



# Final Report

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Task 18 An Assessment of the Need for a National Clearinghouse on Fetal Alcohol  
Syndrome

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## INTRODUCTION

Congress has expressed interest in establishing a national clearinghouse to disseminate research-based information on fetal alcohol syndrome (FAS). A literature review has identified a number of Federal, educational, and private nonprofit organizations that provide information about FAS. However, a central repository synthesizing the information contained in these disparate sources and making it available nationally to all races and ethnic groups does not exist. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) commissioned a study to assess the need for a national clearinghouse on FAS. The objectives of the study are as follows:

To identify the type of resources on FAS needed by professionals and the public.

To determine what FAS resources currently exist and their availability for different user groups.

To identify gaps in services and products.

To determine who the target audience of the clearinghouse should be (i.e., health professionals, the public, or parents and caregivers of children affected by FAS).

To accomplish these objectives, IQ Solutions conducted indepth interviews and a telephone focus group with a diverse group of individuals representing organizations touched by FAS to determine whether a national clearinghouse on FAS and fetal alcohol effects (FAE) is warranted.

## METHODOLOGY

The following discussion presents an overview of the research design and describes participant selection processes and the specific techniques used for data collection.

### **Literature Review**

IQ Solutions conducted a thorough review of all existing data sources related to FAS and' FAE, including Web sites, documents about other clearinghouses, literature available through Medline, bibliographic sources, and the ETOH and IMPAC/CRISP databases. The sources of data included State and Federal agencies and nonprofit and educational organizations. Among them were the NIAAA, the National Clearinghouse for Alcohol and Drug Information (NCADI), the California Alcohol and Drug Programs Resource Center, the National Organization for Fetal Alcohol Syndrome (NOFAS), and the University of Washington. Because Web searches often vary in their completeness and timeliness, we used an exhaustive search method that relied on a variety of search engines and keywords to locate FAS-related documents and Web sites. A table outlining the results of the literature review (appendix A) includes the following information:

- The title of the resource
- The year it was published
- The organization that the resource represents

- The format of the resource
- Whether a sample is available
- A brief summary of the information contained in the resource

Whenever possible, we obtained copies of FAS resources by calling the appropriate organization.

## **Subjects**

A diverse group of nine stakeholders (seven females and two males) participated in the indepth interviews. These participants were chosen because their professional work revolves around the issue of FAS. The participants represented Federal, educational, and private nonprofit organizations that provide information about FAS. The organizations represented include The ARC, the California Department of Alcohol and Drug Programs Office of Perinatal Substance Abuse, Emory University, the FAS Family Resource Institute, the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS), NOFAS, the New Jersey Department of Human Services Office for Prevention of Mental Retardation and Developmental Disabilities, the North Dakota Fetal Alcohol Syndrome Center, and the University of North Carolina at Chapel Hill Bowles Center for Alcohol Studies.

Seven individuals (four females and three males) participated in the telephone focus group. These individuals also represented Federal, educational, and private nonprofit organizations. However, the work of several of the participants involves FAS in only a peripheral way. This group of individuals was selected to give a better understanding of how FAS affects individuals and organizations whose work is not necessarily centered on FAS. The organizations represented in the focus group include the American Library Association, Boston University, the Center on Alcoholism, Substance Abuse, and Addictions, the March of Dimes Birth Defects Foundation, the National Association of School Nurses, the Texas Commission on Alcohol and Drug Abuse, and the National Association for Child Development.

## **Data Collection**

IQ Solutions conducted a comprehensive series of literature reviews, existing-materials audits, and Web searches to identify resources and materials related to FAS. (See appendix A.) As a result of this research, IQ Solutions identified 18 key stakeholders in the FAS arena to participate in the indepth interviews and 17 to participate in the telephone focus group. Lists of these stakeholders and the organizations they represent were presented to the NIAAA. The NIAAA then narrowed down each list to nine potential participants. These individuals were sent a letter signed by Dr. Enoch Gordis, director of the NIAAA, explaining the purpose of the feasibility study and requesting their participation. (See appendix B.) One week after the letters were sent, the participants were contacted by a representative of IQ Solutions to confirm their participation in the study. Several times, the originally designated participant was unable participate in the interview. When this occurred, an alternate participant was identified by the NIAAA. For

the most part, an alternate within the desired organization was able to participate in the study.

