ALASKA LEGISLATURE COMMITTEE FILES 1997-1998 8672
9101 HOUSE HEALTH EDUCATION & SOCIAL SERVICES

CONFIRMATION HEARING: UNIV BRD...

Alaska State Legislature
HOUSE OF REPRESENTATIVES

Official Business

State Capitol
Juneau, AK 99801-1182

Date: April 29, 1997

The Honorable Gail Phillips
Speaker of the House
State Capitol
Juneau, AK 99801

Dear Madam Speaker:

In accordance with AS 39.05.080, the Health, Education and Social Services Committee has reviewed the qualifications of the following and recommends that the appointment be forwarded to a joint session for consideration:

University of Alaska Board of Regents

Annette Nelson-Wright - Juneau

Appointed: 04/21/97 Effective: 06/01/97 Expires: 06/01/99

This does not reflect an intent by any of the members to vote for or against this individual during any further sessions for the purposes of confirmation.

Rep. Con Bunde, Chair

Rep. Joe Green, Vice Chair

Rep. Al Vezey

Rep. Brian Porter

Rep. Fred Dyson

Rep. J. Allen Kemplen

Rep. Tom Brice

Alaska State Legislature
House of Representatives
Office of the Chief Clerk

Official Business

State Capitol, Rm 214
Juneau, AK 99801-1182
(907) 465-3725

MEMORANDUM

DATE: April 24, 1997

TO: Health, Education and Social Services Committee

FROM: Suzi Lowell SL
Chief Clerk

SUBJECT: Governor's Appointments

Speaker Phillips referred the following Governor's appointment to the Health, Education and Social Services Committee:

University of Alaska Board of Regents
Annette Nelson-Wright - Juneau
Appointed: 04/21/97 Effective: 06/01/97 Expires: 06/01/99

Attached is her resume and a committee report for your use.

Attachments as noted.

Annette M. Nelson-Wright
8539 Forest Lane
Juneau, Alaska 99801-9056
907-790-4456

EDUCATION

West Anchorage High School - Diploma May 1986
The Travel Academy - Travel Specialist Certificate July 1988
University of Alaska Anchorage - Education Major
University of Alaska Southeast - 199[illegible] to present, Liberal Arts Major

TECHNICAL SKILLS

IBM-PC - dbase III Plus, Quattro Pro, Lotus, Wordstar 2000 Plus, Wordperfect 5.1, Microsoft Word, Decisions, Procomm, OPhoto, PageMaker, Photoshop.10-key by touch, facsimile, photocopier.

SPECIAL PROJECTS & AWARDS

Jerry Lewis Telethon-1986, Special Olympics-1986, Anchorage Center for Families-1993-1994, AWARE Shelter-1996
Honorable Mention-UAS Writing Contest, UAS Student Scholarship-Alaska Women's Conference

EMPLOYMENT

University of Alaska Southeast, Whalesong
9/96-5/97

Position: Editor. Duties included determining story content, design and layout of student newspaper, story assignment, and editorial page content. Establishment of production schedule and ensuring staff writers compliance with deadlines and policies. Review of stories for accuracy, content, and conformation to journalistic-style writing format. Supervision of Production Manger, Advertising Manager, On-Line Editor and Photo Editor.
Position: Production Manager (11/96-2/97). Duties included production, layout and design of paper using PageMaker, OPhoto and Photoshop to produce camera-ready pages incorporating copy, photos and graphics. Proofreading, correction and final paste up, also delivery to and pick-up from printer and distribution of paper to news stands on campus and in the community.
Position: Advertising Manager (10/96-1/97). Duties included generating advertising for student newspaper, establishing ad accounts and working with clients on design and creation of ads. Revision of ad rates to conform with paper layout, also assignment of ads to production pages, and minimal bookkeeping to reconcile and track income generated.

University of Alaska Anchorage, Environment and Natural Resources Institute, Alaska Natural Heritage Program
5/93-8/95

Position: Administrative Assistant. Duties included A/P, A/R, petty cash, reconciliation of financial reports, assisting principal investigators with monitoring budgets, preparation and processing of personnel paperwork, processing of contractual paperwork, payroll, maintenance of staff awareness of office policy, processing of all travel and expense reports and reconciliation of reimbursements, answering and routing of phone calls, processing and distribution of mail, word processing, creation and maintenance of filing and library system, purchasing of office supplies and maintenance of office equipment at functional level, coordination of meetings and special events, assisted data management in compilation and editing of reports, responded to public inquiries for information, supervision of volunteers and special projects as assigned.

Alaska Natural Heritage Program (cont.)

Special project: Assistant Project Leader, APEX, (Alaska Ecosystem Predator Experiment). APEX was/is designed to test the role of food in limiting the recovery of seabird species following the *Exxon Valdez* oil spill in Prince William Sound and Lower Cook Inlet, Alaska. The project attempts to measure the degree of variability of food resources, their effects on birds, and the reason for such variability. Duties included: assisting the Project Leader in coordination and communications within a $1.8 million ecosystem project. Tracking of budget and procurement of scientific and field equipment for principal investigators and design of an informational brochure about the project. Working interdepartmentally with federal, state and private agencies to ensure efficient transfer of funds, and coordination of field seasons and shared use of limited scientific and field equipment among many researchers.

ERA Professional Real Estate
9/92 - 3/93

Position: Administrative Assistant. Duties included reconciliation of checking accounts, (general, property management, & trust) all A/P, A/R using G/L, payroll, commission disbursements, posting and reconciliation of independent agent accounts, quarterly taxes and preparation of W-2 and 1099 forms. Maintaining property inventory, tracking all sales, preparation of reports for weekly sales meetings, month-end statistics, data-entry into Multiple Listing Service computer and maintenance of personal, property management, listing and transaction files. Also writing and submission of ads to the appropriate publications, miscellaneous correspondence, and back-up receptionist.

Trans World Moving Systems
5/91 - 9/92

Position: Office Manager. Duties included all deposits, A/R, A/P, using G/L, payroll, collection of delinquent accounts, set-up of all move files and completion of appropriate paperwork, as well as organization and maintenance of all personnel files. Also all correspondence, answering of phones, preparation of weekly labor ratio reports, month-end reports, ordering and maintenance of office inventory, writing of instructional manual for accounting software and office procedures, working up rates using outside offices and tariffs, and regulation of drug testing in accordance with DOT standards. Also extensive work with military personnel property office and knowledge of required form and procedures. Preparation and assembly of bids and proposals under a deadline, distribution of mail, tracking of all shipments, scheduling of deliveries in dispatchers absence, and balancing of petty cash checkbook.

Zack's Famous Frozen Yogurt
1/90 -5/91

Position: Manager. Duties included extensive customer service, opening and closing of store, preparation of daily deposits and weekly schedules. Additionally responsible for disassembling, servicing and reassembling of yogurt machines, ordering and receiving of supplies, preparation of monthly ledgers which included labor and sales estimates, as well as reconciliation of same with actual sales and labor expenditures.

Rent-a-Mom
4/89 - 1/90

Position: Caretaker. Duties included dressing, changing, preparing meals for and administering medication to a 94 year old female. Also general housekeeping, grocery shopping and planning recreational activities.

Position: Home Manager. Duties included care and upkeep of 8,500 square foot home, coordination of lawn, home and automobile maintenance with accountability of expenditures and records for same.

Wilbur's Inc.
8/88 - 2/89

Position: Customer Service Agent. Duties included boarding and deplaning flights, checking in passengers and baggage, resolution of passengers complaints, tracing lost baggage, writing tickets, taking reservations and reconciling cash with ticket sales, excess baggage charges and freight charges at end of day. Also arranging charters, scheduling students with flight instructors, scheduling planes for private renters, receiving freight, re-checking pilots weight and balance off flight manifests and assisting in rewriting training manual to FAA specifications.

Unwin, Scheben, Korynta and Huetti, Inc.
11/85 - 4/88

Position: Courier and Office Assistant. Duties included filing, creating new files as needed, logging and distributing in and out submittals, responsible for data entry as well as setting up the appropriate database files, assisted the marketing coordinator with correlating and assembling proposals under a deadline. As back-up receptionist responsible for distributing incoming mail, answering phones, receiving guests, typing forms, metering and stamping outgoing mail.

Annette M. Nelson-Wright
8539 Forest Lane
Juneau, Alaska 99801-9056
907-790-4456

REFERENCES

Dr. David Cameron Duffy
Program Manager/Professor of Biology
Environment and Natural Resources Institute
Alaska Natural Heritage Program
University of Alaska Anchorage
707 A Street, Suite 208
Anchorage, Alaska 99501
(907)257-2703

Mr. Kirk McAllister
University of Alaska Southeast
Whalesong Advisor
1108 F Street, Room 208
Juneau, Alaska 99801
(907)465-6263

Dr. Virginia S. Mulle
Assistant Professor of Sociology
University of Alaska Southeast
11120 Glacier Highway
Juneau, Alaska 99801
(907)465-6405

EDUCATION GUARAN-TEED

Testimony of John Jensen, Ph.D

February 5, 1998, House HESS Committee

I appreciate your interest in how you might help Alaska's children. With the hope that you would like to become known in later years as "the legislature that transformed education," I'd like to make some prepared remarks on three issues, and then follow up with any discussion you wish. The three issues are 1) what went wrong with education, 2) what's needed to correct it, and 3) what legislative initiative is an appropriate starting point.

1. WHAT WENT WRONG. Many authors and researchers have described the problems of education in excruciating detail, but often end almost in hopelessness, concluding that it's a crazy world and that institutions don't change. What we want instead is an understanding of the situation in terms of causality. What small changes can bring about big outcomes? If you plant one seed, you get a cabbage; with another, you get an oak. So we're asking "What went wrong with education that can help us identify changes we need to make?"

In the early part of this century, an eighth grader learned in school more about the world than many college graduates know today because teaching methods then aimed for comprehensive mastery, in-depth academic knowledge. Progressive Education, led by John Dewey, specifically scorned the idea of "piling up information," and wanted students to master their direct experience, shifting the emphasis from learning to good conduct.

This emphasis entered teacher training and in time teachers lost track of how to obtain comprehensive academic mastery. The effect has been the academic deterioration that has frustrated millions of Americans now for so many decades.

To explain the deterioration, many theories of education came along relating poor academic performance to issues of sociology, self-esteem, self-concept, parental interest, learning disabilities, forms of intelligence, class size, and so on. But these descriptions have often complicated and neutralized rather than unified and empowered educational thinking. Educators can legitimately commit to so

many ways of defining needs and services that the demand for resources appears to be never-ending while systemic improvement in outcomes continues to elude us.

So my candidate for the central causal factor, a factor we can do something about, is this: The most basic thing that went wrong was the loss of a common methodology for achieving academic mastery with any student. Now, many if not most teachers don't know how to obtain mastery. All the state and national concern about educational standards is driven by that reality. We collectively don't know how to meet the standards we do have at any given time.

2. HOW TO CORRECT IT. The second step is "What's needed to correct this?" The answer is to set back in motion what was lost, "**a methodology of teacher behaviors for achieving academic mastery in all students.**" We need to answer the question teachers always ask: "What do I do on Monday?" And in this step lies the particular contribution I would like to make. It's based on my involvement with classroom methods extending back to 1971, much research in the course of my Ph.D. study, and then intensive work since 1991 on what I call "the Assimilation Model" described in my book **Education Guaranteed** which is being published this fall by Minerva Press in London. Two major ideas are the basis of it.

The first idea is that "**practice makes perfect.**" One researcher found that "arduous practice" is what most clearly separates top performers from all others. If your twelve year old wants to get better at basketball, what do you say to him or her? You say "Okay, practice!" Want to get better at a musical instrument? Then practice. At public speaking? Then practice. At sales? Then practice. I challenge you to think of anything in the world people get better at without practice! And I believe accordingly that practice is the silver bullet (that educational analysts have been saying for years does not exist) for getting better at **learning**.

My dictionary defines practice as "to do or perform repeatedly in order to

acquire a skill or training." Note the word "repeatedly." This means that there must be something to repeat, a behavior that has a defined boundary. You know that in a sport such as basketball, you select one skill at an elementary level and focus on it till its smoother, and you find yourself integrating it more and more automatically with other parts of skills. You practice the integrated set of the small pieces you worked on.

And some parallel exists between the classroom and what you yourself do when you're about to make a presentation to a legislative committee: **you practice explaining.** To practice, you draw together a basic cluster of ideas and then improve them while talking them out. It's not complicated. In explaining your ideas, you smooth them out, locate details in their context, and become fluid in approaching them from several perspectives. And this, I've found, is exactly what's needed by students from kindergarten through high school. Regardless of their age, attitude or intelligence; regardless of the subject's simplicity or complexity, **successive practice in explaining something without help leads to mastery of it.** To me this central fact is indisputable and is easily validated by anyone willing to try it out.

The chunk is usually a piece of learning presented by a teacher for ten to twenty minutes. So you have the chunk out in the open, up on the board, understood and organized. The question then is, "Will students retain it or not?" The answer is, "They will if they practice it." Students pair up and ask each other the question that identifies the cluster, and students explain that small chunk of learning first till its basically retained, and later till its fluid. Then with the next chunk also mastered, it's easy to integrate the two at a higher level of comprehension.

And in this gradual integration of chunks lies an important truth: that there is an unbroken continuum of knowledge between on one end a kindergartener giving a one-word answer to a question about light and on the other end a senior in high school giving a forty-minute explanation of Einstein's discoveries.

The price of moving up that continuum is teaching for accumulation of learning rather than for losing it with the recognition-based methods that are so common nowadays. To demonstrate what's possible if you accumulate, let me ask you to draw on your direct experience of children you know: how absorbent, how insightful, how eager, how interested they are. Does it seem reasonable to you to expect that these children you know--with learning content at the level of their ability--should be able to come out of every hour of instruction able to explain at least one minute's worth of knowledge learned in that hour? That one minute's worth should be retained and carried forward to integrate with later learning?

My observation of children tells me that that's an achievable goal. But if we can do even that, we get five minutes worth of learning in one day. At home the parent asks "What did you learn today?" and the child can talk interestedly, and competently for five minutes without repeating herself. That doesn't sound like much perhaps, but with a teaching methodology focused on accumulation, it means 25 minutes learned that week--a significant accomplishment. Continuing that modest pace adds up to 100 minutes a month, and 900 minutes for the year which is 15 hours. Imagine your daughter in grade school in early June saying to you "Tomorrow I start my orals" and she can talk about her learning for two days without repeating herself.

You may think that that sounds too optimistic, so let's back it off: Hold on to the methodology of accumulation, but aim just for retaining a **single minute's learning per day**. Surely that isn't too much. But when June rolls around, that adds up to **three hours** of mastered, explainable knowledge! The crux of the problem, in other words, lies not in how much students are <u>presented</u> on any given day, how many pages they covered, but how much they <u>save</u>.

So the first foundation of learning is practice explaining in a manner designed to accumulate learning. The second principle is about synergism. You nourish student energy through doing several things at once that draw on different innate motives in students. I'll mention one motivational factor as a sample: **The**

most powerful ally we have for good education is what students think of each other, their intense desire to appear competent in ways their peers value.

In asking students to do questions and answers with each other in pairs, explaining to each other what was presented, we draw on this motive. Other motives: Students need to write down what they will practice so they own it more, have it organized in a way that makes clarity of task easy. They need to stand and perform chunks of their learning, which generates zest and peer feedback. They need objective and instant scoring of their learning achievement, which validates the effort they've just expended. They need self-checking and peer-checking on communication skills used, to raise the quality of their interactions. They need time spent acknowledging good feelings generated between them, so that they focus on positive feelings instead of on the putdowns and assorted cruelties that are too common. With such a mix of capabilities and motives that are enlisted, classes turn around quickly. All students start to learn, the mood in the classroom turns from negative to positive, students cooperate with the teacher and each other, they want to come to school, parents take more interest and are more easily enlisted in supporting this process, and disciplinary issues drop away.

Some characteristics of employing this approach are:

--It requires no extra money.

--It's completely under the control of the teacher.

--Teachers need no new skills. They just change the way time they use time in the classroom, so it's easy to learn.

--Objective results day by day are measured the same by everyone.

--Accountability by student, classroom, and school is crystal clear.

3. LEGISLATIVE INITIATIVE. So what can the legislature do about this? A legislator many years ago felt he was doing me a favor by diminishing my expectations about what you here can accomplish. He explained that the legislature's very nature is to be reactive rather than proactive. It fends off as best it can problems that are dumped on it, but is seldom in the position of being

able to foresee a need far ahead and forestall it with an initiative of some kind, just because of the way so many different forces are at work within it. And that was even at a time of an expanding rather than a contracting budget.

By now, however, we're no longer asking for foresight: The problem of educational results are upon us all, and anyone that sees a way to help needs to come forward.

My first suggestion is that you use your standard means at hand when there's a clear problem and you don't know what to do about it: **you gather information.** You here are a pipeline of information. Needs come in through each of you and information flows out the other way. And when the legislature as a body agrees that a particular kind of information is important, that a major shift of direction may be needed, what it does is to hold hearings in districts around the state.

By the questions you ask in doing that, you generate public examination of a particular need and how that need is being met. I can easily envision a team of legislators and staff based in this committee that would go to localities around the state. You explain that you are checking out people's experience of educational issues that have policy and financing implications. The policy implication is the design of the educational delivery system of the state. The financing implication is that to the extent the design is inefficient or misdirected, the state wastes money it's spending now, it misdirects funds.

I'm well aware that over the years, many, many attempts have been made to do this. What I'm suggesting you do differently this time, however, is that you take up a zone that policymakers have till now all but ignored: **regaining a consistent classroom methodology resulting in academic mastery for all students.** With whatever else you wish to include, you look at these issues at least:

. Practice: whether it is accomplished, how it is accomplished, its results?

. Accountability: objective, instant scoring compared with standard model?

. Performance: how can learning be performed, is this motivating?

