Women in Recovery Summits:

A Targeted Strategy to Prevent Fetal Alcohol Spectrum Disorders (FASD)

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Abstract
A model to prevent fetal alcohol spectrum disorders (FASD) was developed by piloting three separate summits across the United States. The summit model known as *Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure* was designed to reach two very important targets for prevention of FASD: women with addictive disorders and state policy makers. The inclusion of both groups provided a unique opportunity for them to learn from each other. The experience taught high risk women about FASD and offered both hope and support for continued recovery. The Summit model served as a catalyst for systemic change in each of the states they were held. This model is an important example of how communities can facilitate positive change in both women that drink as well as to create systemic motivation to better prevent, identify, and treat FASD.

Introduction
Over thirty-three years have passed since the term fetal alcohol syndrome (FAS) was introduced to describe a cluster of birth defects seen in children born to alcoholic women. Research has now helped us to understand that prenatal alcohol exposure can cause infants to be born with varying degrees of possible effects. The term fetal alcohol spectrum disorders (FASD) is an umbrella term used to describe the various disorders that occur as a result of maternal alcohol consumption, including FAS, partial fetal alcohol syndrome (PFAS) and alcohol related neurodevelopmental disorder (ARND). FASD is known to be the leading preventable cause of mental retardation as well as a leading cause of birth defects and learning disabilities. However, according to recent studies by The Centers for Disease Control and Prevention (CDC), more than 130,000 pregnant women per year in the U.S. consume alcohol at levels shown to increase the risk of having a baby with FAS or other alcohol-related condition. This translates into more than one in ten pregnant women who report current alcohol use (Flynn, 2003).

While one does not have to be an alcoholic to give birth to a child with affects from drinking while pregnant, it is clearly understood that women with addictive disorders, such as alcoholism, are the highest risk group for having children with an FASD. An assumption might be made that while women are receiving addiction treatment that they receive education on FASD. Surprisingly, few addiction treatment centers include this topic in their educational curriculum. In many treatment centers the FASD materials that are used are dated and only discuss FAS (the rarest, but most identifiable disorder from prenatal alcohol exposure). New research has helped define the spectrum of disorders that can occur from prenatal alcohol use making it essential to use updated educational materials when treating women at high risk for having a child with an FASD.

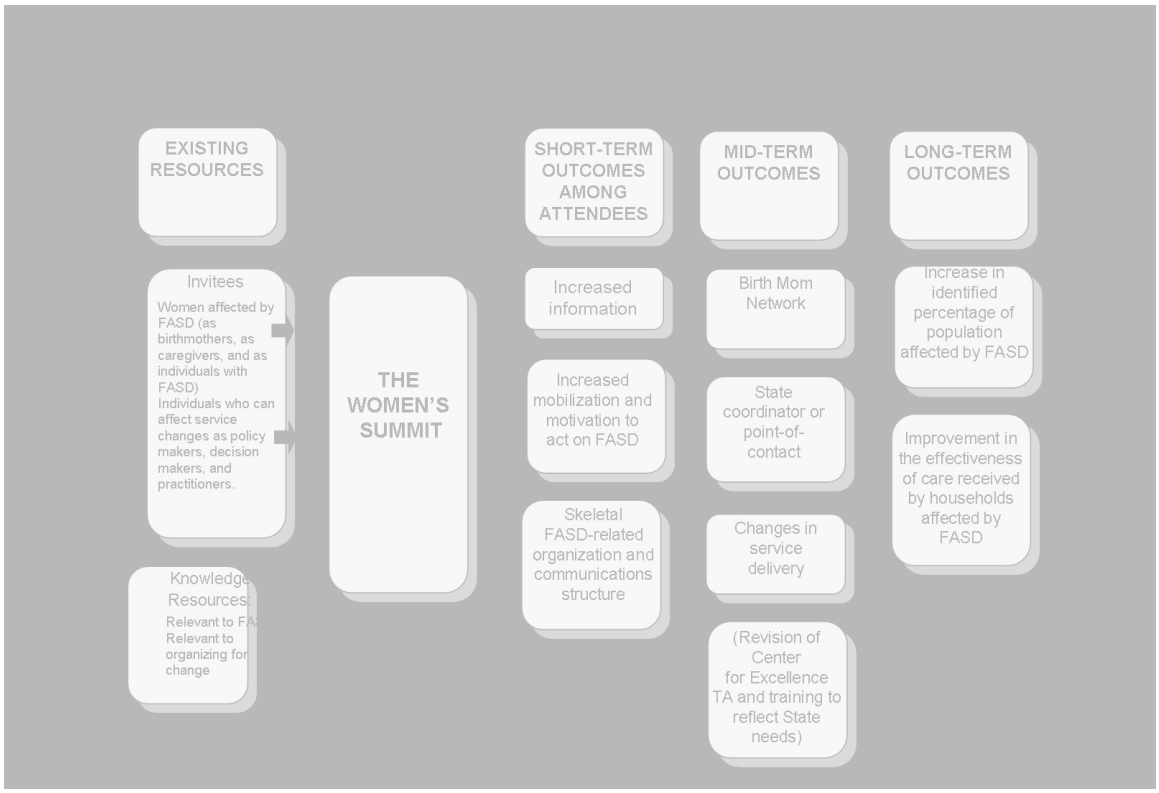
There are many reasons for the lack of attention FASD education receives in addiction treatment. One barrier may be that many counselors that treat women have not been educated on FASD. There are many regions in the U.S. where it would be difficult to access educational seminars on FASD. FASD is not typically addressed on oral or written exams designed for addiction professionals. Another may be that many individuals with an FASD are never correctly diagnosed. Addiction treatment centers treat clients with an FASD and certainly clients that have children with an FASD, but they are rarely