IQ Solutions conducted a total of nine indepth interviews and one telephone focus group with seven participants. The indepth interviews were conducted between July 9 and August 2, 2001, and lasted approximately 45 minutes each. The focus group was conducted on August 15, 2001, and lasted 1 hour. A trained interviewer conducted the indepth interviews using an interviewer's guide developed specifically for this study (appendix C), and a trained moderator oversaw the focus group discussion using a moderator's guide (appendix D) developed specifically for the focus group.

In general, the questions asked during the indepth interviews and the focus group explored the following areas:

- Resources and information available on FAS and alcohol use and abuse and the quality of the information and resources.

- Information and services provided by clearinghouses and used by the participants at the present time.

- Possible resources, services, and information that participants would want to see provided by a FAS clearinghouse.

- Possible target audiences of a FAS clearinghouse.

- Opinions on a possible fee associated with using the clearinghouse.

- Elements to consider when evaluating the performance of the clearinghouse.

- Preferences for receiving information on new resources and materials.

Complete transcripts of the interviews and the focus group discussion are included in appendices E and F, respectively. Because participants were assured that their input would remain confidential, all identifying characteristics have been removed from the transcripts.

## **ANALYSIS AND FINDINGS**

As indicated previously, two distinct qualitative methods were used to collect the information of interest in this study. The instruments used (i.e., the interviewer's guide and moderator's guide) are included in appendices C and D, respectively. The summary results of each of the evaluations are presented separately here. Complete transcripts of the discussions-both indepth interviews and the telephone focus group-are included in appendices E and F, respectively.

### **Indepth Interviews-Summary Results**

*Where do you go for information on FAS and FAE? What sources do you use?*

The key informants responded that they use a variety of sources. They consult Government agencies, including the NIAAA, CDC, NIDA, and SAMHSA; not-for-profit organizations, such as NOFAS, MOFAS, and The Arc; State agencies, such as State

ADT resource centers; professional journals and conferences; and universities, including the University of Washington, San Diego State, and the University of North Dakota. Other sources include State agencies and foundations such as the Robert Wood Johnson Foundation and the Annie E. Casey Foundation.

When asked where they search for information on alcohol abuse and alcoholism in general, the participants frequently cited the NIAAA, CDC, and NIDA. In addition, they mentioned State resources, such as the Division of Alcohol and Substance Abuse and State universities, and professional journals.

To access both FAS and general information, the majority of the individuals use the Internet or bibliographic databases such as PubMed or Medline.

*What types of information are you looking for when you consult these sources?*

In response to this question, all of the participants said that they look for the most recent clinical research related to all aspects of FAS. As one individual explained, "The first thing that we are looking for is the most recent research, the most recent findings that are all related to alcohol use during pregnancy, or alcohol and pregnancy, or alcohol use and women's health." All the key informants agreed that they look for evidenced-based information.

The individuals also seek information about available resources. They look for resources related to treatment or intervention services and educational resources for both patients and providers.

*Tell me about the quality of the information that you find.*

The participants emphasized that the quality of the information available varies greatly depending on its source. As one individual commented:

If it's something that is in a refereed journal, then it tends to be very descriptive and of high quality .... Then sometimes if I'm looking for more project-type information, such as from parent groups and such, it's descriptive, and that's helpful, but typically it does not have very good evaluation measures with it. So there is no way for me to know if it is valid and reliable information.

One individual offered multiple explanations for the inferior quality of the information. He explained:

It's poor for three reasons. One, there is not much of it. Two, very few people do it, so typically what you find is that hardly any of the work has been replicated and most of the really important work hasn't been done yet. It is not that well reviewed before the journals publish it. Lastly, the sample sizes tend to be local and very small.

*When thinking about available FAS information, compared with what you need, would you say that the available information is complete?*

All of the participants stated that the available FAS information is incomplete. The key informants most frequently mentioned needing additional information on research-proven strategies across the entire FAS spectrum (from awareness and diagnosis to education and treatment). They also identified the following information and service gaps:

- An advocate education program
- A FAS clearinghouse
- Information about effective types of awareness, education, and caregiving strategies that are culturally appropriate
- Information about diagnosis and treatment services
- Prevention materials
- Data related to the degree to which FAS information is incorporated into various curricula and discussed by physicians with patients
- Large-scale, multistate clinical trials to determine whether interventions work
- National and State-specific prevalence data
- Bulleted, easy-to-read materials

*Are you aware of any resources (either FAS, alcohol abuse, or alcoholism-related) that should be publicized more broadly? For example, local resources that you think should be publicized nationally?*

Some of the key informants were aware of local resources that should be publicized on a national level, including State treatment centers and curricula developed by local agencies. Rather than identifying specific sources, however, others addressed some of the challenges of dissemination and publicizing local resources. One individual stated:

I think definitely there are some, a range of products and resources, that have been developed, and that is one of the problems. They haven't, whatever, either the funding isn't available or the network to distribute it isn't available. Programs have not been replicated, or good publications haven't been disseminated.