Organization: are students led to consistent arrangement of tools to make practice easy?

. Communication: how are students learning to communicate, are the means effective, do they need to be better integrated into learning?

. Attitude: does teacher-directed activity raise the emotional atmosphere in the classroom?

Certain effects can be expected from doing this: 1) Doing this may easily spark similar discussions in local boards, parent groups, and among school staff. 2) You return with a body of information to use as a lens for checking how the current state-designed educational structure gets results, and would have a basis for more detailed examination of policy changes. 3) You shed light on how you get more educational results for every dollar spent.

This concludes my prepared remarks. Thank you for your time and attention.

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John Jensen, 1012 Second Street, Douglas, AK 99824. Phone 907-364-4600.

FETAL ALCOHOL SYNDROME

I WILL BE GOOD

by Gloria Stuart

I hear Bandit barking. Now he's crying. Maybe there's a moose out there. Don't cry, Bandit. Be quiet, Bandit! He can't hear me. I'll open the window and tell him. This window can't open a lot. Why is my window nailed closed? I want to get out this window. It won't open enough. I'll tell him through this little part. "Be quiet, Bandit!" Ouch, this window makes my face cold. "Shut up, Bandit! You woke me up." Mary had a little lamb, little lamb. Is it morning? It's still dark. I'll see. Everybody's sleeping. I don't want to sleep. I want to play. I want to have my toys. Why is my closet locked? I hate that hook! I want my trucks. I'll pull this dumb door. "You dumb door!" I'll kick this stupid door. "I hate you, hook! A-oh, here comes Mom!"

> "Okay, I won't kick the door. But I want my trucks. No, I don't want to sleep. Yes, it is. It is morning!"

I can't sleep. I'm hungry. I'll go get something to eat. I can't reach the freezer. Maybe there's something good in there. I'll climb up this bottom door. Hey, I'm a gymnastic man.

> "Okay, Mom. I'll close the door. But I'm hungry. I want to eat. I want B-O-L-O-G-N-A. Okay, I'll stay in my room. You can take a shower. But give me my trucks. Please."

I'll line up my trucks. Jingle bells, jingle bells, jingle all the way. Maybe I can give Bandit a toy. I'll throw a truck down to him. I can't open this stupid window now! It's too hard! I'll climb up on the window ledge and try. Hey, now I can open it! "Hi, Bandit! You want a truck?" I can squeeze it through here. Oh, poor Bandit. You can't reach it. You're tied up. Here's another one. You can't reach that one either. Here's a book! Here's another one. A-oh, I need to pee. She locked me in. "Hey, get out of the shower. I have to pee." I'll take off this stupid diaper. I'm not a baby. I don't want to sleep in a diaper. "Let me out!" I'll kick this door. Here she comes!

> "I did not break the door. I had to pee. I didn't pee on the rug. Oh, sorry. It's here too by the heater. Can I take a bath now? Can I pour with your cups? The measure ones. I won't wet the floor. I will be good."

This is fun. I like to pour. She's getting the phone. I can make it rain on the floor. What's in that drawer? Let's see. I'll open this big jar. It feels smooth. I'll put it in the water. The water can't make it come out of the jar. I'll get it out. Oh, yuck! I'll wipe it on the wall.

Yuck. It won't come off. Sick. I can paint it on the wall. I can use the brush. What else is in the drawer? look at all these tube things. I can open this. I'll rub it on my hair. Now what do I look like? Here she comes again!

> "I will be good! I just want to pour. I can't clean that up! I don't want to get washed. I don't want to get dressed. Not those pants! Jeans hurt me. They do! Can Wiskas come in? Owee! These pants hurt me. I won't hurt him. Can he come in later?"

Hey, what's that knob up there? I can reach it if I climb on the piano. Oh, now the knob came off! The fan went on way up there. I'll play the piano. Twinkle, twinkle little star. I want to run on the piano. Now it's LOUD! This is fun.

> "No! PUT ME DOWN! I will be good! I don't want that egg. It's yucky! I want B-A-L-O-G-N-A."

Hey, I can rock my booster chair. Mary had a little lamb. Look out there. An airplane. Oh, now I spilled my juice.

> "More juice. Please. I'm done. Down. I will be good."

I want to play with my trucks. I need a gun to shoot a bear. I need a tool to fix my trucks. I'll take the wheels off my trucks and then I'll fix them. I'll get a tool. A wooden spoon can be a tool. I can fix the glass door. I can hammer it. Oh, Mary had a little lamb. Oh, there's Wiskas. I want him to come in. I can't slide this door open. Mom's in the laundry room. She won't help. I'll go out by you, Wiskas, and be your friend. I'll climb out the window. We can play on this deck. "Come here, Wiskas! You're a heavy cat! Let's go down these steps and see Bandit. Ouch! Don't scratch me, Wiskas!" Now where did he go? I'll go see Bandit. "I'm coming to see you, Bandit. Owee! Don't knock me over, Bandit!" A-oh, here comes Mom. I'll go hide in Bandit's house. Come on Bandit, come in.

> "I'm not here. I don't want to come in! I won't run in the road. I don't want another bath. I'm NOT muddy. I will be good."

Now I'm clean again. Maybe I can watch a movie. I want Winnie the Pooh.

> "Thanks, Mom. I like Winnie. I will be good. I will sit and watch him. He's my friend."

Winnie likes honey and . . . there goes a grader. I like graders. I'll climb up here on the table to see it. Hey, maybe I can swing on this light! It's shiny. Hey, I see me in it. A-oh! I'd better hide under the table.

"I'm not h-e-r-e! Okay. I'll be good."

Oh, she's on the phone. What's in the desk now? Maybe some tape. Pencils! I can make holes with a pencil. I can make lots of holes in this box. I can make holes in the wall and in the chair . .

"I don't want time out! I don't want to read my books. I'll play with my cars and trucks. I'll line them up. I will."

"Come here, Mom. Look. I made a square with my trucks. And I made a circle with my cars. I can make a rectangle with my other cars. Watch. See, Mom. I'm good. I am."

"I Will Be Good" was written to convey what it might be like to live in the skin of a 3-year old with Fetal Alcohol Syndrome. It also shows what it's like to be the primary caregiver for such a child. The challenges of routine jobs, ordinary morning schedules and just keeping track of these children are mind boggling. Exhaustion for parents and children is often an ordinary way of life. To be the child with FAS and experience ADHD must be frightening as well. They surely need our patience and prayers.

Gloria Stuart, Foster Mother

10 Common Misconceptions About Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

Ann P. Streissguth, Ph.D.
Fetal Alcohol & Drug Unit, Department of Psychiatry & Behavioral Sciences
School of Medicine, University of Washington, Seattle, WA 98195

1. **That FAS means mental retardation.**
   - Some people with FAS are mentally retarded, others are not.
   - People with FAS can have normal intelligence.
   - They are brain damaged and have specific areas of strengths and weaknesses.
     - It's more like people who have sustained brain injury from an auto accident.

2. **That the behavior problems associated with FAS/FAE are all the result of poor parenting or a bad environment.**
   - No, being brain damaged can lead to behavior problems because brain damaged people don't process information the same way that other people do, so they don't always behave like others expect them to.
   - Brain damaged children are hard to raise in the best environments.
   - Their parents need help and support, not criticism.

3. **That they will outgrow "it" when they grow up.**
   - Unfortunately, they do not. FAS lasts a lifetime, but the manifestations and type of problems change with each age.
   - It takes a longer period of sheltered living for brain damaged children to grow up.

4. **That to admit they are brain damaged is to give up on them.**
   - Have we given up on children with other defects?
   - We need research to understand the needs of patients with FAS and how to help them. We haven't invested in that area yet. We will learn how to help them when we decide to invest in the problem.

5. **That diagnosing them will brand them for life.**
   - A diagnosis tells you what the problem is, helps you figure out how to treat the problem, and relieves the person of having to meet unrealistic expectations.

6. **That they are unmotivated when they don't keep appointments or act in a way that we consider responsible.**
   - Probably the explanation lies in memory problems, inability to problem solve effectively, or simply being overwhelmed.
   - Sometimes they misconstrue reality.

7. **That one agency can solve any or all of the problems alone.**
   - The multiple needs of patients with FAS/FAE require multiple fronts of intervention and intense interagency cooperation.

8. **That this problem will be solved with existing knowledge.**
   - Research is desperately needed, and the magnitude of the problem will necessitate more research.

9. **That the problem will go away.**
   - FAS is preventable, but alcohol is so much a part of our culture and so aggressively marketed to those least able to resist, that active prevention activities must continue on all fronts to safeguard our children's future and the future of our people.

10. **That their mothers had an easy choice not to drink during pregnancy, and through callousness indifference, permanently damaged their children.**
    - Biological mothers of children with FAS need help with their alcoholism and/or with birth control.
    - Pregnancy is an excellent time for alcohol abusing mothers to stop drinking, but they need help

DIAGNOSTIC CRITERIA: FETAL ALCOHOL SYNDROME

In order to make a diagnosis of Fetal Alcohol Syndrome, the Fetal Alcohol Study Group of the Research Society on Alcoholism recommended that such a diagnosis be made only when an infant has symptoms in each of three categories:

1. Pre- and/or postnatal growth retardation: Weight, length, and/or head circumference are below the tenth percentile when corrected for gestational age

2. Evidence of central nervous system involvement: Signs of neurologic abnormality, developmental delay, or intellectual impairment

3. Characteristic facial dysmorphology with at least three of the following signs: Microcephaly (head circumference below the third percentile) microphthalmia and/or short palpebral fissures (short eye openings), poorly developed philtrum (vertical groove between upper lip and nose), thin upper lip, flattening of the midface.

Fetal Alcohol Study Group of the
Research Society of Alcoholism (1980)

FETAL ALCOHOL EFFECTS

"A child with a history of prenatal alcohol exposure, but not all the physical or behavioral symptoms of FAS may be categorized as having Fetal Alcohol Effects (FAE). **It should be noted that FAE is not the less severe form of FAS; rather, a child with FAE does not have all of the physical abnormalities of FAS.** The cognitive and behavioral characteristics of FAS and FAE are similar."

"Educating Students with Fetal Alcohol
Syndrome or Fetal Alcohol Effects" by
Drs. Donna Burgess and Ann Streissguth
(Pennsylvania Reporter (22:1) 1990)

CONTINUUM OF EFFECTS: PRENATAL EXPOSURE TO ALCOHOL, OTHER DRUGS

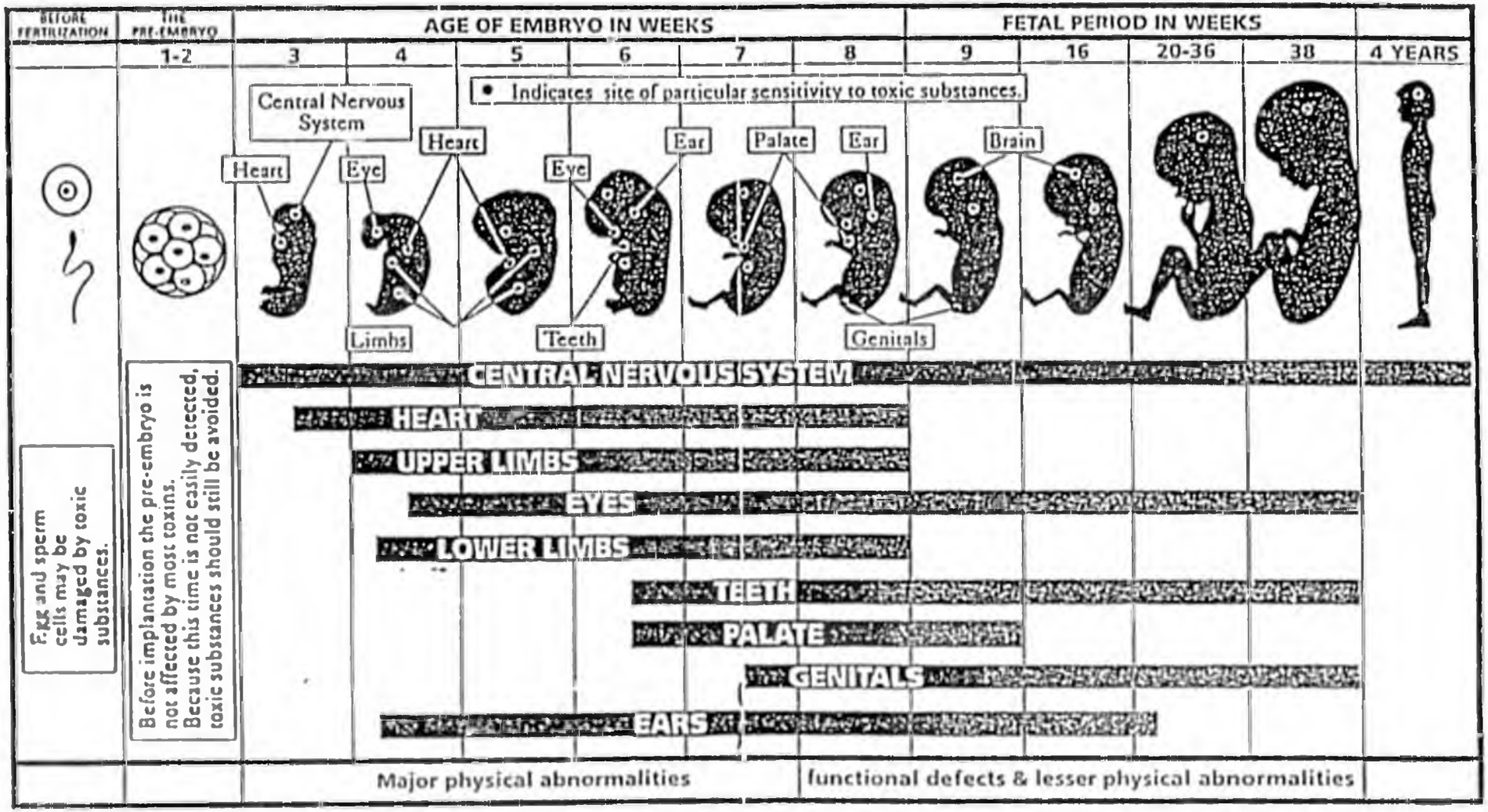
Brain — Growth — External Characteristics — FAS

Minimum >——————>——————>——————>——————>Maximum

Streissguth in lecture, 1990

The Effect of Toxic Substances* on Development

*Such as: Alcohol, tobacco smoke, illegal drug and some over the counter and prescription drugs.



Note: Adapted from Moore, Keith L., The Developing Human, 4th Ed. (W.B. Saunders, Philadelphia, 1988)

VISUAL MODEL FOR RETHINKING BEHAVIORS

Normal brain development is orderly sequential. Rich neural networks provide opportunities to link, integrate, associate

FAS/E: Undergrowth, overgrowth, gaps and tangles. Fewer physical links for retrieval, integration and other options.

Spotty learning and retrieval is normal; strengths may be atypical. As with all people, people with FAS/FAE are always learning, but may require specific cues to access previously stored information.

INFORMATION PROCESSING DEFICITS

1. Difficulty translating information from one modality into appropriate behavior. (Hearing into action, seeing into writing, reading into understanding, feeling into speaking)

2. Difficulty generalizing information (transferring rules into new situations, recognizing patterns, forming associations, predicting outcomes)

3. Difficulty perceiving similarities and differences (discriminating, discerning, weighing and evaluating, comparing and contrasting: Friends and strangers, safety or danger)

Barbara Morse—1991

DB Malbin, MSW. FAS/FAE Counseling and Consultation 503-621-1271

BEHAVIORAL EFFECTS FOLLOWING PRENATAL ALCOHOL EXPOSURE IN HUMANS AND ANIMALS:

HUMANS	ANIMALS
Hyperactivity	Increased activity and exploration
Attention deficits, distractibility	Attention deficits
Lack of inhibition	Lack of inhibition
Mental retardation, learning difficulties	Impaired learning
Impaired ability to adjust to new stimuli or situation	Impaired habituation
Repetition of a mental activity with an inability to switch to another activity (perseveration)	Perseveration
Feeding difficulties	Feeding difficulties
Gait abnormalities	Gait abnormalities
Poor fine and gross motor skills	Poor coordination
Developmental delay (motor, social and reflexes, behavior, language development)	Developmental delay (motor puberty)
Hearing abnormalities	Hearing abnormalities
Poor state regulation (tremors, jitters, aberrant sleep patterns)	Poor state regulation (temperature dysregulation, aberrant sleep patterns)

Source: Adapted from Driscoll et al, 1990, in: Alcohol Health and Research World 18(1) 1994

Supporting Alternate Families and Caregivers of FAE/E Children, Teens, and Adults

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The following is a list of tips and suggestions for supporting alternate families and caregivers compiled by the FAS/E Support Network. The list arose from all the comments, suggestions, and problems mentioned by families who have accessed the FAS/E Support Network for information and/or support.

- If you haven't lived it you haven't been there.
- Listen, Listen, Listen! Really "hear" what is being said and more importantly, what is *not* being said.
- Understand this is not a "quick fix' or "easy solution" problem; it is a life-long disability with profound psycho social implications for families as well as individuals.
- Be available, return phone calls.
- If you don't know say so.
- Learn from the parents and caregivers; they have much to share.
- Provide services pro-actively.
- Find an advocate for the family unit until they can fill that role themselves.
- Understand that parents, especially adoptive ones may view the system as adversarial. They are afraid of you. The system is seen as all-powerful and needs to be more receptive
- Track down resources and aid families in using them. Make initial contacts, sort out red tape, learn the pitfalls, ect.
- Provide access to training for understanding FAS/E and specific parenting techniques.
- Don't wait for caregivers to call you. Check with then regularly, even then things are going well.
- Develop a relationship with families *independent* of crisis.
- Find respite care and/or a way to fund it.
- Access information on the child for the family. Adoptive families often have little or no written information on their child; It may be useful and even necessary to call for the file, and families have the right to know.
- Parents, foster, and adoptive need specific and detailed information on what a child may have been experienced if they are to deal with the aftermath.
- Most FAS and FAE children have suffered from abuse and/or neglect. Understanding how this effects the underlying neurological disorder and conduct problems is crucial. Both social workers and caregivers need training.