recognized. The largest barrier may be that many addiction professionals are in recovery and FASD may be a topic that has personal and difficult implications.

Background

To address the broad issues related to FASD in the United States, Congress created the FASD Center for Excellence as part of the Children's Health Act of 2000. The Center is operated by the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center has six legislative mandates, one of which is to develop innovative ways to prevent alcohol abuse among women in their childbearing years. To address this mandate the SAMHSA FASD Center for Excellence contracted the National Organization on Fetal Alcohol Syndrome (NOFAS) to convene a series of first-ever *Women in Recovery Summits*. From 2003 to 2005 there were three pilot Women in Recovery Summits held across the United States (Maryland, Arizona, and North Carolina) which shaped the *Hope for Women in Recovery Model.* At each of these locations the target group was twofold: women at high risk for having a child with FASD (women who were currently in addiction treatment) and state policy makers. The model was designed to educate both groups on FASD and to educate policy makers on the issues and the impact that FASD has on state systems. The longer term goals included prevention, increased identification, as well as enhanced services for individuals with an FASD and their families.

The following logic model outline laid the groundwork for the Summits:



The Women's Summit Logic Model; Hill, Gary

The women in recovery summit logic model describes the resources (attendees) as individuals affected by FASD who are motivated, or can be motivated to do something about FASD, policymakers who could make systemic change and professionals who are positioned to create change with both clients and systems. The categories of activities designed to cause change among the attendees included transmission of information (speakers, materials, presentations), mobilization (structured interaction among the attendees to mobilize and motivate attendees), organization (time and resources to continue the work of the Summit), and logistic support (support necessary to make the experience positive). The immediate outcomes were measurable changes including knowledge, commitment and organization. Within a relatively short time, the participants of the summit transmit the immediate outcomes of the session to other people within the State, tribe, or community. As more people become informed about FASD and are mobilized to do something about it, they observed changes among individuals affected by FASD, policymakers and practitioners. The establishment of state coalitions and/or other organized efforts to address FASD were developed. The institutionalization of the mid-term outcomes in the form of a sustained system-building effort sought to produce an increase in screening and diagnosis as well as enhanced services.

The Women in Recovery Summit Model

Planning the Summit

The initial step was to form a regional planning committee. Addiction treatment centers that had women's programs were identified and invited to participate in the planning process along with representatives from various human service agencies and Tribes. The first planning committee meeting was held one year prior to the targeted summit date. Each committee met a minimum of four times in order to plan and facilitate details of the summit. The planning committee worked with the NOFAS team to discuss every element of the summit planning and implementation including:

- summit date and location,
- agenda and speakers for both conference days,
- potential panel members for conferences and the town hall meeting,
- women, families and individuals with FASD to participate in panels and other elements of the Summit,
- local community members to provide spiritual, cultural and/or testimonial segments for the conferences,
- local agencies to disseminate information to participants at display tables,
- community contacts to provide in-kind donations for *goody bags* and door prizes, and
- development and dissemination of Summit brochures.

