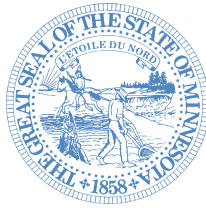


**SUFFER THE
CHILDREN:
THE
PREVENTABLE
TRAGEDY OF
FETAL
ALCOHOL
SYNDROME**



GOVERNOR

ARNE H. CARLSON'S

TASK FORCE ON

FETAL ALCOHOL

SYNDROME

STATE OF

MINNESOTA

FEBRUARY 1998

Governor Arne H. Carlson's Task Force on Fetal Alcohol Syndrome was established in 1997 to make recommendations for a comprehensive approach to preventing and reducing the harm from fetal alcohol syndrome and fetal alcohol effects. It also was asked to raise awareness of the problem of fetal alcohol syndrome and fetal alcohol effects throughout the state and mobilize resources to make positive changes.

Acknowledgements

The Minnesota Department of Health provided financial and staff assistance to produce *Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome*. Minnesota Planning provided staff and editorial assistance.

Upon request, *Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome* will be made available in alternate format, such as Braille, large print or audio tape. For TTY, contact Minnesota Relay Service at 800-627-3529 and ask for Minnesota Planning.

This report satisfies the 1997 session laws, chapter 239, article 12, section 12, that mandates the Minnesota Department of Public Safety to complete a study regarding fetal alcohol syndrome and submit a report by February 1998. The cost to prepare this report was \$14,500.

February 1998

For copies of *Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome*, link to Governor Carlson's World Wide Web site at www.governor.state.mn.us

or contact Minnesota Planning
658 Cedar St.
St. Paul, MN 55155
612-296-3985

or the Minnesota Department of Health
Inventory code for *Suffer the Children*, 141-0486
R.N. Barr Library
717 Delaware St. S.E.
Minneapolis, MN 55440
612-623-5274

**SUFFER THE
CHILDREN:
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Dear Minnesotans:

As First Lady of Minnesota and as co-chair of the Governor's Task Force on Fetal Alcohol Syndrome, I am convinced that the numbers of children born with fetal alcohol syndrome and fetal alcohol effects is a crisis affecting each and every one of us. It is a silent crisis that we as a state, and as a nation, have failed to make a priority.

Through my work as a referee in Hennepin County Juvenile Court, I saw many children I am convinced were damaged by prenatal use of alcohol. Child after child came from families with long histories of alcohol abuse. There is no doubt in my mind, based on what I have seen in court and what I heard around the state with the task force, that the effects of prenatal alcohol exposure are driving many of the increasing costs in our public systems, including special education, out-of-home placements and corrections.

We are fortunate because rarely can we say with confidence that a problem of this magnitude is completely preventable. I urge policy-makers and all Minnesotans to study this report carefully and act now to stop this tragedy while ensuring that affected individuals are given every opportunity for success.

Thank you to my co-chair, Judge Joan Lancaster, and to all task force members for their dedication in beginning this critical work. We thank Governor Arne H. Carlson for recognizing the importance of this issue and giving us the opportunity to join him in making a difference for countless children and families across Minnesota.

SUSAN CARLSON
FIRST LADY
MINNESOTA DISTRICT COURT REFEREE
CO-CHAIR, GOVERNOR'S TASK FORCE ON
FETAL ALCOHOL SYNDROME

Fetal alcohol syndrome and fetal alcohol effects irreversibly reduce human potential. Victims of these conditions often suffer facial and other physical abnormalities that are visible early in life. Less visible, but ultimately far more significant, they suffer brain damage that can result in an inability to learn from mistakes or to interact with others. They often exercise poor judgment, and as adults they frequently cannot keep a job.

As a judge in juvenile court, I regularly see this painful fallout. We all see it in crime rates and tax rates driven by social service costs. Some of us see it in our own families or those of our friends. At public hearings across the state, members of this task force saw that this problem is widespread and serious.

Why would someone so permanently harm a child? It is not absence of love. One reason is a lack of accurate information; the other is chemical dependency. The experience of this task force led to a consensus that there are ways to weaken the grip of both forces on our society. This report proposes concrete means of doing so – means that lie within our reach.

I am persuaded by what I have learned on the task force that there are ways existing systems can be made more helpful for children, adults, families and communities already struggling with fetal alcohol syndrome and fetal alcohol effects. When government intervenes in the lives of families, it carries a special burden to act productively. Interventions that do not work are not only a waste of time, money and effort, they are a waste of human potential. We owe it to those who have already been victimized, and who may victimize others, to use the knowledge we have to stop the multigenerational damage, reduce the secondary effects of the disability, and make actual progress. It's a matter of justice.

JOAN ERICKSEN LANCASTER
JUDGE, HENNEPIN COUNTY DISTRICT COURT
CO-CHAIR, GOVERNOR'S TASK FORCE ON
FETAL ALCOHOL SYNDROME

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CLOSE UP

I STARTED DRINKING WHEN I WAS 10.

I hung out in the arcade downtown, between a bar and a liquor store. I always had a way to get to alcohol. When I was pregnant with my first daughter in 1989, I would literally go to the hospital and beg for help. But at that time, there was no help for desperate women like me, so they sent me home.

My daughter is now 7 and tests confirm that she was exposed to alcohol prenatally. She is hyperactive, repeats sentences and has a hard time remembering things. She suffers a lot from my drinking.

In 1992, I was pregnant again. But when you're an alcoholic, getting pregnant doesn't stop your addiction. Alcoholism is such a selfish thing; it is just downright nasty. I didn't want to get sober. But I also didn't want to hurt my baby. My 5-year-old daughter is being tested for fetal alcohol syndrome because she also shows some effects of my alcohol use.