- Social workers and caregivers (adoptive and foster) who attend training together on an issue are more likely to work together effectively.
- respect the parents opinion and decisions. they must live with the consequences.
- The child you see *is not* the child they live with.
- Do not tell a parent that he is over reacting, or that " all kids do that".
- Work at where parents are, on what they see as the problems.
- Remember that improvement means deferent things to different people, and occurs in such small steps it can be missed.
- Telling a parent that a child is doing "really well" will not always be seen as good news, and in fact, may been seen as just the opposite.
- Asking what you can do to help the parent keep his head above water is important.
- Meeting with both parents -not just the mother- is preferable, and may require adjusting work schedules.
- Finding a support group and/or a buddy parent for the family; find a way to "stage manage" their involvement if they are unwilling; remember that exhausted people do not have the energy to seek out support -support needs to seek them.
- Recognition that most parents who undertake to parent these children find themselves dealing with social and behavioral situations for witch they are totally unprepared.
- Adjustment to long term foster care or adoption is cyclical in nature. Children revisit the stages of grief and loss at different developmental stages, witch simply put, means that managing behavior and dealing with acting out -even independent of FAS or FAE- is an ongoing task throughout adolescence, *FAS and FAE compound the problem.*
- Parents and caregivers also adjust in a cyclical nature and must revisit their own issues and manage their own feelings, especially anger- witch it must be remember is a mask for pain. It is **imperative** that professionals working with families of FAS/E children keep this awareness in the forefront of their dealings with the family if support is to be effective.
- Help parents understand that the above two points do not mean that they are failures or inadequate to the task, rather that this is part of the process.
- View out of home placement as a positive option not a negative one. It is not necessarily an indication of placement breakdown/failure, but may, in fact, represent the commitment of a family to maintaining an adoptive/foster placement in the face of very real difficulty.
- Attend meetings with other systems with the caregivers, if they request; offer to do so.
- In complicated cases, a case manager may be required. Work with the parent to decide who would be best in this role and who would also best meet the needs of the caregiver.
- Provide a family with all the options in a given situation, but allow them to make the decision.

- Support the decision even if you disagree with it, The position of the professional should be to facilitate decision making, not impose personal- or even professional- options.
- Once an adoptive placement has been made, or an official exception to policy permanent plan has been granted, the premise which guided the selection of that family should still be the premise when the family request services or help. They were - and are- the best possible choice for that child. *Nothing* will disempower a family faster than the unstated but implicit opinion of a professional (or support person) that another family could do a better job.
- If the placement has irretrievably broken down, it is imperative that it be handled with the utmost compassion. Families -both long term and foster- are devastated to go through an intense grieving process. It is a death with out a death, Intense in home and in person support which encourages expression of feelings, (no matter how negative) and acknowledges the anger and pain should be provided.
- Counseling for all family members should be accessed
- Some form of long term follow-up and social work support should be provided in a placement disruption. Even if the family is not receptive, they need to know concretely that someone cares, that someone cares. At some point, they will be ready to discuss what happened and what they feel could have been done differently. It is an important step in healing which frequently does not occur because there is no one who's job it is to keep making overtures to these families. Never, ever, discuss a family its children or any problems with any other person, professional, or system with out the express, specific permission for the specific occasion from the parent or caregiver. Confidentiality and the absence of "judgment" are the backbone of effective support.

FAS CONFERENCE ON SECONDARY DISABILITIES

SEATTLE, WA

SEPTEMBER 4-6, 1996

SUMMARY

What follows is a summary of the report provided participants at the FAS Conference in Seattle, September 4-6, 1996.

The study consisted of 473 participants, 178 were diagnosed as Fetal Alcohol Syndrome (FAS) and 295 were diagnosed as Fetal Alcohol Effected (FAE). The age group was between 3 and 51 years. Ninety (90) participants were 21 years of age and older.

The participants diagnosed with FAS had an average IQ of 79, average reading, spelling, and arithmetic standard scores of 78, 75, and 70, respectively and an average Adaptive Behavior score of 61. Those participants diagnosed with FAE had an average IQ of 90, average reading, spelling, and arithmetic standard scores of 84, 81, 76. respectively and an average Adaptive Behavior of 67. A normal score for both IQ and Adaptive Behavior is 100.

Six main secondary disabilities were studied:

- Mental Health Problems were experienced by over 90% of full sample
- Disrupted School Experience was experienced by 60% of sample age 12 and over
- Trouble with the Law was experienced by 60% of sample age 12 and over
- Confinement (defined as confined in a psychiatric, substance abuse or prison) 50% of 12 and over
- Inappropriate Sexual Behavior found in 50% of 12 and over
- Alcohol/Drug Abuse found in 30% of 12 and over

In an effort to determine how many participants became self-sufficient as adults, two additional secondary disabilities were evaluated for the age group of 21 years and older. They were:

- ***Dependent Living*** was found in 80% of the 21 year age group and over (n=90)
- Problems with Employment 80% of the 21 year and over age group----please note that out of the 90 only 7 individuals were living independently and were employed

Males have higher rates of Disrupted School Experience, Trouble with the Law and Confinement than do females; otherwise, rates of Secondary Disabilities are nearly equal across the sexes. Clients 12 years and older have a higher rate of all Secondary Disabilities except Mental Health Problems than younger participants. Compared to clients with FAS, those with FAE have a ***higher*** rate of all Secondary Disabilities, except Mental Health Problems.

A set of 21 possible risk and protective factors were examined through an analysis. Eight factors emerged that are almost universally protective in terms of secondary disabilities. In order of their strength as "universal" protective factors, they are:

1. Living in a stable and nurturing home for over 72% of life
2. Diagnosis before the age of 6 yrs
3. Never having experienced violence against oneself
4. Staying in each living situation for an average of 2.8 yrs
5. Experiencing a good quality home from age 8 to 12 yrs
6. Having applied for or been found eligible for DD services
7. Having been diagnosed FAS rather than FAE
8. Having basic needs met at least 13% of life

Compared to individuals with FAS , individuals with FAE have a higher rate of Secondary Disabilities except for mental health problems.

Also, 30 females in the sample had given birth to a child. Fifty-seven percent (57%) of these children were no longer in the care of the mother and 40% were drinking during their pregnancies with these children. Seventeen percent (17%) of these children had already been diagnosed with FAS and another 13% were suspected of having either FAS/FAE, but were undiagnosed at the end of this study.

The following pattern of relationships between specific secondary disabilities and risk and protective factors was found through analysis of odds ration plots:

- Odd of Mental Health Problems are reduced primarily by the universal protective factors
- Odds of Disrupted School Experience are reduced primarily by the universal protective factors
- The rate of Trouble With The Law is related to all the universal protective factors, most notably, eligibility for DD services
- Confinement also is related to the universal protective factors, especially "living in a stable and nurturing environment, and being diagnosed prior to age 6".
- Odds of Inappropriate Sexual Behavior are reduced by all universal protective factors
- Alcohol and Drug Problems have one specific protective factor in addition to universal protective factors, namely having lived with an alcohol abuser less than the median for the group, which was 30% of a participant's life
- Odds of Dependent Living are increased over fourfold for participants who had an IQ score of 70 or below, an Adaptive Behavior score below 65, or an IQ/Adaptive Behavior Discrepancy score of over 15 points. Other strong intrinsic risk factors for Dependent Living are a high FABS score, a Performance Scale IQ minus Verbal Scale IQ score of more than 15 points, and being male.
- Odds of Problems with employment are increased more than two to four fold by an IQ score of 70 or below, an Adaptive Behavior Score below 65, and IQ/Adaptive Behavior Discrepancy score of over 15 points, and being FAS rather than FAE. Some universal factors are also protective against problems with employment, namely, an early diagnosis, longer time in a stable and nurturing home, longer duration in each household, and not being a victim of violence.

It should be noted that the correlations reported may or may not be causative. They nonetheless suggest courses of action that may be beneficial both to these clients, and ultimately to society. ***Efforts to intervene with alcohol-affected children should proceed simultaneously with efforts to prevent future children from being born with FAS/FAE.***

State of Alaska Epidemiology **Bulletin** *Recommendations and Reports*

Department of Health and Social Services
Karen Perdue, Commissioner

Division of Public Health
Peter M. Nakamura, MD, MPH, Director

Section of Epidemiology
John Middaugh, MD, Editor

3601 C Street, Suite 540, P.O. Box 240249, Anchorage, Alaska 99524-0249 (907) 269-8000
24-Hour Emergency Number 1-800-478-0084

Volume No. 1 Number 2
September 15, 1997

Fetal Alcohol Syndrome

Prevalence

Risk Factors

Prevention

ALASKA FAS STEERING COMMITTEE MEMBERS

Alaska FAS Prevention Project (CDC)

Marvin Bailey
Grace Egeland, PhD
Carl Li, MD, MPH
Kathy Perham-Hester, MS, MPH

State of Alaska

Department of Health and Social Services

Section of Maternal Child and Family Health
Karen Pearson, MS
Debra Caldera, RN, MPH
Section of Nursing
Elaine McKenzie, RN, MPH
Section of Epidemiology
John Middaugh, MD
Brad Gessner, MD
Diane Ingle, BA
Bureau of Vital Statistics
Al Zangri, MA
Division of Alcoholism and Drug Abuse
Suzanne Perry, MS

Department of Education
Richard Smiley, PhD

Indian Health Service (IHS)

Jim Berner, MD
Vicki Hild, MSPH

Compiled by: Kelin Colberg, B.A., Student Intern, University of California at Berkeley School of Public Health; Section of Epidemiology, Alaska Division of Public Health, primarily taken from original publications of Egeland, Perham-Hester, and other contributors to the Alaska FAS Prevention Project.

Preface

This report summarizes six and a half years of work towards the characterization and prevention of fetal alcohol syndrome in Alaska. We compiled key findings from Alaska's surveillance efforts, analytic studies and alcohol-related surveys to help guide the state's future FAS prevention and research efforts directly from previous publications. This monograph would not have been possible without the energy and dedication of the many individuals whose original work advanced our knowledge of FAS.

We have tried to present accurately the major findings and recommendations from original works conducted in Alaska by the AFASPP and others. We were unable to have this document reviewed

prior to publication by all of the AFASPP participants or by other primary authors. The Section of Epidemiology accepts responsibility for the content of this document.

Executive Summary

Birth defects are the leading cause of infant mortality on the United States, accounting for more than 20 percent of all infant deaths. In addition, birth defects are the fifth leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. Fetal Alcohol Syndrome (FAS) is a leading birth defect that causes significant lifetime disability. Unlike many other birth defects, however, FAS has a known etiology and is preventable.

In 1990, the Centers for Disease Control and Prevention, Indian Health Service, and Department of Health and Social Services established the Alaska Fetal Alcohol Syndrome Prevention Project (AFASPP). As a result of the work done by the AFASPP, Alaska is recognized for its leadership in developing science-based, FAS prevention programs.

PREVALENCE

The overall minimum prevalence of FAS in Alaska ranged from 0.8-1.3 cases per 1,000 live births. The prevalence of FAS among Alaska Natives was 3.0 - 5.2 per 1,000 live births compared to 0.2 - 0.3 per 1,000 live births among non-Natives.

While the higher FAS rates among Alaska Natives compared to non-Natives may be due in part to extensive case finding by the IHS and underascertainment of FAS among non-Natives, Alaska Natives are at higher risk of FAS than non-Natives.

RISK FACTORS

- A large proportion of Alaska's identified FAS children were either adopted or in foster care.
- There is a real risk of mothers of FAS children having multiple FAS children -- 14 mothers had ?? FAS chi'dren; one woman gave birth to 4 FAS children and to 3 other children who had a physician notation of FAS in their medical charts. Among the noted problems in their records were physical and sexual abuse, partners with alcohol problems, denial of alcohol problems, alcohol-related emergency room visits, sexually transmitted diseases, involvement with law enforcement officers, suicide gestures, and multiple refusals of alcohol treatment.
- The high prevalence and the characteristics of alcohol consumption among Alaskan women of child-bearing age have important implications.
- Of mothers of FAS children, the majority were unmarried at the time of delivery, many had not completed high school, and most either had no prenatal care or began prenatal care after the first trimester.

PREVENTION RECOMMENDATIONS

- Population-based surveillance of FAS is essential to document the magnitude of the problem, to monitor trends in the occurrence of FAS, and to document the impact of prevention efforts.
- The more that is understood about the women who give birth to FAS and other alcohol-affected children, the better is our ability to target prevention activities to them before they give birth to an alcohol-affected child. The top priority for developing effective prevention is to conduct a risk factor analysis of the women who have given birth to FAS children and the fathers by examining their medical, social, and reproductive histories. DHSS should conduct a maternal risk factor analysis of the biological mothers and fathers of the FAS cases identified through the AFASPP.
- Programs should be targeted at two major strategies:
    1) Reduce alcohol consumption among women of child-bearing age and especially among pregnant women, and
    2) Postpone pregnancy among women who are unable or unwilling to reduce substantially or stop completely alcohol consumption.
- Improve coordination of services and target services to families who are identified through having a child diagnosed with FAS.
- Determine the barriers to treatment for women who have had an alcohol-affected pregnancy.
- DHSS and DOE should conduct an analysis of the relationship of a medical diagnosis of FAS to the need for special education services.

I. Background

Overview

Fetal alcohol syndrome (FAS) is a preventable birth defect which causes a spectrum of lifetime central nervous system impairments including mental retardation, developmental delay, and other cognitive and behavioral abnormalities.

Over 20,000 Alaskan women of childbearing age are self-reported heavy drinkers, and 7% of new mothers in Alaska report having drunk during the third trimester of pregnancy. This has important implications for Alaska, because no universally safe level of alcohol consumption has been determined for pregnant women. Among Alaskan children born 1989-92, at least 18 per year were suspected of or received a clinical diagnosis of FAS.

High economic and societal costs are associated with FAS. In Alaska, minimum Medicaid claims are estimated at $9,000 annually per FAS child. In addition to medical costs, many FAS patients are eligible for Supplemental Security Income (SSI). The 20-year projected SSI cost in Alaska is estimated at $103,000 per person (1993 reimbursement rate). It is believed that these figures represent only a fraction of the total economic burden. A comprehensive study completed outside of Alaska estimated the lifetime cost of both medical treatment and long-term care at $1.4 million per person with FAS (Abel and Sokol, 1987).

Caring for individuals with FAS requires more than tax dollars. The neurological impairments associated with the syndrome often manifest themselves in cognitive and behavioral disabilities which can lead to maladaptive behaviors such as poor judgment, attention deficits, difficulty understanding the relationship between cause and effect, and difficulties in interpreting social cues (Streissguth, et al., 1991). Such outcomes suggest a substantial impact on the state's educational and judicial systems.

Because FAS is a completely avoidable disease with serious individual and societal impacts, a prevention plan is essential. Such a plan must have multiple components. The magnitude of the FAS problem in Alaska must be further assessed and continually monitored. Women at high risk of delivering FAS children must be identified and reached *before* they give birth. The FAS awareness levels of both the general public and health care professionals must be raised. Individuals with FAS must receive the special treatment and attention they need to function productively in Alaskan society. And, appropriate research and programmatic resources must be set to ensure accomplishment of all of the above. This document, and the information it assembles, provides the foundation upon which such future programs can be built.

History of FAS

FAS was first identified as a clinical entity in the United States in 1973 with the publication in LANCET of "Pattern of malformation in offspring of chronic alcoholic mothers," by Jones and Smith who coined the term "fetal alcohol syndrome."

In 1980 the Research Society on Alcoholism through its Fetal Alcohol Study Group standardized the definition for FAS. It had become clear by 1985, however, that the diagnostic criteria or terminology for FAS had not been consistently applied by clinicians or researchers. Therefore, in 1987 the Fetal Alcohol Study Group reevaluated the definition.

In 1989 the Group modified the definition slightly to specify that a child with FAS must manifest signs of abnormality in each of the following categories:

- Prenatal and/or postnatal growth retardation (weight and/or length or height below the 10th percentile when corrected for gestational age);
- Central nervous system impairment, including neurological abnormality, developmental delay, behavioral dysfunction or deficit, intellectual impairment and/or structural abnormalities such as microcephaly;
- A phenotypic face including short palpebral fissures (eye openings), an elongated midface, a long, flat philtrum (groove in the median portion of the upper lip), thin upper lip, and a flat midface.

While these attempts have been made to clarify the terminology used to describe the impact of alcohol on offspring and to enhance the comparability of the results of clinical observations, the diagnosis of FAS remains highly subjective and the application of clinical criteria inconsistent.

Less severe or incomplete expressions of the FAS phenotype have also been classified as Fetal Alcohol Effects (FAE) (Clarren and Smith, 1978). Variations in the amount (or dose) and timing of a fetus' exposure to alcohol may impact its development of alcohol-related defects. Multiple other factors, including genetic susceptibility, nutritional status and the presence of other toxins (e.g., caffeine, nicotine, marijuana) in the placenta, may also influence the severity of the effects. The existence of FAE is debated, and use of the term as a diagnosis has been discouraged by the Fetal Alcohol Study Group and many of the country's top dysmorphologists.

The most recent attempt to clarify the terminology used came in 1995 when the Institute of Medicine convened a committee to study FAS which issued its report in 1996. One of the committee's key charges was to review and evaluate the diagnostic criteria and terminology used for FAS and related conditions. It recommends the use of five diagnoses for describing FAS and alcohol-related effects:

1. FAS with confirmed maternal alcohol consumption,
2. FAS without confirmed maternal alcohol exposure,
3. partial FAS with confirmed maternal alcohol exposure,
4. alcohol-related effects (ARBD), and
5. alcohol-related neurodevelopmental disorder (ARND).