The first summit was held in Maryland and that committee coined the title of *Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol*

Exposure and selected a quote by Margaret Mead, ***"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has"*** to include on all Summit materials. They expressed the importance of including a spiritual element and suggested to open and close the Summit with a song, prayer or ritual. These recommendations were adopted by the other two states are now incorporated into the summit model.

Preparing Addiction Treatment Centers for the Summit

In order to prepare the staff of the treatment centers for the Summit it was necessary to provide a brief pre-training about FASD and to explain the logistics of the Summit to each of the centers who participated. The *mini* workshop was approximately one hour and presented an opportunity to provide an overview of all logistical considerations in hopes of reducing confusion on the day of the Summit. The workshop also provided a format to better prepare the counselors to introduce their clients to the Summit concept and the topic of FASD, also allowing for some clinical discussion on the issue. Counselors were also informed about the following town hall meeting and they were encouraged to testify and to identify clients who may emotionally ready and willing to testify.

The Two-Day Summit

The Summit model was a two day interactive conference style setting. Day one targeted women in treatment and the professionals that treated them. Women who were currently in treatment were transported to the conference site. The day was designed to create excitement and anticipation for the women. They viewed the experience as a "treat" giving them the opportunity to interact with other women in recovery, have an opportunity to learn new information and a day from the "typical" treatment experience. The setting was festive and included lunch, individual gift bags and door prizes (all donations from communities). Nationally recognized women in recovery, who were had children with an FASD were invited to speak on the science of FASD, women and addiction, getting an assessment for children who were exposed and strategies for parenting children with an FASD. *Birth mothers* proved to be an important concept of the summit experience as they provided hope and reassurance for the participants. The term "Warrior Mom" was used during the day one conference to describe the strengths of women who have survived addiction and to remind them of their strengths. Women who attended the summits later reported that the experience helped them to face the shame and left them feeling empowered to face the future.

A Town Hall meeting followed the conference on day one. The Town Hall meeting allowed the women, families, individuals with FASD, and service providers to have an opportunity to share their personal experiences with addiction and FASD before a panel comprised of representatives from state agencies as well as local and federal policy makers. The Town Hall meeting not only served to increase information on FASD, but laid the groundwork for the short term objective of increasing mobilization and motivation to act on increasing both prevention efforts and treatment services.

Day two targeted state policy makers and challenged them on how they planned to improve support for individuals with FASD and their families. This was a half-day

workshop that included topics such as FASD 101, the economic and societal costs of FASD in their state, the realities of families living with the disability, and the current resources (or lack of) designed to address FASD in their state. The format included two interactive panel sessions that were designed to foster dialogue between families and various state agencies. This laid the foundation for NOFAS to pursue the need for a state plan to address FASD.

Summary

The Women in Recovery summit is a distinctive model designed to reach two very important targets for prevention of FASD: women with addictive disorders and state policy makers. The inclusion of both groups in the Summit provided a unique opportunity for them to learn from each other. The setting allowed for policy makers to take time out of their busy routines and hear, first hand, the daily issues and struggles that families deal with. Women that suffer with addiction problems generally suffer with low self esteem, have difficulty asking for help, and may not understand their rights or how to locate assistance for themselves or their children. The summit model serves to both teach women about FASD, but offers them hope and support with a message that *they* matter. This begins the process of empowerment and long tern recovery and true FASD prevention. For many of the women participants the summit offered them their first opportunity to address policy makers and ask for change. As for the state agencies the summit experience was successful in creating change. All three states credited the Women in Recovery Summit experience in created measurable change. FASD Coalitions have been established, successful FASD legislation has passed, and treatment for both mothers and their children have improved. The Summit model has proven to be effective in stimulating change and has lead to the development of a national birth mom network (Circle of Hope) as well as motivated policy makers and state systems to create change to better prevent, identify, and treat FASD.

"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

References:

Flynn, H.A et al. (2003). Rates and correlates of alcohol use among pregnant women in obstetrics clinics. *Alcoholism: Clinical and Experimental Research.* 27(1):81-87.

(Mitchell, K., National Organization on Fetal Alcohol Syndrome Website, 2005)