Another participant discussed the difficulty in identifying where resources have been developed.

*If you have used a clearinghouse as a source of information, what types of information does it offer, what services does it provide, and what services do you find the most valuable?*

A few of the individuals had used a clearinghouse in the past or had a clearinghouse or resource center affiliated with their organization. The goal of these clearinghouses is to

disseminate information to the public. Accordingly, the clearinghouses have an 800 number and a Web site to receive information requests from the public.

*If the NIAAA were to develop a FAS clearinghouse, what would you like to see incorporated?*

Most of the interviewees indicated that there is a need for a FAS clearinghouse. As one participant explained:

We just need to have a source that we can go to that is going to have the latest, most up-to-date information. We're learning a lot of things from parents by trial and error of what they're doing. It is not always scientifically based, so I don't feel comfortable referring that information to other families, for example, but I need to have a clearinghouse, if you will, of places that I can go to, and I can say somebody has said, "This has worked. That's the latest research." It's not there right now. It's all kind of coming secondhand from the organizations we currently work with.

A few individuals, however, thought that there is not an established need. One individual thought that the potential audience was too small, stating, "I don't think that there are that many people seeking materials." This individual also thought that although information is needed, there might be better sources and better mechanisms for disseminating the information. She explained, "I think there ought to be good materials for teachers, but I think they ought to come from one of the educational organizations." Another individual expressed concern that a NIAAA clearinghouse would be a duplicate effort because other Federal agencies are in the process of establishing a clearinghouse.

Regardless of whether they saw a need for the clearinghouse, the respondents provided a variety of things they would like to see incorporated into a clearinghouse. Among the suggestions offered were the following:

- A state-of-the-art production facility and expertise and resources about creating and disseminating public service announcements
- An advisory panel comprising researchers and advocates to plan the structure of the clearinghouse
- A responsive one-on-one connection to local community resources
- A complete inventory of FAS research
- Prevention and education materials for different audiences, in various formats and languages
- Curricula for school children as well as medical students and practicing physicians
- Information and resources for parents and foster parents
- Resource guides
- A peer-reviewed Web site



### *Who should be the target audience(s)?*

All of the respondents identified multiple audiences for the clearinghouse, including the following:

- Families
- Parents
- Students
- Educators
- Social workers, including family and youth workers
- Health professionals, including public health nurses, clinic nurses, pediatricians, and prenatal care providers
- Potential adoptive and foster-care parents
- Juvenile justice and criminal justice systems
- Policymakers

### *What types of information would be available?*

The majority of the interviewees agreed that information related to all aspects of FAS-basic biology, epidemiology, prevention, and treatment-should be available. Participants stated that they want the latest research information and best practices related to intervention, and they also want basic FAS and FAE information provided in a user-friendly manner for the public. The individuals noted that the types of information and materials available would vary depending on the audience. Individuals again addressed the information gaps that exist currently (e.g., prevalence data and proven intervention strategies.)

### *What services would the clearinghouse provide?*

The key informants suggested several possible services:

- PowerPoint presentations or videos for teaching medical students
- Continuing education classes for obstetricians, pediatricians, and family practitioners
- Referral services, including those for referring individuals to local community resources and for referring individuals to research locations or to researchers themselves
- Materials and video loans and dissemination, including materials for people who work with indigent families
- Literature reviews
- A weekly update on newly published literature with a critique
- Downloadable materials or materials on a CD-ROM

*Would there be a fee associated with using the clearinghouse?*

Overall, the participants indicated that a fee should not be associated with the clearinghouse, particularly if the clearinghouse has a Web site. Individuals did not want a fee associated with the Web site. A few respondents indicated that a charge might be applied to specific services or materials, such as specialized research services or bound books. The respondents expressed concern that charging a fee would limit access to the materials and resources, but several individuals indicated that people often associate a fee with the value of the materials or information. Therefore, charging a small fee might afford the information more respect.