Challenges

Exposure to alcohol *in utero* can have a wide variety of cognitive, behavioral and morphological effects on the fetus; FAS represents a specific constellation of these defects. Presently, there is no objective test by which FAS cases can be ascertained. Trained dysmorphologists rely on "gestalt", or a general clinical impression, to diagnose the physical expression of FAS (Clarren and Astley, 1995). (This approach becomes increasingly unreliable as less experienced individuals attempt the FAS diagnosis.) Furthermore, CNS involvement and the characteristic facial dysmorphology may not always be evident in FAS cases. Diagnosis in newborns—even ones born intoxicated—is rarely possible since FAS children often do not have the opportunity to display their behavioral abnormalities or mental deficits until they reach school age. By adolescence many FAS children outgrow their characteristic facial features and growth deficits.

Exacerbating the diagnostic challenge is the fact that the normal facial morphology of several racial groups (Asians, Alaska Native) includes some of the features present in FAS (epicanthal folds, wide intercanthal distance, and flattened midface). Also, the severity of FAS conditions (physical and neurological) is not uniform across cases. Critical to accurately diagnosing FAS is a detailed, objective case definition and the ability to examine children during a very specific time period, ideally between the ages of 3 and 10. While the *International Classification of Diseases, 9th Revision* (ICD-9) now includes a code for alcohol effects on the fetus, the code is not limited to the specific grouping of effects which constitutes FAS.

In summary, FAS diagnosis remains subject to five major constraints:

- subjectivity inherent in the diagnosis;
- difficulty of diagnosing the syndrome in newborns;
- age difference in the expression of the phenotype;
- variability of the severity of conditions associated with the syndrome; and
- the lack of specificity in the ICD-9 code assigned to FAS.

These diagnostic constraints hinder FAS surveillance efforts, essential for ascertainment of the frequency and distribution of the syndrome as well as for the assessment of and ability to target prevention efforts. No detailed, objective, national case definition or surveillance methodology exists for FAS. Calculating rates, much less comparing these rates across years, geographies or populations, is extremely difficult. The lack of any single data source for case finding further compounds the problem.

Surveillance History

Until the methodology of linking multiple data sources for FAS surveillance was developed in Alaska, no surveillance system had been designed to enumerate the occurrence of the condition in the population. However, the Centers for Disease Control and Prevention (CDC) had been monitoring birth defects since 1976 through the Metropolitan Atlanta Congenital Defects Program (MACDP) and since 1974 through the Birth Defects Monitoring Program (BDMP). Both programs are administered by the Division of Birth Defects and Developmental Disabilities (DBDDD) in the National Center for Environmental Health (NCEH).

In 1974, shortly after FAS had been identified as a clinical entity in the U.S., MACDP added the condition to the list of defects it monitored. MACDP collects information on all live-born and stillborn infants born in the five-county metropolitan Atlanta area. It is designed to track infants with a least one major defect diagnosed within the first year of life. It was not designed to track infants with less distinct anomalies such as FAS.

In 1979 the ICD-9 added the code--760.71--that could be used for FAS. ICD-9 was the first revision of the Code since FAS was recognized as a clinical entity in the U.S.

In 1979, BDMP began collecting information on infants assigned the 760.71 code. BDMP is not a population-based surveillance system. It uses hospital discharge data on newborns in approximately 1,200 participating hospitals nationwide.

The limitations on FAS surveillance by both MACDP and BDMP were not apparent until the Alaska methodology of linking multiple data sources was developed.

The Alaska Fetal Alcohol Syndrome Prevention Project

During the 1980s, clinical and epidemiological interest in FAS increased greatly. While at the time there existed no state-based methodology for the surveillance of FAS, DBDDD sought to improve the surveillance and thereby the prevention of FAS and other alcohol-related birth defects.

Alaska provided the opportunity to develop a comprehensive FAS prevention program addressing the entire population of a state. First, the Alaska Area Native Health Service (AANHS) of the U.S. Indian Health Service (IHS) had developed a statewide FAS prevention program targeting Alaska Natives, and secondly, the Alaska Department of Health and Social Services (DHSS) showed considerable interest in developing an FAS prevention program. (Alaska has one of the highest per capita alcohol consumption levels in the nation, the highest rate of alcohol-related hospitalizations in the country, and has one of the highest rates of heavy drinking among women of reproductive age.)

In 1990 DBDDD conducted a site visit to Alaska to determine the level of commitment by AANHS and DHSS to collaborating with NCEH in the development of a statewide FAS surveillance methodology and prevention program to be used as a model for other states. Out of that site visit came separate Agreements to Cooperate between NCEH and IHS and between NCEH and DHSS. These formal five-year agreements established and funded the Alaska Fetal Alcohol Syndrome Prevention Project (AFASPP). The parties formed a steering committee with representatives from AANHS, DBDDD, DHSS and the Alaska Department of Education (DOE) to provide policy oversight and direction to the Prevention Project.

The AFASPP's charge was to develop a surveillance methodology for monitoring the occurrence of FAS. In doing so, it pioneered the methodology of linking multiple data sources. It identified several constraints on FAS surveillance. It documented that the ICD-9 code of 760.71 lacked specificity for FAS surveillance, and demonstrated the need for a surveillance case definition for FAS. The Project also evaluated the usefulness of the 16 different data sources it utilized, demonstrating that birth certificates and hospital discharge data are unreliable sources for surveillance of FAS.

Additional AFASPP efforts have included the demographic and clinical characterization of FAS children and their mothers, the administration of a public awareness survey, and the administration of a survey of health care professionals' alcohol and FAS-related knowledge, attitudes, beliefs and behaviors. A joint DHSS/DOE study of the FAS diagnosis' ability to predict children's special education needs is currently underway.

II. Descriptive Epidemiology of FAS

FAS Case Definition

Establishing a case definition enables the objective and reproducible collection of epidemiologic information. Once explicit and objective diagnostic criteria for a disease have been established, the actual number of cases can be tracked over time and populations. Since no operational, nationwide case definition for FAS surveillance exists, the AFASPP, in consultation with FAS experts, developed its own surveillance definition. Adding to the Research Society on Alcohol's criteria, the AFASPP specifies an FAS case must have medical chart mentions of each of the following:

- any chart notation of FAS by a physician;
- prenatal alcohol exposure or a maternal history of alcohol abuse;
- medical chart notation of at least one characteristic fetal alcohol syndrome facial feature or a comment "stigmata";
- growth deficiency; and
- central nervous system impairment.

The AFASPP definition further details that characteristic facial features include a physician notation of fetal alcohol syndrome stigmata or any of the following: short palpebral fissures, long or flat philtrum, thin upper lip, hypoplastic maxilla (underdeveloped/flattened upper jaw/midface), short nose relative to normal length midface, or flat nasal bridge. Growth deficiency is defined as height or weight less than or equal to the tenth percentile for a given age. Evidence of central nervous system impairment includes any of the following: structural abnormalities (microcephaly or hydrocephaly), other neurologic anomalies (seizures, abnormal EEG, hypertonia, cerebral palsy, tremors, hearing deficits of neurosensory origin, or microphthalmia), or behavioral or cognitive anomalies (mental retardation, hyperactivity, short attention span or attention deficit disorder, learning disability, developmental delay [including fine or gross motor delay or speech or language delay], behavior or conduct problems, or school failures).

Limitations

Underdiagnosis, underreporting of diagnosis and the potential for differentially diagnosing FAS across populations can lessen a case definition's specificity, or ability to capture all true cases (Cordero et al., 1994). The possibility of all three of these limitations should be recognized in the AFASPP case definition. As discussed, the diagnosis of FAS is problematic and may often depend on subjective impression or "gestalt". Also, the ICD-9 code is non-specific, further complicating surveillance based on medical record systems. The potential stigma associated with the FAS diagnosis may contribute to underdiagnosis. The inclusion of documented prenatal alcohol exposure in the FAS case definition may also impact the specificity of the definition: the AFASPP provider survey revealed that a significant portion of doctors do not always report maternal alcohol use, even when alcohol abuse is known or strongly suspected.

FAS in Alaska, due to IHS's efforts, has been a focus in the Native population longer than it has been among non-Native practitioners. Consequently, differing awareness levels among practitioners could lead to a different likelihood of FAS diagnosis among Native and non-Native children. Since the AFASPP case definition relies on available medical charts and the thoroughness of physicians' notations within them, it is almost certain that the actual number of cases detected represents a *minimum* count. While this result is not ideal for total cost or total prevalence estimates, it does permit, as much as possible, a consistent comparison of relative rates over time and peoples. A more lenient case definition may capture a greater number of FAS cases, but it would simultaneously capture more noncases, reducing the diagnostic accuracy, or positive predictive value, of the definition.

A common limitation of surveillance case definitions is that they do not capture all of the true cases of the condition in a particular population of interest (Cordero et al., 1994). The AFASPP utilized multiple datasets plus screening activities to assure a population-based effort attempting to identify all cases within the population rather than extrapolating from a sample of datasets. FAS rates reported for Alaska should be more representative than current surveillance activities in other states, the BDMP, and the MACDP.

FAS-Noted

Bearing in mind the potential limitations of a chart-verified FAS case definition, the AFASPP also cataloged all individuals who had any chart mention of fetal alcohol syndrome (whether or not they had the other FAS criteria). These cases are classified

CORRECTION

THE FOLLOWING DOCUMENT(S)
HAVE BEEN REFILMED TO
ASSURE LEGIBILITY OR PAGINATION

II. Descriptive Epidemiology of FAS

FAS Case Definition

Establishing a case definition enables the objective and reproducible collection of epidemiologic information. Once explicit and objective diagnostic criteria for a disease have been established, the actual number of cases can be tracked over time and populations. Since no operational, nationwide case definition for FAS surveillance exists, the AFASPP, in consultation with FAS experts, developed its own surveillance definition. Adding to the Research Society on Alcohol's criteria, the AFASPP specifies an FAS case must have medical chart mentions of each of the following:

- any chart notation of FAS by a physician;
- prenatal alcohol exposure or a maternal history of alcohol abuse;
- medical chart notation of at least one characteristic fetal alcohol syndrome facial feature or a comment "stigmata";
- growth deficiency; and
- central nervous system impairment.

The AFASPP definition further details that characteristic facial features include a physician notation of fetal alcohol syndrome stigmata or any of the following: short palpebral fissures, long or flat philtrum, thin upper lip, hypoplastic maxilla (underdeveloped/flattened upper jaw/midface), short nose relative to normal length midface, or flat nasal bridge. Growth deficiency is defined as height or weight less than or equal to the tenth percentile for a given age. Evidence of central nervous system impairment includes any of the following: structural abnormalities (microcephaly or hydrocephaly), other neurologic anomalies (seizures, abnormal EEG, hypertonia, cerebral palsy, tremors, hearing deficits of neurosensory origin, or microphthalmia), or behavioral or cognitive anomalies (mental retardation, hyperactivity, short attention span or attention deficit disorder, learning disability, developmental delay [including fine or gross motor delay or speech or language delay], behavior or conduct problems, or school failures).

Limitations

Underdiagnosis, underreporting of diagnosis and the potential for differentially diagnosing FAS across populations can lessen a case definition's specificity, or ability to capture all true cases (Cordero et al., 1994). The possibility of all three of these limitations should be recognized in the AFASPP case definition. As discussed, the diagnosis of FAS is problematic and may often depend on subjective impression or "gestalt". Also, the ICD-9 code is non-specific, further complicating surveillance based on medical record systems. The potential stigma associated with the FAS diagnosis may contribute to underdiagnosis. The inclusion of documented prenatal alcohol exposure in the FAS case definition may also impact the specificity of the definition: the AFASPP provider survey revealed that a significant portion of doctors do not always report maternal alcohol use, even when alcohol abuse is known or strongly suspected.

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as "FAS-noted," and may represent the upper-bound of the actual FAS case count.

Data Sources and Collection Methods

In the rigorous AFASPP surveillance effort begun in 1991, FAS and FAS-noted cases were actively sought from three major sources: the private medical sector, the State of Alaska programs and services, and Alaska Native-specific services and corporations (Table 1). Overall, sixteen individual practices, services and corporations were examined. (Non-Native sources were eligible to be identified in 13 of the 16 data sources.) Where sources had computerized ICD-9 data, searches were made for code 760.71 (noxious influence of alcohol on fetus or newborn via placenta or breast milk) or, if categorized on a more aggregate level, code 760.7 (any noxious influence affecting fetus or newborn). The range of years searched varied by source due to different program initiation dates or variability of data.

Table 1. Sources of data and methods of identifying potential FAS cases in AK

Source of Data	Method of Identifying Potential FAS Cases
Private Sector	
Hospitals	
Anchorage and Fairbanks	ICD-9 code 760.71 on discharge data tapes from 1988-1992. (Largest and fourth largest hospitals in the state.)
Pediatricians	
Anchorage	List of potential FAS patients served in 1993.
Fairbanks	List of FAS/alcohol-exposed patients served from 1990-1992.
State of Alaska[a]	
Infant Learning Program	Potential FAS children 0-3 years of age seen in 1991-1992.
Health Care Program for Children w/Special Needs (HCP-CSN)	ICD-9 code of 760.71 on data tape of program recipients age 0-21 years served in 1992.
Clinic, Cleft lip & palate	Potential FAS children evaluated from 1983-1993.
Clinic, Genetics	Potential FAS children evaluated from 1977-1992.
Clinic, Alcohol-exposed children	Children evaluated from 1992-1993.
Rural Nursing Station	Potential FAS children identified in a public health nursing caseload in 1993.
Medicaid Claims	ICD-9 code of 760.71 on tapes from 1989-1990.
Birth Certificates	FAS check box on certificates filed from 1989-1990.
Death Certificates	ICD-9 code 760.7 as contributing/underlying cause of death from 1977-1990.
Alaska Native Data Sources	
IHS[b] Case File	Patients seen for an alcohol-related diagnosis during 1985-1993. Statewide active screening in 1986 followed by ongoing active screening in Anchorage area and passive reporting from 12 autonomous regional Native Health Corporations.
2 Regional Native Health Corporations (serving the Interior and Southeast regions of Alaska)	ICD-9 code 760.71 on discharge data tapes from 1989-1990 for Interior Alaska, and 1986-1992 for Southeast Alaska.
Native Medical Center, Anchorage	ICD-9 code of 760.71 on discharge data tapes from 1985-1992. (Third largest hospital in the state.)

[a] Alaska Department of Health and Social Services
[b] Indian Health Service

After all potential FAS cases were identified (630), all available medical charts (568) were obtained. An FAS data abstraction form was developed to gather diagnostic information from the medical charts. All information was extracted with appropriate attention to confidentiality as established under state law and through memorandums of agreement.

While no single source identified all of the recorded FAS cases, the use of sixteen different sources did not prove necessary. Screening and referral programs to diagnostic clinics (state genetics and alcohol-exposed children clinics and the Indian Health Service case file), for example, identified 70% of all recorded cases, and 65% of all cases were uniquely identified by these sources. Passive reporting data systems, most notably birth certificates and hospital discharge summaries, did not prove sufficiently "high-yielding." Due to Alaska's unique structure where Native Medicaid claims are billed directly to the federal government, this source was less useful for FAS surveillance than it may prove to be in other states.

Overall, the Indian Health Service case files identified the largest proportion of cases (56%), followed by the Native Health Corporations (19%) and the state's genetics clinic (12%) (Table 2). Interestingly, 57% of all non-Native cases were *not* identified by the private medical sector while only 13% of the Alaska Native cases were not found in the Native-specific sources. This discrepancy may be due to a lower awareness level and/or the stigma associated with an FAS diagnosis in the non-Native population.

Table 2. FAS case ascertainment by source of data, born 1977-93, AK

	Potential cases identified	Charts Abstracted		FAS-noted[a]		FAS cases		% Total FAS Cases
Source of Data	N	N	(%)[b]	N	(%)[c]	N	(%)[c]	
Private Sector								
Hospital, Fairbanks	16	16	(100)	12	(75)	4	(25)	3
Hospital, Anchorage	34	29	(85)	21	(72)	11	(38)	8
Pediatrician, Fairbanks	117	116	(99)	25	(22)	17	(15)	12
Pediatrician, Anchorage	44	38	(86)	10	(26)	7	(18)	5
ADHSS[d]								
Program, Infant Learning	31	24	(77)	17	(71)	14	(58)	10
Program, HCP-CSN[e]	3	3	(100)	3	(100)	3	(100)	2
Clinic, Cleft lip & palate	9	9	(100)	4	(44)	3	(33)	2
Clinic, Genetics	50	50	(100)	23	(46)	18	(36)	12
Clinic, Alcohol-exposed children	41	41	(100)	11	(27)	8	(20)	6
Rural nursing station	15	15	(100)	11	(73)	8	(53)	6
Medicaid claims	46	38	(83)	22	(58)	16	(42)	11
Birth Certificates	20	17	(85)	4	(24)	2	(12)	1
Death Certificates	3	1	(33)	1	(100)	1	(100)	1
IHS[f]/Regional Native Health Corporations								
IHS case file	218	190	(87)	124	(65)	81	(42)	56
Regional Native Health Corps (serving Interior & Southeast AK)	94	92	(98)	53	(58)	28	(30)	19
Native Medical Center, Anchorage	31	30	(97)	19	(63)	12	(40)	8
Total Unduplicated Count	**630**	**568**		**248**		**145**		

[a] Denotes individuals with a physician chart notation of FAS suspected or diagnosed
[b] % of potential cases identified
[c] % of charts abstracted
[d] Alaska Department of Health and Social Services
[e] Health Care Program for Children with Special Needs
[f] Indian Health Service

FAS Prevalence

Prevalence rates quantify the proportion of individuals in a population who have a disease (or syndrome) at a specific point in time. Birth defects are traditionally measured by a prevalence rate which compares the number of individuals born with a given abnormality to the number of live births during the period of time in which the cases were born.