My parental rights have been terminated with both of my daughters. I pretty much lost it when I lost them. In 1996, I was pregnant again, and I knew that if I lost another child, I'd kill myself. I was sent to a treatment center and got support from community programs. I had help getting to doctor appointments, help with transportation, help with the bare necessities that a poor woman needs when she is trying to get off the streets and get her addiction under control. By the grace of God, those resources were available to me, but they are not as available as they need to be. I have been clean for 17 months and had a clean baby in 1996.

I am lucky because I am still very much a part of my daughters' lives. It wasn't as bad as it could have been. But it is very painful to watch my 7-year-old go through what she goes through knowing that there is nothing I can do to get inside her to change what I've done and the permanent effect my addiction has had.

I finally made a commitment to change my life. I don't believe that saying you are trying is making a commitment. I talk openly and honestly about my experience to anyone who will listen. I am not ashamed of it, it is not an embarrassment. It is what has happened in my life, and I hope it will prevent someone else from having to go through what I went through and what I continue to go through.

27-YEAR-OLD MOTHER, MINNEAPOLIS

Task Force

GOVERNOR ARNE H. CARLSON'S TASK FORCE ON FETAL ALCOHOL SYNDROME

CHAIRS

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Judge Joan Lancaster, Hennepin County District Court (executive committee member)

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Carole Basil, president, Minnesota Beer Wholesalers Association

Linda Berglin, state senator

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Justice Kathleen Blatz, Minnesota Supreme Court (executive committee member)

Bob Brick, executive director, Arc Minnesota

Pi-Nian Chang, pediatric psychologist, University of Minnesota Medical School

Don Davis, commissioner, Minnesota Department of Public Safety

David Doth, commissioner, Minnesota Department of Human Services

Jim duBois, president, Minnesota Broadcasters Association

Joline Gitis, adoptive mother of a child with fetal alcohol syndrome

Joyce Glass, executive director, Thunder Spirit Lodge; adoptive and biological mother of children with fetal alcohol syndrome

Lou Gonzales, commissioner of health and human services, Mille Lacs Band of Ojibwe Indians

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Peter Hayden, president, Turning Point, Inc.

Don Helmstetter, president, Minnesota Association of School Administrators; superintendent of Spring Lake Park School District

Joyce Holl, vice president, Pathfinder Resources, Inc.; program manager, Minnesota Healthy Roots Coalition

Dr. Neal Holtan, medical director, St. Paul-Ramsey Public Health Department

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Judy Schaubach, president, Minnesota Education Association

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SUFFER THE
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Summary

SUMMARY

Alcohol use during pregnancy is the leading cause of preventable mental retardation in Minnesota. In only three other states do women in their child-bearing years drink more than in Minnesota, according to a national survey.

Thousands of babies are exposed prenatally to alcohol each year. Some develop lifelong disabilities. These children often have trouble learning, controlling impulses, thinking abstractly, getting along with people, paying attention, remembering things and making good judgments — problems that follow them into adulthood. Often they are unable to live on their own and have difficulty holding a job.

Fetal alcohol syndrome includes all three of the following characteristics, and fetal alcohol effects include some:

- > abnormal facial features
- > slow growth both before and after birth
- > brain injury

Like alcoholism, fetal alcohol syndrome and fetal alcohol effects cross social, economic, racial and ethnic lines. The true extent of this tragedy and its cost are unknown. Officials in one Minnesota county expect to spend over \$2 million on just one family for such services as out-of-home placement, social services and counseling. Medical care costs will add to the bill.

Governor Arne H. Carlson established the fetal alcohol syndrome task force in 1997. Co-chaired by First Lady Susan Carlson and Hennepin County District Court Judge Joan Lancaster, the task force held public meetings across the state to learn firsthand from Minnesotans about fetal alcohol syndrome and effects. Birth parents, adoptive parents and foster parents told stories of struggle, discouragement, love and persistence. Professionals from health care, social services, education, law and other fields spoke about what they see on the front lines. No community is immune from the devastating effects of alcohol use during pregnancy.

Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome summarizes task force findings from the public hearings. The report recommends action steps, changes in state policy and improved funding to prevent the harm wrought by this condition.

KEY FINDINGS AND A SAMPLING OF THE TASK FORCE'S RECOMMENDATIONS ARE:

- > **Low public awareness impedes prevention efforts.** Minnesota needs ongoing state and local awareness campaigns, a central information source and business partnerships to raise employee awareness.
- > **A lack of solid data masks the full costs and extent of the problem.** Minnesota must learn the breadth and severity of the problem, and estimate the monetary cost of fetal alcohol syndrome and fetal alcohol effects in the state.
- > **Alcohol advertising overshadows public messages about responsible drinking.** Minnesota must engage the alcohol industry in prevention campaigns and ensure that high-impact warning messages are displayed wherever alcohol is served.
- > **Widespread failure to warn pregnant women about drinking and identify those likely to drink prevents women from getting help.** Minnesota must train professionals in health care and other key fields to routinely screen pregnant women; it also must expand the options available to help women identified as likely to drink.
- > **A staggering number of children are not diagnosed at all, diagnosed late or misdiagnosed.** Minnesota must develop a statewide diagnostic network, and ensure that screening for fetal alcohol syndrome or effects happens in many agencies, programs and settings.
- > **There is a dramatic shortfall in services for those with fetal alcohol syndrome or effects.** Minnesota should fund pilot projects in schools, provide training and support for families of these children and address fetal alcohol syndrome and effects in the justice system.
- > **A child's condition worsens without timely and appropriate help.** Minnesota must evaluate and expand successful efforts to prevent other disabilities (secondary disabilities) that may arise as a result of fetal alcohol syndrome and effects.
- > **Key professions have too little knowledge of fetal alcohol syndrome and effects.** Minnesota must ensure that those who work with affected families have a thorough understanding of these conditions by including fetal alcohol syndrome and effects education in academic training, continuing education and licensing requirements.
- > **Poor coordination hampers prevention, diagnosis and services.** Minnesota needs a state office to coordinate all fetal alcohol syndrome activities and should fund activities through public and private sources.

