will be publicly available through the FASD Center for Excellence Web site, and may be duplicated for further use outside the FASD Center's control.

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Print Name

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Signature

Date: \_\_\_\_\_



# APPENDIX F

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*Press Release*

## APPENDIX F: PRESS RELEASE

FOR IMMEDIATE RELEASE  
January 01, 2008

CONTACT: XXXXXXXX  
(XXX) XXX-XXXX

### **Hope for Women in Recovery National Organization on Fetal Alcohol Syndrome Hosts Summit**

WASHINGTON—On June 29 and 30, NOFAS will host a 2-day summit at the Regency Hyatt in downtown Phoenix, bringing women in treatment together with addiction and fetal alcohol spectrum disorders (FASD) experts, State legislators, and State agencies. The summit is the second in a series; the first took place in Maryland and served as a pilot project in the national effort to combat FASD. The event is sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA) FASD Center for Excellence.

An estimated 40,000 infants are born with alcohol-related effects every year in the United States. Fetal alcohol syndrome (FAS) and other FASDs are the leading known preventable cause of mental retardation, birth defects, and learning disabilities. Still, they often go undiagnosed and untreated. Problems with attention, behavior, judgment, memory, and social development are lifelong issues for these children and their families. Despite the statistics, there is a severe lack of prenatal education, health care, and treatment for those at risk or affected. In Arizona alone, millions of dollars are spent each year to cover the needs of affected individuals through special education, mental and physical health care, shelter costs, and additional costs associated with involvement in the justice system.

The first day of the summit introduces women currently in addiction treatment in Arizona to FASD experts. It also features a town hall meeting to provide women the opportunity to share their experiences with addiction and the possible effects of alcohol they have seen and experienced with their own children before a panel of various State representatives, including Senator Robert Cannel and State Representative Linda Lopez. The summit will also feature presentations from leading FASD experts from around the country, including Kathy Mitchell, NOFAS Vice President and National Spokeswoman; Ardyce Turner, Office of Children's Services; Candace Shelton, FASD Center for Excellence; and Suzanne Kuerschner, FASD Educator, among others.

Day 2 will include a keynote address given by Lieutenant Governor Mary Thomas. Additionally, a panel will feature the Honorable Joni Ramos, President, Salt River Pima Maricopa Indian

Community, and various State department representatives who have a vested interest in the issue. They will discuss the action steps that have been taken by the State of Arizona and the commitment the State will continue to make to FASD.

“It is time for Arizona to get proactive in preventing FASD. Arizona spends millions annually to treat thousands of women for addiction disorders, yet tragically women receive little education on the effects of alcohol on the developing fetus,” said Kathleen Mitchell, Director of the Women in Recovery and National Spokesperson for NOFAS. “Many women leave treatment still convinced that as long as they don’t use illicit drugs while pregnant, their child is safe, and that beer and wine don’t count. Nothing could be further from the truth. As long as they drink, their children are at risk.”

“It takes a brave person to speak about personal addiction and adversity, especially when it affects his or her children,” said NOFAS Executive Director Tom Donaldson. “It is through this bravery that Arizona regulators, legislators, and policymakers will hear the truth: Any amount of alcohol is a threat to an unborn child, and its consequences place a severe burden on the State.”



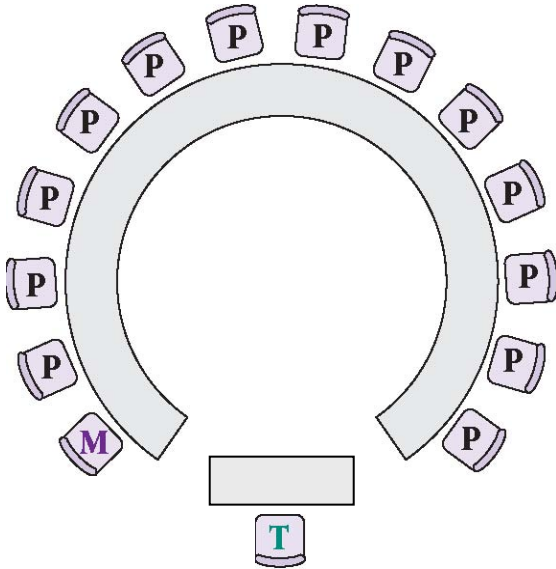
# APPENDIX G

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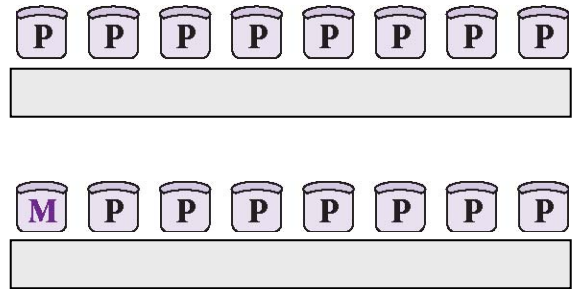
*Sample Room Setup for the  
Town Hall Meeting*

## APPENDIX G: SAMPLE ROOM SETUP FOR THE TOWN HALL MEETING




### U-Shape

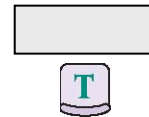


### Two-Tiered



### Key

-  **P** Panelist
-  **M** Moderator
-  **T** Testifier





# APPENDIX H

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*Summit Logo*

## APPENDIX H: SUMMIT LOGO

The original NOFAS-sponsored summits were entitled *Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure*. NOFAS created a summit logo that illustrates the term “Warrior Mom,” representing the strength of women in recovery. Please contact NOFAS if you would like to use the logo for your summit signs or materials. You may also order “Warrior Mom” T-shirts from NOFAS.





# APPENDIX I

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*Tips for Meeting with  
Elected Officials and  
Policymakers*

## APPENDIX I: TIPS FOR MEETING WITH ELECTED OFFICIALS AND POLICYMAKERS

**Be Prompt and Patient:** When it is time to meet with an official, be punctual and be patient. It is not uncommon for a legislator or staff person to be late or to have a meeting interrupted. If interruptions do occur, be flexible.

**Dress Professionally:** Don't let appearances detract from your message or impair your credibility.

**Be Prepared:** You may have 10 to 20 minutes to state your case. Know what points you will cover and make your presentation brief and to the point. If you are in a group, coordinate the points each person will make.

**Take Materials With You:** Given limited time for your meeting, it is helpful to have brief fact sheets or other material that you can leave behind with the legislator and staff. If possible, attach your business card to any written material you leave with the office.

**Assume No Knowledge:** Members and staff may know little or nothing about FASD. Be sure to explain all acronyms and programs. Use vignettes to illustrate your points.

**Be Political—Localize:** Legislators want to represent the best interests of their district or State. Wherever possible, demonstrate the connection between the information you are presenting and the interests of the member's constituency.

**Know Your Target:** Be sure to know the person's past record on issues that may be related to FASD. Knowing these facts will help guide your discussion and show that you have done your research.

**Be Responsive:** Be prepared to answer questions or provide additional information, in the event the member expresses interest or asks questions. Questions may be a sign of interest.

**Stay on Course:** Resist any side conversations or tangential issues. Making small talk may be useful and sometimes can help build a connection but remember your time is limited—discussing your local team won't advance your issue.

**Follow Up and Don't Forget To Say Thank You:** Follow up the meeting with a thank-you letter that outlines the different points covered during the meeting, and send along any additional information and materials requested.