During the first six years of the AFASPP, the team completed a two-phased FAS prevalence assessment based on their surveillance findings (Table 3):

Phase I (documented in the AFASPP Interim Report, March 24, 1993, and MMWR, 1993): presents minimum Native prevalence rates using 83 cases identified from the first five data sources reviewed (birth certificates, death certificates, Medicaid claims, IHS case files and one pediatric practice).

Phase II (documented in "Fetal Alcohol Syndrome in Alaska, 1977-1992: An Administrative Prevalence Derived from Multiple Sources" [*American Journal of Public Health*, in press]): presents comprehensive prevalence rates (Native and non-Native) using the 248 cases identified from the sixteen data sources.

Between these two phases of active case finding, an applied analysis was performed to evaluate and bound the Phase I prevalence estimates. This applied analysis used a technique called capture-recapture[1].

[1] Capture-recapture is a statistical technique used most frequently in the enumeration of wildlife populations. In an epidemiologic setting, capture-recapture measures the amount of overlap between two independent samples (or data sources) to estimate the true disease prevalence. It assists in determining the extent to which observed rates reflect differences in completeness of case ascertainment.

Table 3. Fetal Alcohol Syndrome (FAS) Prevalence Studies, Alaska

Analysis	Birth Years Covered	No. FAS Cases	Minimum Alaska FAS Prevalence Rates (per 1,000 live births)			Key Finding(s)
			Overall	Native	Non-Native	
Phase I	1978-1991	83	0.5 (FAS) (range of 0.4 - 0.6)	2.1 (FAS) (range of 1.4 - 2.9)	insufficient data	• high prevalence of FAS among Native Alaskans • underascertainment of cases likely (only 14% overlap btw. sources)
		129 FAS-noted		3.3 (FAS-noted)		
Capture-Recapture	1982-1989	50	N/A	*3-6 yrs old:* 2.0 (observed) 3.1 (predicted) *7-10 yrs old:* 3.1 (observed) 3.8 (predicted)	N/A	• poorer case ascertainment among the younger cohort • multiple sources necessary — even for Native ascertainment
Phase II (detailed further in Table 4)	1977-1993	145	0.8 (FAS)	3.0 (FAS) (range of 1.4 - 4.1)	0.2 (FAS) (range of 0.1-0.3)	• high FAS prevalence among Natives confirmed • appears case ascertainment improving among non-Natives
		248 FAS-noted	1.3 (FAS-noted)	5.2 (FAS-noted) (range of 2.4 - 6.6)	0.3 (FAS-noted) (range of 0.2-0.4)	

Case Ascertainment

Closer analysis of the Phase II findings suggests that FAS rates vary among different birth cohorts (Table 4). Rather than represent a change in actual rates, these differences (particularly in the Native population) may reflect poorer ascertainment in the oldest and youngest cohorts: children grow out of the facial dysmorphology of FAS during adolescence, and young children have not had the same opportunity to be diagnosed (i.e., demonstrate behavioral or cognitive abnormalities). This hypothesis is supported by the capture-recapture analysis which found that half of the difference in rates between the two Native birth cohorts could be attributed to a lower case ascertainment rate among the youngest cohort (Table 3).

The greater FAS rates among Alaska Natives relative to non-Natives may be attributed, in part, to the extensive case finding activities of the Indian Health Service, and to underascertainment of FAS among non-Natives. The rate of non-Native cases in the most recent birth cohort (1989-1992) was nearly twice that in the previous birth cohorts, and non-Native children in the younger birth cohorts had median ages at the time of first chart mention of FAS that were comparable to those of Alaska Natives, suggesting that case ascertainment may be improving for non-Natives. However, the large discrepancy between Native and non-Native FAS prevalence rates cannot likely be attributed entirely to differences in ascertainment between the two populations. Alaska's Native population appears at higher risk of FAS than the non-Native population.

US Prevalence Comparison

The national BDMP, which estimates FAS prevalence rates based on sampled hospital birth records, reports an FAS prevalence rate for the U.S. of 0.5 cases per 1,000 live births. Low socioeconomic status appears to be associated with higher FAS rates as the BDMP reports rates among Native American, black and white U.S. populations at 3.0, 0.6 and 0.1 cases per 1,000 live births. Direct comparison with the U.S. estimates is difficult due to differences in the case finding methodologies, but Alaska's findings do support the inverse socioeconomic relationship. The national health goal for the year 2000 is an overall FAS prevalence rate of .12 cases per 1,000 live births and a rate of 2.0 cases per 1,000 live births among Alaska Natives/American Indians. Achieving these goals in Alaska will require a concerted focus on FAS prevention across the state.

Table 4. Rates for FAS-noted individuals and FAS cases per 1,000 live births, for Alaska Natives and non-Natives

	Native				Non-Native			
	FAS-Noted[a]		FAS Cases[b]		FAS-Noted[a]		FAS Cases[b]	
Birth Years	(N cases/live births)	Rate	(N cases)	Rate	(N cases/live births	Rate	(N cases)	Rate
89-92	(57 / 11,262)	5.1	(28)	2.5	(16 / 35,695)	0.4	(11)	0.3
85-88	(68 / 10,346)	6.6	(42)	4.1	(7 / 37,716)	0.2	(6)	0.2
81-84	(53 / 8,968)	5.9	(34)	3.8	(7 / 37,098)	0.2	(4)	0.1
77-80	(17 / 7,160)	2.4	(10)	1.4	(5 / 28,686)	0.2	(2)	0.1
Total	(195 / 37,736)	5.2	(114)	3.0	(35 / 139,195)	0.3	(23)	0.2

[a] Denotes individuals with a physician chart notation of FAS suspected or diagnosed.
[b] Case meets 5 criteria case definition for FAS.

Demographic Characteristics of FAS Cases

FAS is a permanent condition. Familiarity with clinical and demographic characteristics of FAS can help health care providers, social service workers and educators to recognize suspected FAS cases. Only through diagnosis will these individuals have an opportunity to receive the special assistance they may need. Recognition of FAS in one child also may help prevent the subsequent birth of similarly affected siblings.

The AFASPP findings suggest that FAS occurs disproportionately in Alaska Native children, but there does not appear to be a favoring of one sex over the other. Among the 145 identified FAS cases, 83% were Alaska Native, 12% were white and 4% were black (compared to 22%, 68% and 5% of all live births in 1994). Fifty-three percent of the cases were male. Median age at the time of the first chart mention of any alcohol-related diagnosis (i.e., fetal alcohol syndrome, fetal alcohol effects, or alcohol-related birth defects) was quite young, averaging 8.4 months of age with a range from birth to 16 years of age[1] (Table 5).

The largest number of cases (33% of FAS and 30% of FAS-noted) was identified in the cohort born between 1985 and 1988, the group entirely within the 3-7 year age window at the time of the study. Seventy-five percent of all cases had an alcohol-related diagnosis mentioned in their chart by age three. Only 43% of the cases had been diagnosed as fetal alcohol syndrome or "possible fetal alcohol syndrome" by a dysmorphologist.

Sixty-seven percent of those with known custody status (127) were either adopted or in foster care. A similar custody status profile was described in the AFASPP's Interim Report (Figure 1). This finding, along with the high prevalence of physical/sexual abuse and neglect noted among alcohol-exposed children in the Alaska clinics, suggests a strong role for social services in the recognition and proper referrals of both FAS cases and families.

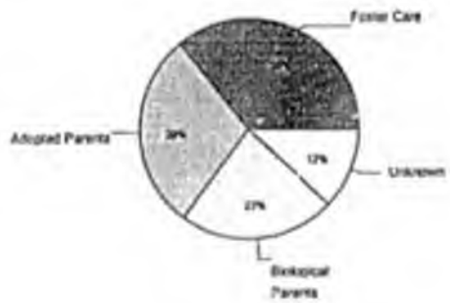
[1] The median age at first chart notation was comparable for Natives and non-Natives by birth cohort with one exception: non-Native children born in the eldest cohort (1977-1980) had a significantly older age at time of syndrome recognition in medical charts (median age of 12.7 years) than natives (median age of 2.8 years) (Kruskal-Wallis one-way analysis of variance, $p < .05$) (Table 5). Again, this variance may represent a waning reluctance to diagnose FAS in non-Native children.

Table 5. Median age and year at first medical chart notation of FAS, by birth cohort for FAS-noted cases

Birth Years	(N)	First Chart FAS Notation Age (years) Median (Min, Max)	Year Median
89-92			
Native	(57)	0.0 (0, 2.8)	90.8
Non-Native	(16)	0.5 (0, 2.8)	91.1
85-88			
Native	(68)	0.6 (0, 7.0)	87.8
Non-Native	(7)	0.4 (0, 7.0)	88.1
81-84			
Native	(53)	2.1 (0, 9.0)	85.4
Non-Native	(7)	2.9 (0, 8.6)	87.3
77-80			
Native	(17)	2.8 (0, 16.1)*	84.0
Non-Native	(5)	12.7 (7.5, 13.9)	89.6
Total	(230)	0.6 (0, 16.1)	88.0

*Kruskal Wallis One-Way Anova test, $p<.05$

Figure 1. Custody status of Alaskan FAS cases



- 65% were either adopted or in foster care
- Custody Status of Alaskan Chart-verified FAS Children (N=83)

Clinical Features of FAS Cases

The most prevalent facial features noted among the FAS cases were long or flat philtrum (70%), short palpebral fissures (66%), and thin upper lip (Table 6). Two or more of the characteristic facial features were noted in 79% of the cases. The most prevalent central nervous system impairments were developmental delay (76%), and microencephaly (37%). Eighty-one percent of the cases had some type of delay or learning disability. With regard to growth deficiencies, 64% of cases had both a birth-weight or -height measurement and a postnatal-weight or -height less than or equal to the tenth percentile. Fifty percent were born at <= 37 weeks gestation (i.e., preterm deliveries).

Table 6. Facial features, central nervous system impairments, growth characteristics and other conditions among FAS cases, born 1977-1992, Alaska, based on notations in medical chart.

Facial Features	n	%
Long, flat philtrum	102	70
Short palpebral fissures	96	66
Thin upper lip	75	52
Hypoplastic maxilla	56	39
Flat nasal bridge	45	31
Short nose relative to normal length face	34	23
2 or more features	115	79
4 or more features	51	35
Central Nervous System Impairment		
Developmental delay	110	76
Speech/language delay	59	41
Gross motor delay	32	22
Fine motor delay	30	21
Microcephaly	54	37
Short attention span or attention deficit disorder	40	28
Learning disability or mental retardation	29	20
Seizures	29	20
Any delay or learning disability	118	81
Growth Characteristics	**n**	**%**
Failure to thrive	32	22
Birth weight (≤ 10%ile)	107	74
Birth length (≤ 10%ile)	68	47
Preterm delivery (≤ 37 wks)	72	50
Small-for-gestational-age	62	43
Postnatal weight (≤ 10%ile)	106	73
Postnatal height (≤ 10%ile)	99	68
Malformations and Other Conditions		
Palmar crease anomalies	45	31
Digital or limb anomalies	43	30
Strabismus	33	23
Congenital heart disease	26	18

Characteristics of FAS Mothers

Critical to the prevention of future FAS cases is the ability to identify those women at risk of drinking during pregnancy. Birth certificates obtained for 102 cases (70%) showed that 63% of FAS mothers were not married at delivery. Forty-one percent had not completed high school, and 69% either had no prenatal care (33%) or began prenatal care after the first trimester (36%). (In contrast, for the general population only 15% of Alaska mothers delivering between 1989 and 1993 had not finished high school and only 18% had no or late prenatal care.) These women are older mothers who frequently have had previous children. Medical charts and birth certificates documented an average maternal age at delivery of 29 years (SD=5.0, Range=[15,45]). The average number of living children born prior to the child with FAS was 2.4 (SD=2.0).

There also appears a real risk of FAS mothers producing multiple FAS children. Thirteen percent of the women (14/111 identified mothers) had multiple FAS births, averaging 2.3 FAS children each. One woman alone gave birth to four cases and to three other children who had physician mentions of fetal alcohol syndrome in their charts. In addition, one FAS-noted individual was the mother of another FAS case. Medical charts also mentioned prenatal tobacco use among 39% of the FAS mothers, cocaine use in 8%, and marijuana use in 8%.

A profile of six FAS mothers completed during Phase I of the AFASPP suggests additional commonalties among mothers of multiple FAS children. The women were prone to report histories of physical and sexual abuse, have partners with alcohol problems, deny alcohol problems, alcohol-related emergency room visits, have psychiatric illness, and refuse alcohol treatment.

A study outside of Alaska correlated continued drinking during pregnancy (despite information on the risks and referral for intervention) with early onset of drinking, heavy drinking in parents and siblings (especially female relatives), evidence of alcohol-related physical problems, and qualifying for a diagnosis of alcohol dependence (Institute of Medicine, 1996). The Institute of Medicine suggests an even broader list of psycho-social predictors for drinking among women in general including familial and genetic factors, demographic and social role variables (lack of social roles, unemployment, cohabitation, divorce or separation), individual psychological factors (depression, anxiety, eating disorders), relationship variables (partner's drinking habits, relationship conflict/violence), physical and sexual victimization, and drinking contexts (behavior of coworkers and significant others). While the AFASPP findings do not constitute a scientifically based psychosocial profile of Alaskan FAS mothers,

they are supported by the results of these other studies.

Little information is available from the APASPP to characterize FAS fathers, who may be influential in encouraging or ensuring an alcohol-free pregnancy. A study outside of Alaska by Abel (1983) found that FAS fathers also tended to abuse alcohol, suggesting effective prevention may need to target both the mother and her partner (Institute of Medicine, 1996).

III. Statewide Drinking Trends and FAS Awareness

Crafting an effective FAS prevention strategy requires an understanding of the current drinking habits and FAS-awareness levels of all Alaskans.

Adult Alcohol Consumption

Behavioral Risk Factor Survey

The prevalence and characteristics of alcohol consumption among Alaskan Natives and women of childbearing age are of particular interest in the effort to prevent FAS. Such behavioral information is gathered on an ongoing basis through the Behavioral Risk Factor Surveillance System (BRFSS). This national system surveys adults (18 years of age and older) by a random-digit-dialed telephone method.

While overall alcohol use from 1991-1993 was reported less frequently among Natives than non-Natives, statewide binge rates (consuming 5 or more drinks on a single occasion) were higher among Natives (Figures 2 & 3). Geographically, Southeast Alaska reported the highest binge rates overall (32% Natives, 25% Non-Natives). As of 1994, Alaskan women most likely to binge were aged 25-34, a range which captures the age of most FAS mothers (Figure 4). These statistics, combined with the previously described maternal risk profiles, may imply that FAS prevention should focus heavily on the reduction of binge drinking during pregnancy. Toxicological studies of animals also support this idea. A high dose of alcohol delivered during a concentrated time period (binge drinking) interferes with brain development more than the same dose delivered over a longer period of time (Institute of Medicine, 1996).

Figure 2. Alcohol Use in Past Month by gender and race, 1991-1993, BRFSS

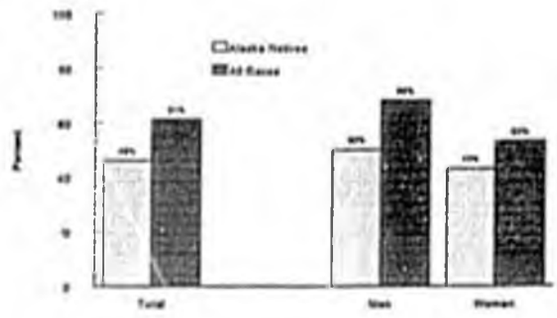


Figure 3. Binge Drinking (five or more drinks at one time in the past month) by gender and race, 1991-1993, BRFSS

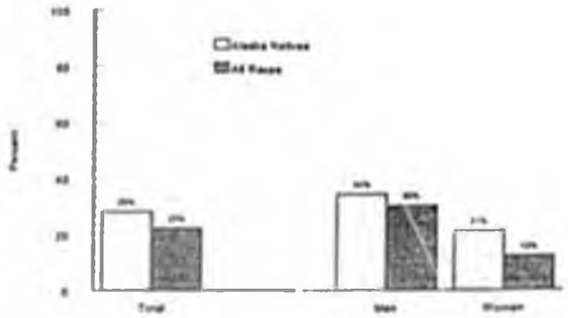
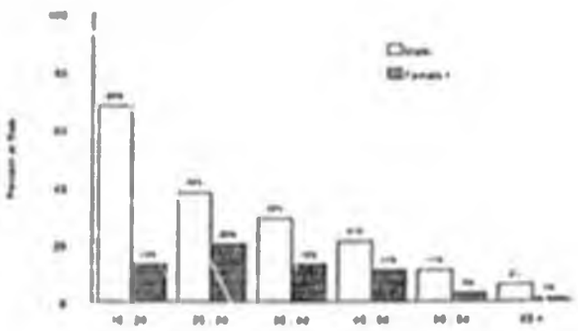


Figure 4. At Risk for Acute Binge Drinking in Alaska by age and gender, 1991-1993, BRFSS



Weighted results for the 1991 BRFSS found that 55% of Alaska women of childbearing age (18-44) reported drinking during the previous month: 38% classified as light drinkers (<31 drinks a month) and 17% classified as heavy drinkers (>30 drinks in a month or 5 in on a single occasion). While non-Native women were over two times more likely to report light drinking than Native women (41% vs. 17%; PR=2.4, 95% CI=1.6-3.8), the prevalence of heavy drinking among non-Native women was half that among Native women (15% vs. 32%; PR=0.5, 95% CI=0.2-0.9).

Because heavy drinkers are most likely to continue drinking during pregnancy, determining ways to identify or predict heavy drinking behavior may become an important element of the FAS prevention strategy (Institute of Medicine, 1996). Smoking and education level may be two such predictors. Women who smoked were more likely to report heavy drinking than were nonsmokers (29% vs. 13%; PR=2.2, 95% CI=1.2-3.9), and women with at least a college degree were less likely to report heavy drinking than were women with less education (6% vs. 20%; PR=0.3, 95% CI=0.2-0.6). Unweighted analysis of the data also associated heavy drinking inversely with both marriage and children in the household (Epidemiology Bulletin, March 24, 1993). This analysis did not find an association between women's drinking habits and their employment type.