Government cannot tackle this crisis alone. Collaborative efforts are critical between health care professionals, tribal leaders, teachers, bar owners, law enforcement agencies, parents, caregivers and service providers. The task force calls upon every Minnesotan to take action to prevent prenatal exposure to alcohol and protect Minnesota's children.

IN THEIR OWN WORDS

Don't forget I have brain problems that don't show.

I can't change my brain, but you can help me change stuff around me that causes me to have worse problems.

I can learn if you will teach me hands-on – and if I'm really interested.

I am able to understand with my heart – and I have a good heart.

I want to succeed.

I want to feel good and be able to live a good life.

Love me, just as I am.

SOURCE: ICEBERG,
SEPTEMBER 1997

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A devastating but **A DEVASTATING BUT PREVENTABLE PROBLEM** *preventable problem*

Fetal alcohol syndrome and effects rob children of their full potential and leaves them, their families and their communities with daunting lifelong burdens. Caused by drinking alcohol during pregnancy, the destruction is completely preventable.

To prevent and reduce the harm from alcohol use during pregnancy, Governor Arne H. Carlson created the fetal alcohol syndrome task force in 1997, co-chaired by First Lady Susan Carlson and Hennepin County Juvenile Court Judge Joan Lancaster.

Six of 12 children in one family in our county were diagnosed with fetal alcohol syndrome. All of the children, ranging in age from 4 to 23, have been placed in foster care for periods ranging up to a dozen years. None has graduated from high school and three of the daughters have or are expecting children; one new baby is now in foster care. Excluding medical care, the county has spent about \$800,000 for foster care, mental health and social services, day treatment, specialized care and more. Another \$1.3 million will probably be needed to care for family members still under age 18.

– COUNTY SOCIAL SERVICE PROFESSIONAL

Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome contains the findings and recommendations of the task force. The report looks at how fetal alcohol syndrome affects individuals, their families and their communities, how much it costs, and what can be done to prevent this tragedy.

Suffer the Children is a blueprint for action that can guide the state for years to come. Many of the recommendations will take time to implement and to marshal the necessary financial resources. It is the beginning of a journey that will make a difference to future generations.

FETAL ALCOHOL SYNDROME IS THE LEADING CAUSE OF PREVENTABLE MENTAL RETARDATION

Fetal alcohol syndrome occurs at least three times more often than Down syndrome and almost eight times more often than spina bifida, making it the number one cause of mental retardation and developmental disabilities in Minnesota, as well as the United States, according to the Minnesota Department of Health. The incidence rate of fetal alcohol syndrome in Minnesota is based on a national estimate of 1.9 for every 1,000 live births. Like alcoholism, fetal alcohol syndrome affects people of all social and economic groups.

Children do not outgrow fetal alcohol syndrome or effects. They may have poor impulse control and social skills, problems with memory, attention or judgment. To compound the problem, many children who have fetal alcohol syndrome or effects are not always eligible for special education and vocational education services because their IQ scores often are in the normal range. Even without a diagnosis of fetal alcohol syndrome or effects, many of these children could be eligible for special education services for other reasons, such as learning or behavioral disabilities.

These children often have trouble communicating and getting along with others. They often fail to consider the consequences of their actions. Many have problems that make it difficult for them to function independently as maturing teens and adults. They often are diagnosed as having other disabilities, such as attention deficit or hyperactivity, but treatment approaches for these other conditions are not always successful for children with fetal alcohol syndrome or fetal alcohol effects.

Two of the greatest worries many parents expressed at public hearings across the state were that their children may never be able to live independently or may get into trouble with the law when they reach adolescence because of disabilities from fetal alcohol syndrome and fetal alcohol effects. Confirming this fear, a study by the National Center for State Courts found that boys with learning disabilities, compared to those without, were more likely to become involved in violence, substance abuse and school disruption.

Parenting children with fetal alcohol effects is frustrating, exhausting and discouraging. Yet the system expects parents facing poverty, and drug and alcohol abuse to raise their brain-damaged children. I am convinced that my children would not be alive today if they were raised by their birth family.

**ADOPTIVE MOTHER,
HENNEPIN COUNTY**



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ALCOHOL CAN BE MORE HARMFUL THAN ILLICIT DRUGS

Prenatal alcohol exposure seems to have a more devastating long-lasting effect on the child than other street drugs. It is often difficult to identify the harm caused by illicit drugs because they are frequently taken in combination with alcohol. The following chart describes the destruction that may be caused by various street drugs compared to alcohol.

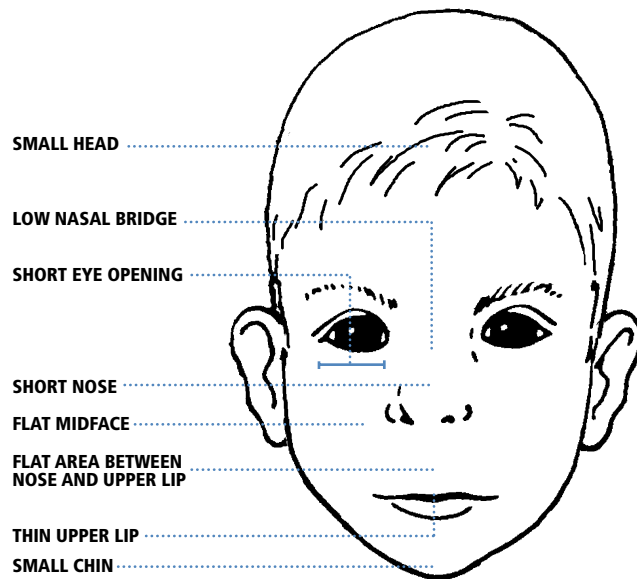
EFFECT	ALCOHOL	MARIJUANA	COCAINE	HEROIN	TOBACCO
LOW BIRTH WEIGHT	X		X	X	X
IMPAIRED GROWTH	X				
FACIAL MALFORMATION	X				
SMALL HEAD SIZE	X				
INTELLECTUAL AND DEVELOPMENTAL DELAYS	X	X			
HYPERACTIVITY, INATTENTION	X	X		X	X
SLEEPING PROBLEMS	X	X	X	X	
POOR FEEDING	X		X		
EXCESSIVE CRYING	X	X	X	X	
HIGHER RISK FOR SUDDEN INFANT DEATH SYNDROME				X	X
ORGAN DAMAGE, BIRTH DEFECTS	X				
RESPIRATORY PROBLEMS	X			X	X

Alcohol destroys cells in the fetus, causing malformations. Problems with daily living skills and academic setbacks resulting from fetal alcohol syndrome and effects continue into adolescence and adulthood. Some effects of cocaine tend to diminish over time, and long-term damage may not be as severe as was originally predicted. Test scores of children exposed to heroin show their physical and psychological development are usually within normal range.