*What elements/factors would be important to consider when evaluating the performance of the clearinghouse?*

When evaluating the performance of the clearinghouse, the respondents most frequently mentioned customer satisfaction and cost-effectiveness as key evaluation factors. The respondents were also interested in knowing who uses the clearinghouse and for what information and services. Other evaluation factors included the knowledge of the staff and the range and depth of materials provided by the clearinghouse.

*What is the best way to make you aware of new resources and materials?*

Most of the participants indicated that e-mail and the Internet are the best ways to make them aware of new resources and materials. Other vehicles included professional conferences, academic journals, and listservs. To reach their constituencies, however, the respondents suggested newsletters and community dissemination points, such as clinics, beauty parlors, and churches.

### **Focus Group-Summary Results**

*What is the first thing that comes to mind when you hear the term "Petal alcohol syndrome"?*

One participant responded that he thinks of a disability that is "under-diagnosed, under-treated, and under-recognized." The general feeling was that a tremendous variance exists throughout the United States in awareness about FAS; that is, one region may know more about it than another. Participants also indicated (1) a perceived variance within subpopulations in a region, (2) a concentration of the full-blown syndrome in lower socioeconomic groups, and (3) a concern about FAS among middle- and upper-class groups. The participants voiced their concern about a possible disconnect between where the problem exists and where the knowledge and concern are.

*Have you needed to obtain information about FAS in your professional capacity, and what has been your experience with looking for that information or services related to FAST*

For those individuals involved in FAS research or services, finding specific information was not deemed to be difficult. However, participants indicated that people who are less

well-connected in the field have a very difficult time finding accurate (i.e., science-based) information or resources. The participants expressed concern that reliance on the Internet as a source of information can be dangerous because, in many instances, information posted on the World Wide Web is not credible.

*Have any of you used a clearinghouse to obtain information, or for those of you who are generating it, used a clearinghouse to place information?*

Participants indicated that they are more involved in generating information that might be used by a clearinghouse than in trying to access it. Discussants questioned what information would be included in a clearinghouse.

*Would an FAS clearinghouse be a valuable asset?*

Discussants agreed unanimously that a clearinghouse on FAS would be valuable, particularly if it were to provide information relevant to a variety of distinct audiences.

Among those audience would be foster parents and adoptive parents, adoption workers, special education teachers, classroom teachers, guidance professionals, welfare and other outreach caseworkers, workers in programs targeted to low-income women and adolescents, women in their childbearing years, criminal justice professionals, and clinicians (e.g., pediatricians, obstetricians, psychiatrists, and family physicians).

*Are there other ways to address some of the issues or challenges that you have been talking about? Ways other than clearinghouses?*

Participants suggested making FAS a routine part of medical training and including questions about the condition in licensing examinations. In addition, they suggested that postgraduate courses with CMEs and CEUs be offered on the topic.

*if the Federal Government were to develop a FAS clearinghouse, what would you like to see incorporated?*

Discussants offered the following specific suggestions:

- Appropriate science-based resources on a spectrum from education to behavior to treatment options
- Information for parents and families
- Information for adults with FAS
- Information on where to go for diagnosis
- Consumer-based information
- Information about available resources

*Would you consider the development of a national education campaign as viable? And what might that type of campaign include?*

Participants felt strongly that a national FAS education campaign would be helpful and useful because it could target exact populations, particularly in regard to prevention. They noted that many at-risk individuals, such as teenage mothers and problem drinkers, are unlikely to seek out research information. Other potential populations that should be targeted by the national FAS education program include people who will influence the pregnancy and drinking, such as spouses, parents, and bartenders and servers. Focus group members emphasized that the national campaign must encourage members of the target audiences to take action without making them feel guilty. One respondent remarked that too often people are told not to do something, but not how to not do it. The campaign must "motivate people into the system, not push them away."

*What special services should a clearinghouse provide?*

Participants suggested the following special services:

- Referral services for materials that would be too voluminous or too expensive to house in a clearinghouse; these materials could be housed in a public or educational library system.
- A full spectrum of information, ranging from basic information for parents or teenagers to sophisticated research materials.
- Curricula for teachers to assist them in managing children with FAS, including teaching tips and strategies for success.
- Materials for dissemination in pharmacies and places where people buy alcohol.
- Tracking and monitoring of FAS materials and services in other countries.