Pregnancy Risk Assessment Monitoring System

The Alaska Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing mail survey of mothers of newborns which gathers information on health risk behaviors and circumstances of pregnant and post partum women[1]. Data collected during 1990-1991 revealed that third trimester drinking, while relatively uncommon overall, was strongly associated with older age and drug (cocaine or marijuana) use. Women who were older than 30 were 3.5 times more likely to report drinking during the third trimester than were women under 20 (14.7% compared to 3.9%). Third trimester drinkers were 5 times more likely than non-drinkers to use drugs (13.9% compared to 2.8%).

Additional factors associated with any third trimester drinking were non-Alaska Native race, domestic violence, post-high school education, prenatal cigarette smoking, and exposure to more than one significant life stressor. Non-Native mothers reported third trimester drinking 1.4 times as often as Native mothers (11.4% overall vs. 8.3%), but Native women were more than twice as likely to have experienced domestic violence (26.7% overall vs. 11.4%) (Figures 5 and 6). Across both races, mothers who drank were more likely to have experienced domestic violence.

Figure 5. Percent of Mothers by Drinking Category, Alaska, 1990-1991, PRAMS data

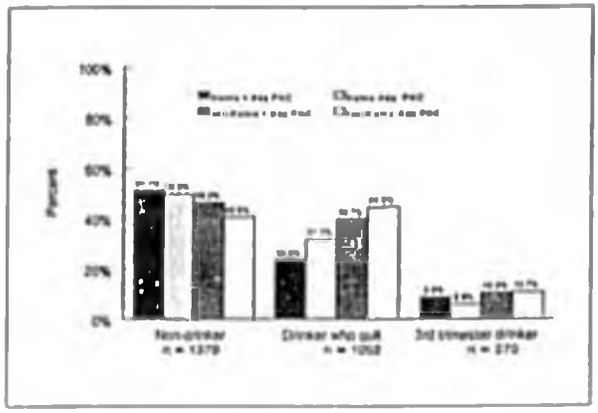
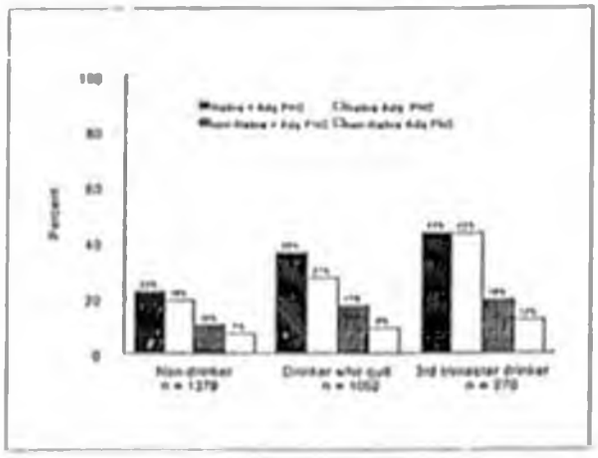


Figure 6. Percent of Mothers Experiencing Domestic Violence by Drinking Category and Stratum, Alaska, 1990-1991, PRAMS data



[1] PRAMS data is stratified by mother's race (Native or non-Native) and the amount of prenatal care she received (adequate or inadequate). Drinking behavior is classified by non-drinkers (no reported drinking the 3 months before and the last 3 months of pregnancy), drinkers who quit (drinking reported the 3 months before but not the final 3 months of pregnancy) and 3rd trimester drinkers (drinking reported during the final 3 months of pregnancy). Many of the figures presented display results across all of these categories while the text reports more aggregate findings.

Women with greater than a twelfth grade education reported any drinking during the third trimester of pregnancy more often than women with less than a twelfth grade education (12% vs. 5.3%). Third trimester drinkers were also twice as likely to smoke as non-drinkers (36% vs. 20%) (Figure 7). Geographically, Southeast Alaska reported the highest percentage of third trimester drinkers, the Yukon-Delta region the lowest (Figure 8).

Figures 7. Percent of Mothers (Postpartum) Currently Smoking by Drinking Category and Stratum, Alaska, 1990-1991, PRAMS data

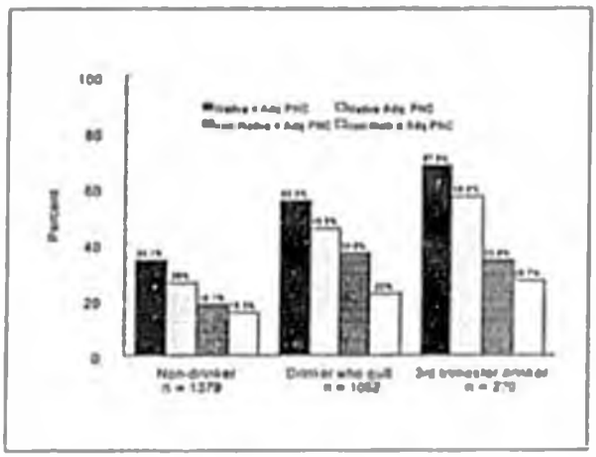
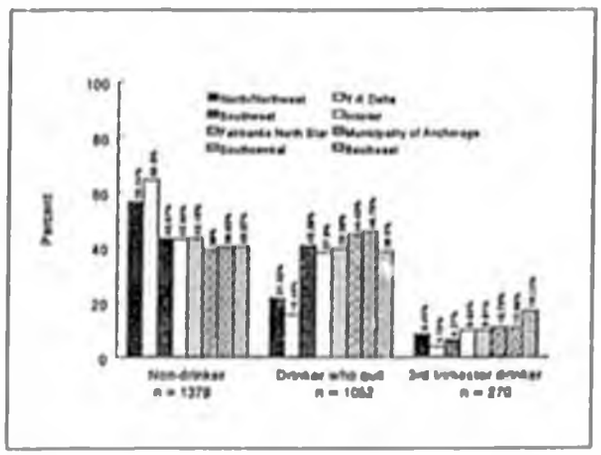


Figure 8. Percent of Mothers within a Region by Drinking Category, Alaska, 1990-1991, PR/ MS data



The mothers reporting third trimester drinking tended to report a greater prevalence of life stressors during the 12 months prior to delivery (someone close with a drinking or drug problem, separation from a partner, getting into debt, etc.) than other women (Table 7). The PRAMS data reinforce the idea that prevention efforts should target not only the behaviors of pregnant women (binge drinking, smoking, etc.) but their environments (support systems—or the lack thereof, familial/social influences, etc.).

Table 7. Percent of Mothers Citing Top 5 Life Stressors During the 12 Months Before Delivery, 1990-1991

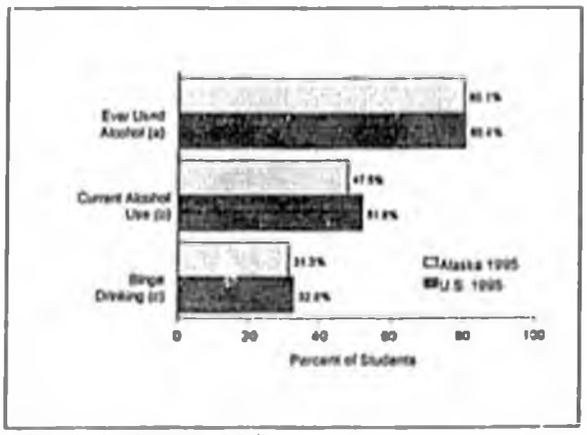
Lifestyle Stressor	Non-Drinker	Drinker-Who-Quit	3rd Trimester-Drinker	Total (weighted)
1. Family member very sick	25.8	24.7	25.5	25.4
2. Someone close drinking/drugs	17.5	19.9	25.8	20.3
3. Separated from partner	13.5	16.9	19.2	16.0
4. Got into debt	13.5	15.2	18.2	15.1
5. Family member died	13.6	14.9	14.1	14.5

Table 8. Rate of drinking during the third trimester of pregnancy, 1991-94, Alaska

Any drinking of alcoholic beverages during the third trimester:				
1991	1992	1993	1994	1991-1994
10.3%	10.9%	7.7%	7.4%	9.2% (statistically significant trend)

Note that PRAMS estimates of "Prenatal use of alcohol" are limited to any amount (starting from less than a drink a week (dose) and are indicated for third trimester use only (timing) and as such are considered to be minimal prevalences of prenatal alcohol use in general. PRAMS surveillance is limited to mothers who delivered a live birth.

Figure 9. 1995 AK and 1993 U.S. YRBS--Alcohol Use Among High School Students



a) Ever had at least one drink.
b) Had at least one drink in the 30 days prior to the survey.
c) Had five or more drinks within a couple of hours, in the 30 days prior to the survey.

Youth Alcohol Consumption

The optimal timing for any behavioral intervention is before the deleterious behavior is established. An important FAS prevention question is "when are (heavy) alcohol drinking behaviors first apparent in FAS parents?" Unfortunately, this information is not presently available. However, the Youth Risk Behavior Survey (YRBS), a nationally administered in-school survey of health risk behaviors, provides a means of addressing this question by evaluating the drinking patterns of Alaska's public high school students.

Unlike the adult population, Alaska's high school students do not report significant differences in drinking behaviors by race nor do the Alaskan rates differ much from National averages (Figure 9). The 1995 YRBS found that 80.4% of U.S. high school students reported ever drinking. In Alaska, 80.1% of high school youth (83.2% of Natives) reported this behavior. When asked about drinking within the last 30 days, 51.6% of U.S. youth responded affirmatively while only 47.5% of Alaska youth (43.9% of Natives) reported this behavior. Alaska youth were also slightly less likely to report binge drinking within the past 30 days (31.3% overall, 31.3% Natives) than the US average (32.6%). In an unweighted analysis of female responses, Native females were even less likely to binge than their non-Native peers (26% vs. 30%). The one alcohol-related question to which Alaska youth reported consistently higher rates than the U.S. average was drinking before the age of 13 (36.7% Alaska, 35.7 Alaska Natives, 32.4% U.S.).

Overall these findings suggest that adult drinking patterns, particularly differences between Native and non-Native behaviors, are not necessarily patterned in Alaska's high school students, underscoring the opportunity for comprehensive in-school education on the effects of alcohol during pregnancy. What is not clear is the relation of these rates to those of youth who become FAS-parents or who are not members of the regular public school system (i.e., drop outs and students in correctional schools). As has been discussed, individuals with less education are already at greater risk of drinking during pregnancy, thus their behaviors may differ from the average. This possibility further encourages the inclusion of alcohol-related education early in children's schooling.

Drinking Trends

Heavy drinking among Alaska women may be declining. Between 1991 and 1995, the percentage of Alaska women of childbearing age drinking heavily dropped from 17.6% to 15.0% (BRFS). PRAMS also suggests women in Alaska may be drinking less during pregnancy. Between 1991 and 1994 the system reported a statistically significant decline in the percent of women drinking any alcohol during the third trimester of pregnancy (from 10.3% to 7.4%) (Table 8). During the same time, however, the national rate of frequent drinking among pregnant women increased 4 times (from 0.8% to 3.5%, $p < .01$) (MMWR, vol. 46, no. 16). The impact and validity of a declining drinking trend in Alaska remains to be determined.

Community Awareness of FAS

While youth education may offer an ideal component of the long-term FAS prevention effort, alcohol- and FAS-related information needs to be disseminated to the group most actively procreating. Many Alaskan adults do not have accurate or sufficient knowledge about the syndrome.

In March of 1993, the AFASPP conducted a statewide survey to determine the FAS awareness level of Alaskans and to help identify segments of the public which need to be reached in educational campaigns. Using a simple random-digit dialed phone survey, 400 adults (age >=18) were interviewed between March 12th and 15th.

Most Alaskans (91%) had heard about FAS, but only 41% were able to answer accurately 7 true or false questions about the syndrome. Educational level directly related to individuals' FAS knowledge: 28% of high school educated respondents scored correctly on the 7 questions compared to 35% for those with 1-2 years of college, 56% for those with 3-4 years of college, and 65% for those with post-college education.

Geographic location also seemed to impact FAS knowledge. While 35% of Anchorage respondents were "knowledgeable", 40% of rural respondents, 42% of Fairbanks respondents, 47% of Valdez/Kenai-Mat-Su respondents, and 53% of Southeast respondents answered all 7 questions correctly. Race also predicted FAS knowledge: 43% of non-Natives vs. 27% of Natives answered the 7 questions correctly. Knowledge levels did not vary significantly by sex, marital status, age, or number of children in the household. Importantly, individuals who were knowledgeable about FAS were also more likely to report they would be very likely to talk to a pregnant friend or family member about the harmful effects of alcohol on the fetus (93% vs. 75%, respectively).

Slightly fewer respondents expressed a willingness to talk to the individual about seeking professional services to help her quit (80% vs. 63%). The low FAS knowledge levels among less educated individuals and Alaska Natives again support the selection of these groups as primary targets for FAS education and reinforces the need to target middle and high schools for educational programs.

Health Professionals' Alcohol-Related Knowledge, Attitudes Beliefs and Behaviors...and Needs

One of the most effective conduits for FAS education and prevention may be health care. Healthcare professionals, however, are often not prepared to deliver the type of information and support that drinking women of child-bearing age require.

During 1992 and 1993, the AFASPP conducted a survey of 467 health care professionals throughout the state to assess their knowledge, attitudes, beliefs and behaviors (KABB) related to alcohol abuse issues and FAS. The overall response rate was 66% (306 surveys), but it varied by profession: 76% for public health nurses, 58% for pediatricians, 67% for ob/gyns, and 61% for family practitioners.

The majority of providers (95-100%) believed it was their role to address alcohol abuse problems among their patients and their patients' families (Table 9). Considerably fewer, however, reported always referring a patient to an alcohol abuse or outpatient service when they knew or suspected an alcohol abuse problem (19-64%), and almost 50% of public health nurses and pediatricians felt minimally prepared or unprepared to deal with a patient/parent in the area of alcohol abuse. The providers who felt very or somewhat prepared to deal with alcohol issues were more than 2 times as likely to also report that they always refer alcohol-abusing patients to treatment programs (PR=2.2, 95% CI=1.4,3.5). The survey identified the need to facilitate referrals from health care providers and to enhance providers' levels of preparedness in dealing with patients in the area of alcohol abuse.

Table 9. Health care provider beliefs on alcohol-abuse and FAS

"Belief/Behavior"	Public Health Nurses (n=107)	Pediatricians (n=38)	Family Practice Physicians (n=132)	OB/Gyns (n=29)
Agree that it is the role of their profession to address alcohol abuse issues among patients and their families	98	95	97	100
Believe FAS is an identifiable & diagnosable syndrome	94	97	92	90
Believe making a diagnosis of FAS can improve treatment plans for the affected child	88	63	81	79
Believe discussing alcohol abuse will frighten or anger patients/parents and/or deter them from continuing to see the provider	10	11	11	10
Felt minimally prepared or unprepared to deal with patients/parents in the area of alcohol abuse	47	47	8	11
Always referred a patient to alcohol abuse inpatient or outpatient services when they knew or strongly suspected an alcohol abuse problem	34*	19*	64	63

*Pediatricians and public health nurses were asked about parents of pediatric patients.

Although 92% of the 1991 PRAMS respondents reported that a doctor or nurse had asked them about their alcohol consumption, only 77% reported that a doctor or nurse had counseled them about the effects of drinking on their fetus. These statistics match those reported by the OB/GYNs in the KABB survey (Table 10). Ninety-three percent of the doctors reported always asking patients if they use alcohol, but only 79% indicated they always informed their patients about the dangers of alcohol on the developing fetus. Of particular concern for FAS surveillance and prevention is the fact that 50% or less of delivering doctors reported always noting alcohol use on the birth certificate in cases where alcohol abuse was known or strongly suspected. Education regarding the benefits (as opposed to the stigma) of diagnosing FAS is strongly indicated. Supporting this conclusion is the fact that only 63% of pediatricians (vs. almost 80% of other providers) believed making an FAS diagnosis could improve the treatment plans for the affected child.

Many health care providers reported not having the information they need to educate effectively—or identify—FAS patients and families. Resources most frequently requested by the KABB respondents were:

- lists of referral resources for children with FAS (family practitioners, PHNs)
- materials on identifying FAS (family practitioners)
- lists of resources for parents with alcohol problems (pediatricians, PHNs, ob/gyns)
- FAS literature for parents (pediatricians, PHNs, ob/gyns)
- support group referral resources for FAS parents (pediatricians)
- registry of specialists for consultation for children suspected of FAS (PHNs)
- registry of specialists in women's treatment issues available for consultation (ob/gyns)

Table 10. Delivering Physician Beliefs on Alcohol-abuse and FAS

Percent of survey respondents* for belief and behavior questions regarding alcohol abuse among obstetric patients by health care provider, Alaska 1993.

"Belief/Behavior"	Family Practice Physicians (n=132)	OB/Gyns (n=29)
Always ask obstetric patients if they use alcohol	86	96
Always inform obstetric patients about the dangers of alcohol on the developing fetus	82	79
Ever referred a woman to an alcohol treatment/counseling program	90	90
Always approached the topic of alcohol abuse with the patients seen in the last year with a known or suspected alcohol abuse problem	83	96
Always noted alcohol use on the birth certificate, in cases where alcohol abuse was known or strongly suspected	46	50

* For any question, the proportion of respondents with missing data was no greater than 8 percent.