Sources: U.S. Department of Health and Human Services, 1994; Day et al., 1994

FETAL ALCOHOL SYNDROME IS PERMANENT

Children with fetal alcohol syndrome have three characteristics: abnormal facial features, stunted growth and brain injury. Fetal alcohol effects has been used to describe individuals who have a history of prenatal alcohol exposure but not all the physical or behavioral symptoms of fetal alcohol syndrome. Although not all fetal alcohol syndrome symptoms occur in children with fetal alcohol effects, both disabilities are devastating.



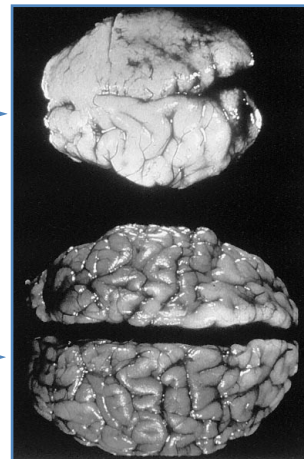
Source: Streissguth et al., 1988

EFFECT OF ALCOHOL ON THE BRAIN

NEWBORN BABY'S BRAIN DAMAGED BY ALCOHOL

- > DECREASED SIZE
- > NOT FULLY DIVIDED INTO LEFT AND RIGHT HEMISPHERES
- > SMOOTH SURFACE AND FEWER FOLDS INDICATE LACK OF DEVELOPMENT

NEWBORN BABY'S NORMAL BRAIN



Source: Dr. Sterling Clarren, University of Washington

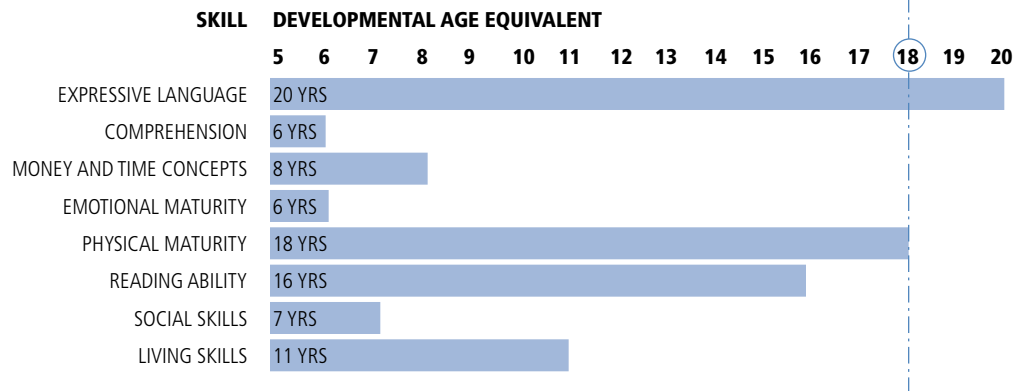
The irreversible damage caused by prenatal alcohol use is, in my opinion, the most significant factor in the cycle of poverty in the inner city.

DR. LYDIA CAROS
PEDIATRICIAN,
MINNEAPOLIS

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AGE AND DEVELOPMENT DIFFER GREATLY FOR PEOPLE WITH FETAL ALCOHOL SYNDROME AND EFFECTS

SKILL LEVELS OF AN INDIVIDUAL WITH A CHRONOLOGICAL AGE OF 18:



Source: Malbin, 1994, Streissguth, Clarren et al.

FETAL ALCOHOL SYNDROME AND EFFECTS CAN LEAD TO MULTIPLE DISABILITIES

Other problems, or secondary disabilities, arise because needs go unmet for children with fetal alcohol syndrome and fetal alcohol effects. Many of these difficulties were described in a 1996 report of more than 400 people, median age of 14, who have fetal alcohol syndrome or fetal alcohol effects.

- > 90 PERCENT HAD MENTAL HEALTH PROBLEMS
- > 80 PERCENT WERE DEPENDENT FOR DAILY NEEDS
- > 80 PERCENT HAD EMPLOYMENT PROBLEMS
- > 60 PERCENT WERE DIAGNOSED WITH ATTENTION DEFICIT DISORDER
- > 60 PERCENT WERE EXPELLED FROM OR DROPPED OUT OF SCHOOL
- > 60 PERCENT HAD TROUBLE WITH THE LAW
- > 50 PERCENT HAD INAPPROPRIATE SEXUAL BEHAVIOR
- > 50 PERCENT WERE CONFINED FOR MENTAL HEALTH REASONS, INCLUDING DRUG OR ALCOHOL TREATMENT, OR AS A CONSEQUENCE OF LAW VIOLATIONS
- > 30 PERCENT HAD ALCOHOL OR DRUG PROBLEMS

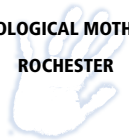
Source: Streissguth et al., 1996

The extent of the tragedy and its costs are unknown

THE EXTENT OF THE TRAGEDY AND ITS COSTS ARE UNKNOWN

My son has fetal alcohol syndrome. He was diagnosed at age 8. I got pregnant between high school and college. I was a social drinker and have never had any problems with alcohol. I did not know I was pregnant until I was three-and-a-half months along. I stopped drinking then, but it was too late. The damage was done. Though I did not set out to harm my child, I did, and now I need to do whatever I can to make things easier for him.