*What factors would be important to consider when evaluating the performance of the clearinghouse?*

Rather than specifically addressing this question, discussants indicated that it would be helpful for the clearinghouse to assist in consensus development among those in the FAS research and clinical communities and to coordinate discussions among researchers, nonresearchers, and others who deal with this problem to develop clear messages.

*if there were a fee associated with using the clearinghouse, would it make a difference? What maximum would you pay for a service?*

Participants struggled with this question. Although it was generally agreed that greater value is placed on information with an associated fee, participants pointed out that those individuals most in need of FAS-related information are frequently the least able to pay for it. It was suggested that a fee could be placed on some materials, whereas others could be made available free of charge.

*Specific to each of you, what is the best way to make you aware of new resources or new materials in the field? For example, do you like e-mail, or direct mail, or other sources?*

The participants indicated that e-mail and blast faxes were effective methods of alerting them to new information.

*What do you consider to be the most important element that was discussed today?*

Discussants indicated that development of a clearinghouse on FAS was important because of the need to provide access to accurate and up-to-date information to multiple constituencies.

## **IMPLICATIONS AND RECOMMENDATIONS**

The results of the qualitative analyses indicate clearly that a national clearinghouse on FAS would be valued and welcomed by the study participants. However, discussants also expressed the need for activities and functions that are more typically related to a national education initiative. For example:

- Participants noted repeatedly that no consensus exists regarding the best techniques for prevention, diagnosis, or treatment of FAS. In addition, the lack of data regarding prevalence and incidence of FAS was identified. Although such activities are traditionally beyond the scope of a clearinghouse, discussants hoped that the NIAAA would facilitate or coordinate consensus development and monitor data collection efforts.
- Participants indicated that those individuals most in need of targeted interventions related to FAS are the least likely to have access to relevant information or resources. Although outreach activities and materials development are not typical clearinghouse functions, discussants expressed a desire for the NIAAA to develop a wide range of materials for disparate audiences (e.g., general information for teenagers, curricula for classroom or special education teachers, and awareness campaigns to increase sensitivity and knowledge of issues related to FAS). Any fees associated with the acquisition of these materials should be determined with the particular target audience in mind; for example, community-based organizations might be charged for shipping and handling, whereas materials for teenage drinkers might be free.

Participants emphasized the importance of continuing education programs about FAS and FAE targeted to physicians and other professionals. Discussants urged the NIAAA to develop and disseminate CME and CEU activities to enhance knowledge of FAS research findings.

The types and kinds of activities and materials identified by the participants suggest that a national clearinghouse on FAS within the context of a national FAS education program might best address the identified gaps in information.

Should the NIAAA elect to pursue a national clearinghouse on FAS-either in concert with or independently from-a national FAS education program, the following activities are recommended:

- Target audience *identification*. The NIAAA must determine specific target audiences for any ongoing education or clearinghouse initiatives (e.g., members of the FAS research community, health professionals, parents, at-risk individuals, or any combination of these or other populations).
- Message *development*. The NIAAA must develop clear and concise messages that are based on the latest scientific information and that are appropriate for each of the target audiences. Because FAS disproportionately affects members of specific minority or ethnic groups, messages should be culturally and linguistically appropriate.
- Promotional activities. The NIAAA must use a multifaceted approach to reach the members of the individual target audiences. For example, members of the FAS research community prefer to receive information through e-mail, fax, and professional journals and conferences, whereas at-risk women may best be reached by means of a public service announcement or physicians' offices.
- Partnership *development*. A wide variety of organizations are involved with or may be influenced by FAS-related issues. The NIAAA must actively involve these organizations in the design and development of ongoing initiatives to ensure program success.
- Evaluation activities. It is ironic that the very organizations that must be considered as partners with the NIAAA in any successful FAS initiative (e.g., SAMHSA, CSAT, CSAP, NIDA, and CDC) are of necessity its competitors in terms of funding and resource allocation. Although analyses such as needs assessments are valuable tools for the identification of new programs and initiatives, the importance of process, impact, and outcome assessments to justify ongoing appropriations cannot be overemphasized.

It is important to emphasize that although indepth interviews and focus groups are qualitative research techniques that can provide useful, detailed insight, the results of the analyses may not be generalizable to a larger audience. Rather, these research findings are intended to provide a general assessment of the need for a FAS clearinghouse as well as guidance to NIAAA in determining how best to proceed.