IV. Prevention: Approaches and Recommendations

Summary of Key Findings and Implications

The AFASPP's efforts to date have focused on characterizing FAS in Alaska. Key findings and implications to be considered in the creation of an FAS prevention plan include:

- active, multi-source surveillance (using an objective case definition) is essential for accurate FAS case ascertainment and rate determination and to measure trends over time.
- Alaska's prevalence rates for drinking among women of childbearing age are among the highest in the country.
- Alaska Natives are at the highest risk of delivering FAS children and the public awareness survey indicates that their knowledge level about the disease could be greatly improved.
- in addition to race, education level attained and smoking behavior (both indicators of heavy drinking risk) are potential indicators of a woman's likelihood to drink during a future/current pregnancy.
- older age and drug use are the strongest identified risk factors for drinking during the third trimester of pregnancy.
- marital status, and birth of a previous FAS child predict women at highest risk.
- a clear psychosocial profile of Alaska's FAS mothers does not currently exist, but the suggestion of an association between maternal drinking and other life stressors does.
- little is known about the characteristics of FAS fathers.
- effective prevention may require a focus shift from simply changing maternal drinking behaviors to ameliorating at-risk women's social environments.
- public knowledge about FAS is generally low and could be improved.
- many health care professionals are not effectively prepared to address alcohol abuse in women of child-bearing age.
- Alaska's youth drinking behavior does not differ significantly by race, suggesting (along with the maternal risk characteristics) that the public school system may be an important conduit for FAS education.
- a broad range of professions, organizations and lay people touch FAS parents and children and need to be involved in the FAS prevention plan (e.g., health care providers, social service providers, educators, friends and families)
- knowledge of FAS seems to correlate with a willingness to take preventative action on the part of both lay people and health care professionals.

Prevention Approaches

Disease prevention is frequently discussed in terms of three levels: primary, secondary and tertiary. Primary prevention, reducing the number of new cases of disease, represents the ultimate goal of most prevention efforts. Primary prevention does not address those individuals who already have or are developing the disease. Primary FAS prevention would include very broad, population- or risk group-based programs geared towards preventing maternal drinking prior to and during pregnancy, or postponing pregnancy in women who are unable to stop drinking. Its success depends on the ability to reach and influence at-risk women.

Secondary prevention, reducing the prevalence of existing cases, generally requires effecting some sort of cure or clinical turnaround. In the case of FAS, secondary prevention necessitates an ability to reduce or ameliorate the effects of alcohol on an already exposed fetus/child. While there is no known "cure" for FAS, preliminary research described by the Institute of Medicine suggests that certain chemicals or dietary supplements may modulate the effects of alcohol on a growing fetus. Reducing the dose of alcohol that a fetus receives may also reduce the extent of neonatal damage. To implement secondary prevention, women drinking during pregnancy would have to be identified and an effective treatment established.

Tertiary prevention focuses on reducing the ultimate consequences of disease through treatment and rehabilitation. It focuses on the FAS child instead of its mother. Again, FAS therapy is a largely unexplored area. The Institute of Medicine reports that the combination of stable family environment, good diet, and intervention programs has met with some success in enabling FAS children to better function in their families and schools. Success of a tertiary FAS prevention program would, therefore, depend on enhanced FAS diagnostic ability and the development of FAS treatment programs.

Future Prevention Recommendations

FAS prevention is challenging. The FAS prevention strategy needs to combine elements of all three prevention levels (primary, secondary, and tertiary), requiring the involvement of a large number of individuals and professional organizations. As summarized in the FAS Prevention Program Matrix (Table 11), each prevention level can be applied to different approaches (educational, interventional, legal) and targets (the general public, specific age/race/professional groups, FAS parents). Many of the resulting program options overlap in terms of the individuals and resources involved, but it is unrealistic to assume all prevention alternatives can—or should—be implemented.

The FAS prevention strategy will need to balance the anticipated impact/benefit of each approach with its estimated costs and feasibility of implementation. The appropriate chronological order for the efforts may also need to be considered. Regardless of the ultimate programs selected, the FAS prevention plan will need to include surveillance and research activities, not explicitly means of prevention themselves, but essential to the continued evaluation and development of prevention programs.

Table 11. FAS Prevention Program Matrix

Approaches:	Primary Prevention preventing women from drinking during pregnancy	Secondary Prevention preventing/ameliorating the effects of alcohol on a growing fetus	Tertiary Prevention ameliorating the lives of FAS victims and their families
Professional Education/ Training	• *Targets*: health care (ob/gyns, ER physicians, family practitioners, PHNs, Native Health Corps.), social services (mental health, MCH, family services, alcohol/drug abuse, WIC, etc.), educators (middle/high school) • *Programs*: the basic facts about FAS/FAE, maternal risk characteristic identification, resources available for individuals with alcohol problems, resources offering free/accessible birth control, how to approach a patient/client intervention (less for educators)	• *Targets*: health care (ob/gyns, ER physicians, family practitioners, PHNs, Native Health Corps.), social services (mental health, MCH, family services, alcohol/drug abuse, WIC, DFYS, etc.), justice (municipal police, state troopers) • Programs: resources available for parents with alcohol problems, value of secondary prevention efforts, legal rights/bounds of intervention, resources available for counseling mothers and their partners/families, potential treatment options-primarily for health care professionals (diet, medication), how to approach a patient/client/civilian intervention	• *Targets*: health care (pediatricians, PHNs, family practitioners, ob/gyns, Native Health Corps.), social services (child protective, DFYS, youth corrections, family services, mental health, MCH, healthy baby, nursing, WIC, Head Start, etc.), educators (special education) • *Programs*: value of diagnosing/ treating FAS individuals, clinical/behavioral/ demographic FAS characteristics (ability to diagnose or refer cases), resources available to FAS individuals, appropriate follow-up guidelines, resources available to FAS parents/ families, legal rights of FAS parents, treatment options/approaches for FAS children (as are developed)
Public Education/ Awareness	• *General Targets*: women and men of childbearing age, general public, middle and high school students • *Programs*: basic facts about FAS, maternal risk characteristic identification--simplified, how to prevent FAS (what you can do) • *Selective Targets:* Native Alaskans of childbearing age, Women in halfway houses/ shelters/alcohol-drug treatment programs, women/men with previous FAS children • *Programs:* basic facts about FAS, maternal risk characteristic identification--simplified, resources available for individuals with alcohol problems, resources available for free prenatal care, resources offering free/ accessible birth control/ family planning assistance		
Interventions	• *Target*: women at-risk, their partners and families • *Programs:* circles of care, adopt an at-risk mom/ family, community pledges, alcohol treatment centers *Active option:* seek out women with multiple FAS children (birth defects registry, AFASPP surveillance) *Passive option:* screen/refer women with high risk characteristics (when they seek medical or social services)	• Target: pregnant women who are drinking, their partners and families • *Programs:* circles of care, adopt an at-risk mom/ family, alcohol treatment centers, and anti-toxicity therapy(as developed) *Passive:* screen/refer pregnant women with high risk characteristics (when they seek medical or social services)	• *Target: FAS* children and their families • *Programs:* diagnostic clinics with care assessment and coordination, active case management, respite care, special education, FAS parent/sibling support groups *Active:* have health care professionals refer all patients with documented in utero alcohol exposure *Passive*: offer to FAS/FAE parents trying to learn how to teach/nurture their children

Legal Actions	• *Target*: general (drinking) public • *Program*: decrease availability of alcohol (e.g., limited selling hours)	• *Target*: women continuously abusing alcohol during pregnancy and their partners/families • *Programs*: force hospitalization for alcohol abuse treatment, threaten removal of child/children	• *Target*: FAS children whose parents are unable to provide necessary care • *Program*: force removal of FAS child/children from mother/parents
Economic Actions	• *Target*: general (drinking) public • Program: increase the cost of alcohol (e.g., additional tax)		
Research	• characteristics of FAS fathers • additional maternal risk factor detail, clarification (motivations, beliefs, drinking histories, etc.) • effectiveness of professional education/ training programs • effectiveness of public education/awareness programs • effectiveness of intervention programs, particularly ability to involve partners and family members • access of AK populations to FAS resources: alcohol treatment centers, well woman care, family planning, prenatal care, etc. • biomarkers for alcohol abuse detection	• ability of certain co-factors to increase or decrease the effect of alcohol on the fetus • better understanding of the dose-response relationship of alcohol on human fetal development	• effectiveness of FAS programs/ treatments (for children and adults) • more detailed estimates on the economic and social costs of FAS • biomarkers for FAS diagnosis
Disease Surveillance	• drinking behaviors/ trends (especially among women of childbearing age and Native Alaskans) • public awareness of FAS professional awareness of/preparedness for alcohol-related issues and FAS	• drinking behaviors/trends of pregnant women and their families • characteristics of women who drink during pregnancy, including partner and familial profiles	• trends in FAS and FAS-noted rates (geographic as well as racial/ethnic changes) • characteristics of FAS cases and parents

Primary FAS Prevention

Primary FAS prevention is complex, but essential. The goals of primary FAS prevention are to change the drinking behavior of women prior to conception, change drinking women's childbearing behavior, or both. Three different target groups need to be involved: the health care and social services providers who can influence women of childbearing age and identify those women at-risk; the women at risk of drinking during pregnancy, their partners, and their families; and the general public who (with the media's assistance) determine acceptable social norms. Each target group requires different programmatic approaches, all of which focus on the at-risk women and their environments (Figure 10).

As demonstrated by the KABB survey of Alaska's health care providers, education and training programs are strongly indicated for this group. Resource materials and lists will need to be developed. The demographic profile of FAS mothers also indicates a strong need for social service providers to be educated about FAS and trained to refer women (and their families) to appropriate resources and to make these resources available and accessible.

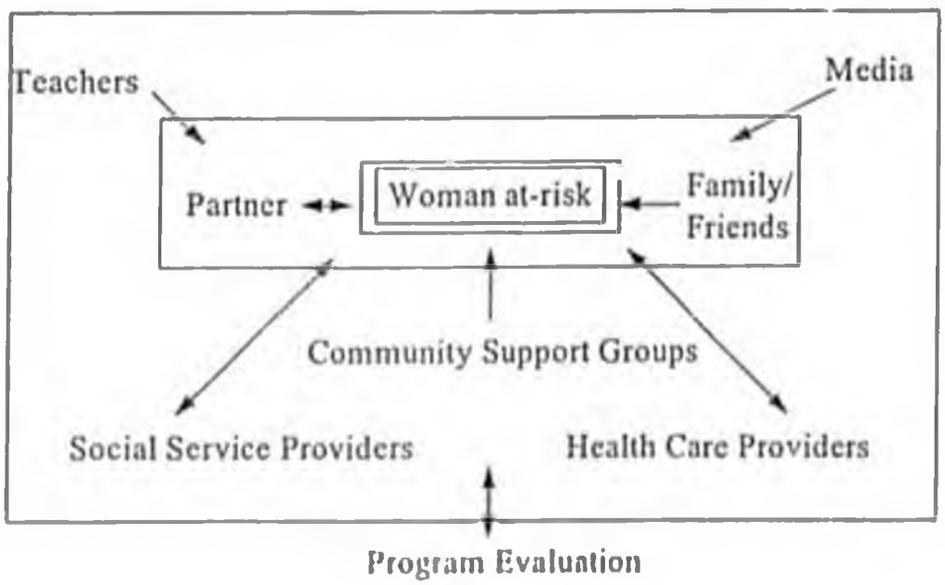
Programs to reach women at risk need to be developed or expanded. Such programs can range from the establishment of "circles of care" or "adopt an at-risk mom" coalitions, to the establishment of community-wide pledges of support,[4] to the founding of alcohol treatment centers. Regardless of the precise programs implemented, research strongly suggests that these efforts need to include an emphasis on the partner and family/friends of the at-risk woman. Also essential to the effectiveness of primary prevention efforts will be their economic, cultural and logistic accessibility to at-risk women and the complement of support services they offer (family planning, domestic violence counseling, nutritional planning, etc.)

Programs geared towards educating the general public could include media campaigns which discuss the outcomes of drinking during pregnancy *and* the means to help someone stop drinking. Public education should focus on the role of men as well as women in the prevention of FAS in their children. The most effective messages and communication channels need to be determined. These general awareness efforts should also include the development/enhancement of alcohol-related health curriculum for middle and high school students.

Legal and economic actions, such as decreasing the availability of alcohol or increasing its price, may also be considered. However, these programs, may meet with significant resistance.

[4] The Pueblo of Zuni have written a vision statement and the Spokane Tribal Community has implemented family pledges supporting FAS prevention efforts in their communities (IOM, 1996).

Figure 10. Primary FAS Prevention Model



Secondary FAS Prevention

Secondary FAS prevention offers the most difficult and limited prevention options. Until the development of treatments to moderate or reverse the effects of fetal alcohol exposure, secondary prevention efforts will focus on reducing or eliminating fetal alcohol exposure. Its goal, then, is to change the drinking behavior of women who are continuing to drink during pregnancy. Targets are the health care and social services providers who can influence and identify pregnant women who are drinking, the women themselves, their partners, and their families. Programs basically include the extension of primary prevention efforts: provider education and training; and community outreach or intervention programs for pregnant women, their partners, and families.

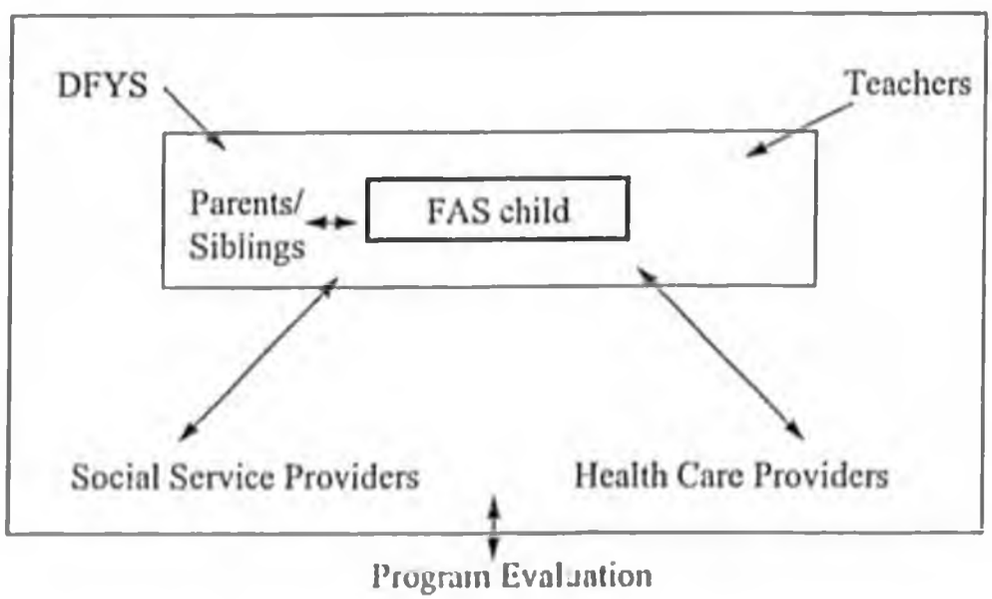
Tertiary FAS Prevention

Tertiary FAS prevention shifts the emphasis from mother to child. Its goal is to improve FAS children's ability to function and develop in their families and communities. The targets for tertiary prevention programs are the health care and social/educational providers who may come in contact with alcohol affected children, the FAS children, and their families. As with primary prevention, a very large number of organizations and individuals may be involved in the tertiary prevention model (Figure 11).

The AFASPP research revealed that educational programs about FAS diagnosis and treatment and resource lists of services available to both FAS children and parents are needed. Programs for FAS children and families also need to be developed or expanded. Such programs may range from diagnostic clinics to assess children's needs, to case management to assure care plans are being followed, to family support groups to help FAS parents and siblings, to respite care facilities designed specifically for children with FAS-type disabilities. Special education classes (and teacher training) may also factor into tertiary care efforts. Again, economic and logistic accessibility to these programs is required for their effectiveness. Qualification for special social services (SSI, ILP) may reduce the economic burdens; physical proximity may prove more of a challenge in Alaska. An ongoing DHSS/DOE study should prove helpful with the development of special education materials and approaches.

As with secondary prevention, the legal (or voluntary) removal of a child from its mother/family may be a necessary consideration. Based on the custody status of most of Alaska's FAS cases, this event is the norm rather than the exception.

Figure 11. Tertiary FAS Prevention Model



Policy Implications

Ensuring an effective FAS prevention plan should not require any major federal or state policy changes. The AFASPP's research, however, has suggested at least one legislative consideration:

- reevaluate the Maternal Child Health Block Grant requirement that grant recipients monitor and annually report the proportion of live births with FAS (House Resolution 2651) since the use of birth records alone substantially understates the prevalence of FAS in a population.

Prevention Recommendations

- Population-based surveillance of FAS is essential to document the magnitude of the problem, to monitor trends in the occurrence of FAS, and to document the impact of prevention efforts.
- The more that is understood about the women who give birth to FAS and other alcohol-affected children, the better is our ability to target prevention activities to them before they give birth to an alcohol-affected child. The top priority for developing effective prevention is to conduct a risk factor analysis of the women who have given birth to FAS children by examining their medical, social, and reproductive histories. DHSS should conduct a maternal risk factor analysis of the biological mothers and fathers of the FAS cases identified through the AFASPP.
- DHSS and DOE should conduct an analysis of the relationship of a medical diagnosis of FAS to the need for special education services.
- Programs should be targeted at two major strategies:

  1) Reduce alcohol consumption among women of child bearing age and especially among pregnant women, and

  2) Postpone pregnancy among women who are unable or unwilling to reduce substantially or stop completely alcohol consumption.

- Improve coordination of services and target services to families who are identified through having a child diagnosed with FAS.
- Determine the barriers to treatment for women who have had an alcohol-affected pregnancy.

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State of Alaska Epidemiology **Bulletin** *Recommendations and Reports*

State of Alaska, Section of Epidemiology
PO Box 240249
Anchorage, AK 99524-0249

H.E.S.S. Committee Presentation - Doug and Gloria Stuart - 3/98

For the past thirteen years we have been foster parents to two delightful boys, brothers who come from a large family. Both boys have F.A.S. Actually eight out of the ten children in this family are effected. Five of these children are in state custody. We have had our two boys since they were new infants.