**BIOLOGICAL MOTHER,
ROCHESTER**



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Reliable numbers simply do not exist about the extent and cost of fetal alcohol syndrome and fetal alcohol effects. Numbers currently used are only estimates at best.

Fetal alcohol syndrome is difficult to diagnose in newborns. The facial characteristics are not always recognized, behavioral problems often cannot be determined until a few years after birth, and children with mental retardation have a fairly high postnatal mortality rate. Consequently, estimates of the prevalence of fetal alcohol syndrome, as well as fetal alcohol effects, are likely to be conservative.

A previous report has put the number of Minnesota babies born with fetal alcohol syndrome and effects at 268 to 804 out of about 67,000 total in 1993, but far more than that number are exposed to alcohol in the womb. Various reports say fetal alcohol effects could be two to 10 times higher than fetal alcohol syndrome. A 1989 Human Services survey of 1,639 pregnant women found that 41 percent of those age 18 to 40 drank at least once during their pregnancy. Based on this information, 27,000 Minnesota babies each year would have some prenatal alcohol exposure.

FREQUENT DRINKING IS HIGH IN MINNESOTA

Alcohol is one of the most widely used drugs in the state, says the U.S. Department of Health and Human Services. Alcohol's popularity has given Minnesota the dubious distinction of being home to the fourth highest rate in the nation for frequent drinking among women of childbearing age. A 1995 national survey found that almost 18 percent of Minnesota women of childbearing age (18 to 44 years old) said that in the previous month, they drank alcohol frequently – a rate defined as more than 30 drinks in one month or five or more drinks at any one time.

MINNESOTA RANKS FOURTH HIGHEST IN DRINKING BY WOMEN OF CHILD-BEARING AGE, 1995

RANK	STATE	PERCENTAGE OF WOMEN WHO CONSUME MORE THAN 30 DRINKS MONTHLY OR FIVE OR MORE DRINKS AT ONE TIME
1	WISCONSIN	19.4%
2	IOWA	18.9%
3	PENNSYLVANIA	18.8%
4	MINNESOTA	17.6%
5	NEVADA	17.5%
46	MARYLAND	5.8%
47	NORTH CAROLINA	5.6%
48	WEST VIRGINIA	5.3%
49	KENTUCKY	5.2%
50	TENNESSEE	4.0%

Source: Centers for Disease Control

The U.S. Surgeon General has stated that there is no known safe level of alcohol consumption during pregnancy. Social drinking increases the risk of subtle and lifelong brain damage, but binge drinking (five or more drinks at one time) causes the most devastating effects. Based on animal studies by Maier and colleagues, greater damage, including smaller brain size, can occur to fetuses exposed to binge drinking.

The women most likely to report having alcohol problems are under age 35, and the vast majority of pregnancies occur between age 20 and 34. In 1991, 80 percent of all Minnesota pregnancies occurred in women between age 20 and 34. Approximately 11 percent of this group had alcohol-related problems or dependency. A 1995 school survey found that in the month preceding the survey 17 percent of the ninth-grade girls and 35 percent of the girls in 12th grade consumed four or more drinks at one time.

Women who have delivered one child with fetal alcohol syndrome are at greater risk for delivering another child with the syndrome. A national expert, Ernest Abel, estimates the risk at 70 percent. Within a family, younger siblings have a much higher incidence rate of fetal alcohol syndrome than their older brothers and sisters.

COSTS ARE ESTIMATED IN THE MILLIONS

Fetal alcohol syndrome costs Minnesotans millions of dollars each year in health care and support services for its victims. At task force hearings, child welfare workers consistently maintained that a significant number of children in child protection have fetal alcohol effects. Many of these children end up in foster care, residential treatment, correctional and other out-of-home placements. Added to those costs are the hidden administrative expenses of court, social services and health agencies. The high costs in fetal alcohol syndrome and fetal alcohol effects are believed to be related to a substantial portion of the money spent for the following services:

- > In the 1995-96 school year, Minnesota spent about \$700 million on special education services, including all disabilities, for almost 101,000 children ranging in age from birth to 21. Of this total, \$130 million was spent for about 17,000 children with emotional and behavioral disorders.
- > At least \$59 million is spent annually to place delinquent youth in residential correctional facilities and \$160 million to incarcerate adults.
- > About \$164 million each year goes for out-of-home placements for about 17,500 children. According to a Hennepin County report, 90 percent of the county's child protection case openings over a six-week period involved a history of alcohol or substance abuse in the family.
- > Chemical dependency treatment programs cost Minnesota more than \$40 million in 1996.
- > The cost of services for people with mental retardation, including family support, semi-independent living, training, case management and residential care, was about \$478 million in 1996.

Minnesota has many pressing needs for reducing the hardship and cost of fetal alcohol syndrome and fetal alcohol effects. There are also many promising ideas for meeting many of these needs. These findings and recommendations set out the highest priorities for addressing fetal alcohol syndrome and fetal alcohol effects in Minnesota.

FINDING: Low public awareness impedes prevention efforts.

Education efforts to prevent fetal alcohol syndrome have not been widespread or ongoing. A 1994-1995 media campaign to raise awareness of the dangers of drinking during pregnancy has suffered from inconsistent funding. Minnesota must increase public understanding of how fetal alcohol syndrome and effects occur.

RECOMMENDATIONS

- > Establish ongoing statewide and local public awareness campaigns. Use positive messages that appeal to both males and females and reach those of all cultural backgrounds. Include an evaluation component.
- > Establish and publicize a central source of information on fetal alcohol syndrome and fetal alcohol effects. Services would include a toll-free help line for information and referrals, along with information packets that cover diagnosis, services, and a directory of services, diagnosticians and speakers. It would serve families, professionals and the general public.
- > Encourage businesses to offer their employees incentives for healthy pregnancies, to increase awareness of fetal alcohol syndrome and fetal alcohol effects and to encourage chemical dependency screening, referral and counseling. Work with the Minnesota Business Partnership and Minnesota Chamber of Commerce to promote these concepts.
- > Work with nonprofit, civic, religious and service groups on awareness and prevention education.
- > Include prevention messages about drinking during pregnancy in school-based drug and alcohol awareness programs and in sex education and parenting classes. Make this a requirement for programs seeking state and federal funds.
- > Fund research to better understand fetal alcohol syndrome and effects.

EMPLOYER SUPPORTS HEALTHY PREGNANCIES

The Marvin Windows and Doors company encourages expectant mothers to give their babies a good start in life. The company's Perfectly Pregnant program offers free prenatal training and contracts with pregnant employees to stay healthy, keep regular doctor appointments and abstain from alcohol. As an added incentive, employees who have complied with the contract receive \$400 to apply toward health care bills. In addition, the company pays for any unusual complications not covered by health insurance.

This is a health issue that is totally preventable. The primary focus should be on community awareness as a whole, not simply on the individual. Community attitude and support are key.

**PUBLIC HEALTH NURSE,
COON RAPIDS**

**SUFFER THE
CHILDREN:
THE
PREVENTABLE
TRAGEDY OF
FETAL ALCOHOL
SYNDROME**

FINDING: A lack of solid data masks the full costs and extent of fetal alcohol syndrome and fetal alcohol effects.

Only rough estimates are available on the number of children born each year who are affected by alcohol exposure in the womb. Although experts in the field are convinced the problem is large and costly, no solid information exists on the extent of the problem. Without such a baseline, it is difficult to identify the full impact of the problem or measure progress in prevention and treatment. The lack of solid data arises in part from the absence of uniform and widespread screening for fetal alcohol syndrome. Minnesota must document the extent and impact, including costs, of fetal alcohol syndrome and fetal alcohol effects.

RECOMMENDATIONS

- > Conduct statewide research to reliably estimate the incidence of new cases and the total number of Minnesotans with fetal alcohol syndrome or fetal alcohol effects.
- > Estimate the monetary cost of fetal alcohol syndrome and fetal alcohol effects in Minnesota and make this information known to the Legislature, state agencies and other organizations.

FINDING: High-impact advertising of alcoholic beverages overshadows public messages about responsible drinking.

Advertising alcoholic beverages significantly increases consumption. On the other hand, high-profile advertising that points out the consequences of irresponsible drinking has also been effective, such as media campaigns against drunk driving. Minnesota must support high-impact advertising aimed at responsible drinking to offset heavy commercial promotion of alcohol use.

RECOMMENDATIONS

- > Involve the alcohol beverage industry in public awareness campaigns and education about the dangers of alcohol use during pregnancy.
- > Make sure the prevention message is clearly displayed wherever alcohol is served. Develop higher-impact warning signs that appeal to both males and females and make them available in several languages. Regularly check bars to make sure they post the signs, and fine those that do not comply. Require warning messages in menus at restaurants that serve alcohol.
- > Provide a model ordinance and technical support for communities to restrict the number and location of alcohol-related billboards. Baltimore has successfully used such an ordinance.

Public information campaigns should not just target female adolescents, but also the males. Creativity and humor should be used in the ads.

CITIZEN, FERGUS FALLS

It is important to work with the media and raise awareness about alcohol consumption and its consequences.

CITIZEN, MANKATO

SAMPLE MODEL ORDINANCE RESTRICTING ALCOHOL BILLBOARDS

Minnesota law and municipal code make it unlawful for any person under the age of 21 to purchase or consume alcoholic beverages. Outdoor advertisements are a unique and distinguishable medium of advertising that subjects the general public to involuntary and unavoidable forms of solicitation. For these reasons, an ordinance restricting the placement of outdoor signs and billboards advertising alcoholic beverages will take effect on [fill in date].

No outdoor sign or billboard advertising alcoholic beverages shall be placed within 1,000 feet of any school, day care center, playground or other area where children are present. Furthermore, no outdoor sign or billboard advertising alcoholic beverages may be placed in an area where the content of advertisement may be viewed by children attending any school, day care center or playground.

One of the things that would have helped me when I was pregnant, or even as a teenager, was treatment.

MOTHER, ROCHESTER

Primary care providers need to make clear statements about no alcohol use before conception and during pregnancy.

PUBLIC HEALTH NURSE,

DULUTH

FINDING: Too little is done to identify, warn and help women who are likely to drink during pregnancy.

Many physicians do not routinely screen women for alcohol use during pregnancy. Nor do women always receive from their doctors or nurses the message that alcohol use during pregnancy can harm their baby. Some even hear that it is all right to drink in moderation during pregnancy. Women who do not receive any prenatal care are the most difficult to reach with a prevention message.

Minnesota must systematically screen for alcohol use and abuse during pregnancy and must have effective treatment options for women who are likely to drink during pregnancy. Only two halfway houses are available in the state for women who want to bring their children with them to treatment, and the waiting list ranges from one to six weeks.

RECOMMENDATIONS

- > Train health care professionals to routinely screen for alcohol use during pregnancy. Child protection workers, social workers, correctional officers and people in other related professions should be trained to look for signs of alcohol use during pregnancy and to provide referrals for treatment.
- > Expand maternal-child substance abuse projects, such as those now in place in Hennepin and Ramsey counties, to make them available statewide.
- > Develop a specialized chemical dependency treatment program for pregnant women who may themselves have fetal alcohol syndrome or fetal alcohol effects.
- > Create a model program to prevent additional births of children with fetal alcohol syndrome or fetal alcohol effects to women who already have such a child.