Both Gloria and I had alcoholic parents. My parents died of alcohol before they had a chance to enjoy their grandchildren. I would say that my wife and I represent an <u>average</u> couple, with <u>average</u> backgrounds. What is wrong with this statement? Alcohol - or rather the excess of it.

For how many generations have children grown up in dysfunctional families caused by alcohol abuse? How many of these children were damaged? How many adults are in prison today, on welfare, divorced , or living in poverty due to the effects of alcohol? How much time, energy and money is spent on these problems? Think about it--this committee sits here today taken up with issues caused mainly by alcohol abuse. We must educate to have successful prevention, but we must deal with the current generation of effected children because it is in this way that we will break the cycle. Breaking the cycle is the key to prevention.

1. F.A.S. is now believed to be the leading cause of mental retardation in the western world and the only preventable one (Clarren 1992).

2. 97 % of children with F.A.S. are in foster care or adopted (Streissguth, Ladue and Randels 1988).

3. Research shows that the long-term effects of alcohol on fetuses are more powerful than those of other drugs, including cocaine (Chasnoff 1991).

What can we do when a child is born with F.A.S./F.A.E.? We think the most impact can be made in the early years. Early diagnosis of the syndrome, early intervention, and a stable placement for the child is crucial. Why? With this program <u>services can end, or be greatly reduced,</u> by the time they are young adults. Early intervention will make a tremendous difference in the amount of money spent on later social services. Bottom line-- spend it now-- save it later. Any current funding requests for the model now being formulated to deal with the F.A.S./F.A.E. problem, should be looked upon

with favor. A very real difference can be made for these unfortunate children. These programs will actually save money.

Along with the funding, we need a different set of rules and regulations for the children in the foster care system who are alcohol damaged. Mandated reunification does not work! Early diagnosis, early intervention, and a stable home situation does work! These children are difficult to raise. Because of this, multiple placements are the rule not the exception. Multiple placements are devastating! If this happens, the damage lasts a lifetime. A large percentage of these damaged people are in state-supported, social systems long term. They are in prisons, mental care facilities, and in assisted living programs.

For thirteen years the State of Alaska has spent money on our boys. Would guardianship or adoption work? Yes, it would. However, our situation like many F.A.S. situations, is very complicated. These placements would be a lot easier on everyone if seperate rules and regulations governing F.A.S. placements were enacted. Long term placement should have at least one foster parent be at home 24 hours a day. Stability is the key word here. Special funding for these parents must be available. My wife gave up a teaching career to accomplish what she has done for our children, and I took early retirement from ARCO because I was needed at home.

The point I wish to make is this: because our children had special care from the time they were born, they are doing extremely well. From all indications they will not cost the state as much money as those children who were not given a stable home. If you could see our kids in karate, on the swim team, in Civil Air Patrol, or running our 42 ft. commercial fishing vessel, it would be evident that they are doing far better than expected. One of their brothers was in fourteen placements by the time he was two years old! He never bonded with a parent figure, and now will need monitoring and care for the rest of his life. His life has been ruined by what was done to him before birth and then by a system that caused him to be in fourteen placements by the time he was only two years old!

Please listen to what our statewide F.A.S. coordinator, other F.A.S. experts, and what we and other long-term foster parents are saying! Early diagnosis, early intervention, and a stable loving placement works.

Thank You

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

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Centers for Disease Control
and Prevention
Office of Communication
Division of Media Relations
1600 Clifton Road, MS D-25
Atlanta, GA 30333 USA

Facts About Fetal Alcohol Syndrome

April 25, 1997

- Consuming alcohol during pregnancy is the cause of Fetal Alcohol Syndrome (FAS), a leading preventable cause of birth defects and mental retardation.
- FAS is a serious, lifelong condition that is characterized by facial abnormalities, growth retardation, and central nervous system deficits including learning and developmental disorders. Not all children affected by prenatal alcohol use are born with the full syndrome, but may have selected abnormalities. Estimates of the prevalence of FAS vary from 0.2 to 1.0 per 1000 live births.
- A new study released by CDC finds that rates of frequent drinking (≥7 drinks per week or 5 drinks on any occasion in the past month) among pregnant women have increased substantially from 0.8% in 1991 to 3.5% in 1995. The rate of 3.5% in 1995 translates to at least 140,000 pregnant women drinking at these more harmful levels each year.
- Health advisories urging women --pregnant or planning a pregnancy-- not to drink alcohol were first issued by the U.S. Surgeon General in 1981, and were reiterated by the Secretary of Health and Human Services in 1990 and 1995.
- Prenatal alcohol consumption is a leading, preventable cause of birth defects and mental retardation.
- Health-care providers should advise pregnant women and those planning a pregnancy not to drink alcohol.
- "Alcohol and Other Birth Defects Awareness Week" is May 11-17, 1997.

Manitoba Association
of Registered Nurses

Position Statement: Fetal Alcohol Syndrome/Effect

Fetal Alcohol Syndrome (FAS) is the leading cause of mental retardation in Canada and North America (Casiro et al, 1994).

FAS is the end result of maternal ingestion of alcohol during pregnancy. Some very preliminary studies indicate that the paternal use of alcohol may also contribute to the development of FAS/FAE. Children diagnosed with this syndrome manifest with: "prenatal and postnatal growth retardation; failure to thrive; central nervous system involvement including irritability, hyperactivity, intellectual impairment; and facial dysmorphology" (Kuffel & Pietrantomi, 1991). Further defects include cardiovascular, skeletal, spinal, genital anomalies, and emotional disorders. Children with Fetal Alcohol Effect (FAE) often do not manifest the physical characteristics of full scale FAS, however they may suffer the permanent central nervous system sequelae and associated emotional and behavioral disorders.

The misuse of substances occurs in all cultural/social/economic groups and may affect all family members. In families where substances are being misused, children with FAS/FAE may be born into highly stressed families with limited coping skills. This environment coupled with the child's increased irritability and hyperactivity may place these children at an increased risk of many types of abuse and neglect (Children of Alcoholics Network, 1992).

Registered Nurses are the largest group of health care professionals in contact with men, women, families and communities at risk for FAS/FAE children. The role of the Registered Nurse includes education, screening, counselling, support and referral to appropriate resources. This role is in keeping with primary health care concepts of wellness promotion and illness prevention.

All health care disciplines should collaborate on early identification and intervention for FAS/FAE.

The MARN Position of FAS/FAE is that

The National Organization on Fetal Alcohol Syndrome

Strategies for parents and caregivers of FAS and FAE children

*Prepared by Patricia Tanner-Halverson, Ph.D.

Keys to working successfully with FAS/FAE children are structure, consistency, variety, brevity and persistence. Because these children lack internal structure, caretakers need to provide external structure for them. It is important to be consistent in response and routine so that the child feels the world is predictable. Because of serious problems maintaining attention, it is important to be brief in explanations and directions, but also to use a variety of ways to get and keep their attention. Finally, we must repeat what it is we want them to learn, over and over again.

Many FAS children:

- Have difficulty structuring work time.
- Show impaired rates of learning.
- Experience poor memory.
- Have trouble generalizing behaviors and information.
- Act impulsively.
- Exhibit reduced attention span or are distractible.
- Display fearlessness and are unresponsive to verbal cautions.
- Demonstrate poor social judgment.
- Cannot handle money age appropriately.
- Have trouble internalizing modeled behaviors.
- May have differences in sensory awareness (Hypo or Hyper).
- Language Production higher than comprehension.
- Show poor problem solving strategies.

Effective strategies include:

- Fostering independence in self help and play.
- Give your child choices and encourage decision making.
- Focus on teaching daily living skills.
- Encourage the use of positive self talk.
- Have child get ready for next school day before going to bed.
- Establish a few simple rules. Use identical language to remind them of the rules. "This is your bed, this is where you are supposed to be."
- Establish routines so child can predict coming events.
- Give child lots of advance warning that activity will soon change to another one.
- For unpredictable behavior at bedtime/mealtime, establish a firm routine.

CORRECTION

THE FOLLOWING DOCUMENT(S)
HAVE BEEN REFILMED TO
ASSURE LEGIBILITY OR PAGINATION

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All health care disciplines should collaborate on early identification and intervention for FAS/FAE.

The MARN Position of FAS/FAE is that

- fetal alcohol syndrome is completely preventable;
- both men and women need to take responsibility for the prevention of FAS/FAE;
- there is no known "safe" level of alcohol consumption during pregnancy therefore abstinence should be recommended to women where there is or may be a pregnancy;
- prevention of FAS/FAE requires identification of the social and economic sources of alcohol abuse;
- prevention programs should focus on education of the public at large including school children;
- care and treatment of those affected by FAS/FAE should include family and community. Though the effects cannot be erased, interventions can be applied to optimize the affected child's potential, and to maintain the integrity of the family. Families and communities with FAS/FAE children require a great deal of support to raise these children and to break the recurrent cycle of FAS/FAE (CNA Brief to the House of Commons, 1992).

Approved by the Board of Directors: May 1995

Contact MARN at:
647 Broadway, Winnipeg, MB R3C 0X2
Telephone: (204) 774-3477
Toll free (Manitoba only): 1-800-665-2027
Fax: (204)775-6052

e-mail at: marn@marn.mb.ca

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The National Organization on Fetal Alcohol Syndrome

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- Break their work down into small pieces so they do not feel overwhelmed.
- Be concrete when teaching a new concept. Show them.

Discipline:

- Set limits and follow them consistently.
- Change rewards often to keep interest in reward getting high.
- Review and repeat consequences of behaviors. Ask them to tell you consequences.
- Do not debate or argue over rules already established. "Just do it."
- Notice and comment when your child is doing well or behaving appropriately.
- Avoid threats.
- Redirect behavior.
- Intervene before behavior escalates.
- Avoid situations where child will be overstimulated.
- Have child repeat back their understanding of directions.
- Protect them from being exploited. They are naive.
- Have pre-established consequences for misbehavior.

FAS | NOFAS | Strategies | Curriculum | Resources | NOFAS Home Page

National Organization on Fetal Alcohol Syndrome
1819 H Street NW - Suite 750 - Washington, DC 20006
Phone: (202) 785-4585 - Fax: (202) 466-6456 - e-mail: nofas@erols.com

Please include your mailing address if you would like to receive our information packet.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) - National Center for Environmental Health (NCEH) - Division of Birth Defects and Developmental Disabilities (DBDDD) - Birth Defects Prevention - *Last updated: December 20, 1996*

What CDC is doing to

Prevent Fetal Alcohol Syndrome and Other Alcohol-Related Developmental Disabilities

Introduction | The Problem | The Approach | Prevention Activities | Prevention Partners | Research Needs | Meeting the Challenge | Public Information

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Introduction

The Division of Birth Defects and Developmental Disabilities of the National Center for Environmental Health (NCEH) strives to prevent fetal Alcohol Syndrome (FAS) a leading preventable cause of birth defects and mental retardation. In fact, FAS accounts for about 2,000 new cases of preventable birth defects in the United States each year.

Although the exact rate of learning disabilities and behavioral abnormalities caused by fetal exposure to alcohol is unknown, some of our data suggest that another 4,000 children who do not meet the clinical definition of FAS may experience significant cognitive and behavioral impairment due to fetal exposure to alcohol.

We know that the reported rates of FAS are higher among Native Americans and African Americans. These differences may be due to actual differences in the occurrence, or may in part reflect under-diagnosis among some racial/ethnic groups, and over-diagnosis among others. Nonetheless, we must help all women to realize the dangers associated with fetal exposure to alcohol.

The Problem

Children with FAS suffer from the following:

- Growth retardation.
- Physical, mental, and behavioral abnormalities.
- Central nervous system impairment, including developmental delay, small head size, and speech or language delay.

- Facial abnormalities.

In addition, fetal exposure to alcohol appears to cause a spectrum of these physical and behavioral problems that may be less obvious than problems associated with FAS and even more difficult to detect.

FAS and other alcohol-related birth defects can be prevented if women do not drink alcohol during pregnancy, or if they use reliable birth control methods when they engage in patterns of binge drinking (5 or more drinks on one occasion) or regular drinking at a level of more than 7 drinks per week. CDC is working to develop innovative approaches for identifying women at high risk of having a child with FAS, for helping them understand the risks that drinking poses for their unborn babies, and for helping them change their behavior. CDC currently funds projects that are testing a variety of methods:

- Screening in prenatal clinics
- Detecting cases of FAS in order to identify women at high risk of giving birth to another child with FAS
- Counseling and support to achieve abstinence
- Case management and follow-up

Methods that prove effective may be integrated into existing health care delivery systems, such as public health clinics and other health care practice settings.

The Approach

To establish affordable and efficient methods for estimating the prevalence of FAS, we provide financial and technical support to state health departments and universities. Cooperative agreements with these agencies and institutions support investigation of clinic-based, school-based, and social services-based approaches to FAS case identification and development of prevention programs.

In 1991, CDC signed an inter-agency agreement with the Indian Health Service and the state of Alaska for a joint program to prevent FAS. Voluntary organizations also participate in this program, which involves--

- Surveillance of FAS to provide an accurate count of affected children throughout the state.
- Technical consultation in developing culturally appropriate prevention programs, such as education and screening programs in prenatal clinics, at the community level.
- Funds and technical assistance for developing new approaches to prevent FAS.

In 1992, we funded cooperative agreements with three universities and five state health departments

- To develop surveillance methods for identifying women at high risk for giving birth to a child with FAS.
- To design prevention strategies
- To evaluate the effectiveness of these strategies.

In addition, we provide technical assistance to 15 state health departments for FAS surveillance and prevention programs through the Disability Prevention Program at NCEH.

Prevention Activities

Our focus on preventing FAS directly supports the Healthy People 2000 goals for children's health. We are working to -

- Design and implement epidemiologic approaches for determining the prevalence of FAS and identifying high- risk target groups for prevention efforts.
- Design data-driven prevention programs and evaluate their effectiveness. For example, we are studying women who have given birth to a child with FAS so that we can develop intervention sc ces to prevent future FAS-affected pregnancies.
- Establish collaborative partnerships with states, universities, and other organizations to develop state and locally based systems for surveillance of FAS and other alcohol-related birth defects. For instance, we worked with state and local health departments in Washington to develop a population-based model for FAS surveillance among first grade students in two counties in the state. We identified previously unknown cases of FAS and referred the children for therapeutic and special education services. Their mothers were referred to local health care providers.
- Disseminate information, in collaboration with other agencies, from the ongoing systematic collection, analysis, and interpretation of FAS data. State and local programs can use this information to modify their activities so that they are using the most cost-effective strategies to combat FAS and other alcohol-related birth defects.

Prevention Partners

- The Indian Health Service has signed an inter-agency agreement with CDC for a joint program to prevent FAS.

- Three universities and five state health departments have cooperative agreements with us to develop surveillance methods for identifying high-risk women, to design prevention strategies, and to evaluate the effectiveness of these strategies.

- A project exists with the Association of Schools of Public Health, Emory School of Public Health, and Georgia Mental Health Institute to develop an accurate method for conducting active, hospital-based FAS surveillance and a case-control study of risk factors for FAS.

- Monroe County Health Department (NY) has a cooperative agreement with us to use a follow-up program for high-risk infants to develop methods for identifying children with FAS after the newborn period.

- In addition, we provide technical assistance to 15 state health departments for FAS surveillance and prevention programs through the Disability Prevention Program at the National Center for Environmental Health.

Research Needs

To reduce the incidence of FAS, we must increase the number of women who abstain from alcohol use during pregnancy. To reach those goals, we need further research

- To improve public health surveillance methods for FAS.
- To refine our methods for identifying children who have been affected by exposure to alcohol during fetal development.
- To demonstrate the effectiveness of prevention programs for women of reproductive age who are at high risk of drinking during their pregnancies.
- To investigate effective secondary intervention strategies, such as special education strategies for children born with FAS or alcohol-related birth defects.
- To identify biological markers for recognizing problem drinkers or children exposed to alcohol in utero.
- To identify genetically determined markers for susceptibility to in-utero alcohol damage.

Meeting the Challenge

The FAS Prevention Section seeks to reduce the human suffering and societal burden resulting from the harmful effects of alcohol use during pregnancy. State health departments and other organizations can become partners in this critical endeavor by taking advantage of the scientific and financial assistance that we provide.

Public Information

We also seek to promote ways of giving people accurate and timely information about FAS. We respond to requests for information from state and local agencies, health professionals, universities, and the general public.

For more information, please contact:

Fetal Alcohol Syndrome Prevention Section
Division of Birth Defects and Developmental Disabilities
National Center for Environmental Health, MS F-15
Centers for Disease Control and Prevention
4770 Buford Highway NE
Atlanta, GA 30341-3724

Telephone: (770) 488-7370
FAX: (770) 488-7361
Email: ncehinfo@cdc.gov

Birth Defects Prevention

Division of Birth Defects and Developmental Disabilities (DBDDD)
National Center for Environmental Health (NCEH)
CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Fetal Alcohol Syndrome

A Time for Action

A review of the status of fetal alcohol syndrome in the State of Alaska

~what the data shows us
~what we have accomplished to date
~projects/actions currently underway
~gaps in our service delivery system
~ recap and recommendations from the FAS Summit, Nov. 6, 1997

Sponsored by

The Governor's Council on Disabilities and Special Education
The Alaska Mental Health Board
The Advisory Board on Alcoholism and Drug Abuse
The Department of Health and Social Services
and
State Representative Fred Dyson (Eagle River)and
State Representative Reggie Joule (Kotzebue)

February 1998

Tony Knowles
Governor

Karen Perdue
Commissioner
Department of Health and Social Services

L. Diane Worley
Statewide FAS Coordinator
Department of Health and Social Services

This publication was prepared by Lori Namyniuk, FAS Summit Facilitator; L. Diane Worley, DHSS Statewide FAS Coordinator; and the FAS Summit Steering Committee.

"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~