**SUFFER THE
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- > Fund a statewide program to help women who are at the highest risk of abusing alcohol or of having additional children with fetal alcohol syndrome or fetal alcohol effects. Seattle’s Birth to 3 Project could serve as a model.
- > Require children’s mental health programs, family service collaboratives, early childhood screening and other similar programs to provide prevention education about the risk of drinking during pregnancy.
- > Develop and support coordinated efforts among public health nurses, community health agencies, managed health care providers and social services to identify and help women likely to drink while pregnant.
- > Direct the Department of Human Services to develop a long-range plan to provide chemical dependency treatment services statewide to pregnant women.
- > Expand the number and capacity of programs offering comprehensive services (counseling, family planning, parenting skills and support groups) to help women stop drinking during pregnancy, as well as the number of inpatient and outpatient treatment centers and halfway houses serving pregnant women and women with children.
- > Change chemical dependency assessment criteria so that the use of alcohol during pregnancy is a qualifying factor for admission to treatment.
- > Develop a mandatory reporting process for referring a pregnant woman to chemical use screening and assessment.
- > Expand the Civil Commitment Act to allow for a pregnant woman unable to stop abusing alcohol to be placed in the least restrictive alternative necessary to receive appropriate treatment. Revise the definition of “chemically dependent person” to include a pregnant woman who has engaged in acts of alcohol abuse (as defined in the proposal for mandatory reporting). Include an evaluation component in any legislation implementing this expansion of the Civil Commitment Act.

INDIAN HEALTH BOARD CLINIC OFFERS SCREENING MODEL

Prevention is the ultimate goal of the Indian Health Board Clinic, which since 1989 has offered a comprehensive program to deal with fetal alcohol syndrome. Serving Minneapolis patients, 80 percent of whom are Native American women and children, the family practice clinic provides prenatal care, postpartum support services, pediatric care and fetal alcohol syndrome assessments.

Clinicians use questionnaires, assessments and care plans to treat chemically dependent women in the clinic setting. “We are much more effective with the identification of the problem than with our main goal, which is prevention,” writes Dr. Lydia Caros, of the Indian Health Board.

Source: The Provider, December 1993

Women who can't make a choice to stop should be forced to stop, and when that should occur is a decision to be made by the medical community. I think it would be good to add alcohol to the civil commitment law.

MOTHER OF A CHILD WITH FETAL ALCOHOL EFFECTS, MINNEAPOLIS

The need for diagnosis is important, especially for people when they are older, so that they can understand why they are experiencing life differently. It is also important in helping parents know how to best care for their child.



**SUFFER THE
CHILDREN:
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PREVENTABLE
TRAGEDY OF
FETAL ALCOHOL
SYNDROME**

MATERNAL CHILD SUBSTANCE ABUSE PROJECTS PROPOSED FOR MINNESOTA

Improving the well-being of substance-abusing women and their babies is the goal of 30 proposed statewide projects, including follow-up support to women referred to local county welfare agencies or reservations. Project workers would provide:

- > *Coordination of health services*
- > *Outreach and education to medical personnel*
- > *Basic client outreach and intervention*
- > *Consultation services for treatment programs*
- > *Basic needs that are not covered under other assistance programs*

Source: Minnesota Department of Human Services

SEATTLE'S INTERVENTION EFFORTS SUCCEED

Seattle's Birth to 3 project has had remarkable success with mothers who are chronic substance abusers. The program's paraprofessionals establish intensive relationships with clients, their families and neighbors. Paraprofessionals also coordinate services, define client responsibilities and teach basic life skills. After two years, 80 percent of the clients received treatment, almost half abstained from alcohol and drugs for six months or more, and 61 percent used birth control measures. The program costs \$3,800 annually per client.

Source: Grant et al., 1996

A PROPOSAL FOR MANDATORY REPORTING OF ALCOHOL USE DURING PREGNANCY

Under a mandatory reporting process, a woman would first have the chance to voluntarily receive treatment before involving her in the legal system.

A woman would be considered to be abusing alcohol during pregnancy if she meets one of the following conditions:

- > *requires detoxification during pregnancy*
- > *habitually consumes three or more drinks at one time since knowing of the pregnancy*
- > *refuses to stop excessive drinking during pregnancy*
- > *appears intoxicated based on two or more of the following indicators: odor of alcohol; slurred speech; disconjugate gaze (eyes do not track together); impaired balance; difficulty remaining awake; consumption of alcohol; responding to sights or sounds that are not actually present; or extreme restlessness, fast speech or unusual belligerence.*

If a pregnant woman failed to follow the recommendations made at the assessment, a report would be made to the local welfare agency or maternal-child substance abuse project. If the chemical use assessment indicated that the woman needed treatment, the local welfare agency would arrange for appropriate treatment. If the woman continued to abuse alcohol and did not comply with treatment recommendations, the local welfare agency could take action including referral for emergency admission to a treatment facility.

Legislation implementing this mandatory reporting process for Minnesota should not take effect before August 1, 1999, so that more chemical dependency treatment services for pregnant women can be developed and made available statewide. The legislation should include training for professionals required to do this kind of reporting and should include an evaluation of the new process.

FINDING: A staggering number of children with fetal alcohol syndrome or fetal alcohol effects are not diagnosed at all, diagnosed late or misdiagnosed.

There is a general lack of training about fetal alcohol syndrome and effects. Many family physicians and pediatricians do not understand the importance of an early diagnosis. Physicians may be reluctant to make a diagnosis for several reasons, including perceived difficulties in making an accurate diagnosis, the potential stigma attached to the diagnosis and the perception that the diagnosis will not necessarily lead to effective treatment options. Some also question the adequacy of current screening and diagnostic methods, especially those for fetal alcohol effects.

Systematic screening is vital for ensuring that children get the help they need and for a better grasp of the extent of the problem. Minnesota needs a system of clinics and diagnosticians who are able to correctly identify fetal alcohol syndrome and fetal alcohol effects.

RECOMMENDATIONS

- > Develop a statewide diagnostic clinic network through the University of Minnesota, the Mayo Clinic and the Minnesota Children with Special Health Needs program at the Department of Health. This network should be accessible to rural areas and should coordinate services and information among screening programs, diagnosticians, clinics and other centers.
- > Ensure that comprehensive screening for fetal alcohol syndrome and fetal alcohol effects includes all age groups and is done by many agencies, as well as in hospitals and outpatient programs. The screening should include behavior and thought processes characteristic of fetal alcohol syndrome and fetal alcohol effects. Provide training to many agencies and health care programs on how to screen children and refer them for needed services. Incorporate this screening into early childhood and special education screening.

- > Require screening of children the court has found in need of child protection or services, when there is evidence of chemical dependency problems in the biological mother. Also require screening of any other person named in the petition for whom chemical dependency problems are alleged.
- > Include fetal alcohol syndrome and effects screening as part of the chemical dependency assessment process.
- > Work to have definitions of fetal alcohol syndrome and fetal alcohol effects included in important diagnostic codes such as the *Diagnostic and Statistical Manual of Mental Disorders* and the *International Classification of Diseases*, which are used by physicians, psychologists, social workers and others.
- > Integrate diagnostic protocols and clinical experience related to fetal alcohol exposure into the academic training of physicians and nurses. Provide continuing medical education statewide on screening and diagnosis.
- > Raise awareness in the health care profession of the link between early, accurate diagnosis and access to services that can improve outcomes.
- > Fund research on methods to quantify the central nervous system impairments associated with fetal alcohol exposure in order to develop clinical diagnostic tools for the intellectual and behavioral problems associated with fetal alcohol syndrome and fetal alcohol effects.

I have educated many professionals about fetal alcohol syndrome. One of my frustrations has been the tendency of professionals to discount what I as a parent think is best for my child.



NETWORK OF DIAGNOSTIC CENTERS PROPOSED

Early diagnosis of the fetal alcohol syndrome and effects may lead to better understanding by the children afflicted, their families and providers. Diagnosis can help children gain early access to services which, in turn, can help them lead more productive lives. This concept inspired the proposal of a diagnostic network for children affected by prenatal exposure to alcohol. By combining resources of the University of Minnesota and the Minnesota Department of Health, at least seven existing centers will provide standardized, specialized assessment to children and families throughout the state. A network in Washington state will serve as a model for Minnesota.

Source: University of Minnesota

Children with fetal alcohol syndrome and effects are lovable, but they have unbearable problems. They do not have good reasoning skills, are quick to anger, and have low self-esteem resulting in problems at school. The emotional drain on parents is overwhelming.
PARENT, CROOKSTON

Teachers in upper grades are not as aware of what to do with children who are affected, especially the ones who are not diagnosed or misdiagnosed. They do not understand why these children are forgetful, can't do abstract thinking, etc. Teachers need to understand that these children learn differently, and they may need to design a different type of classroom. Teacher training is needed.
ADOPTIVE MOTHER, MANKATO

**SUFFER THE
CHILDREN:
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SYNDROME**

FINDING: There is a dramatic shortfall of services to meet the complex needs of those with fetal alcohol syndrome or fetal alcohol effects.

Because the characteristics of children with fetal alcohol syndrome and fetal alcohol effects are not well understood, it is not always clear how to intervene and provide the right services for each child. The children may not qualify for services because their condition does not meet the criteria, or they may be misdiagnosed and given services that do not match their needs. A child's IQ may be too high to qualify for services even though the child may desperately need the service. Many parents of children with fetal alcohol syndrome or fetal alcohol effects say that special education services are not geared to their children. The difficulties caused by fetal exposure to alcohol may include lower intelligence, learning disabilities, inappropriate behaviors, speech and language delays, poor eating and sleeping patterns, and delays in developmental milestones, such as learning to roll over, sit up and walk. Hyperactivity, as well as severe vision or hearing problems, often compound the learning difficulties of these children. Other consequences for children with fetal alcohol syndrome or effects include serious difficulty solving problems, controlling behavior, using learned information and understanding abstract concepts.

Minnesota must address the specific needs of children with fetal alcohol syndrome and fetal alcohol effects. The large number of recommendations in this area reflects the overwhelming public outcry for appropriate services for these children.

RECOMMENDATIONS

- > Fund pilot projects in several school districts to develop "best practices" for educating children and youth with fetal alcohol syndrome or effects. Provide funding for educational programs designed specifically for children with fetal alcohol syndrome or effects. Expand classroom assistance, including classroom aides to assist such children.
- > Study extending eligibility through age 18 for the federally funded services that give states money to help infants and toddlers with disabilities. Revise eligibility criteria to include children with fetal alcohol syndrome and fetal alcohol effects. Investigate the possibility of including diagnoses associated with prenatal alcohol exposure.
- > Obtain funding from the Legislature for pilot projects that build on effective local initiatives, combine several funding sources and provide a continuum of services for those with fetal alcohol syndrome or fetal alcohol effects and their families. Give priority to projects that include pregnant women and women who have a child with fetal alcohol syndrome or effects. Require evaluation of pilot projects.
- > Explore requiring adoption or foster care agencies to fully disclose records of prenatal care, the birth mother's alcohol or drug use and the child's assessment for fetal alcohol syndrome, fetal alcohol effects or drug-related prenatal damage. Examine the feasibility of conducting a comprehensive fetal alcohol syndrome and effects evaluation in all adoptions.
- > Offer training to all people raising children with fetal alcohol syndrome or effects, including out-of-home care providers such as foster homes, group homes and child care providers.
- > Require fetal alcohol syndrome and effects education in child protection case plans where the child or the care giver has been diagnosed with fetal alcohol syndrome or fetal alcohol effects.

- > Provide respite care for parents of a child with fetal alcohol syndrome or effects.
- > Establish group homes for children and adults with fetal alcohol syndrome or effects whose families cannot care for them and who cannot live independently.
- > As children near adulthood, provide transitional services such as housing assistance, vocational training and placement, and medication monitoring. Mentors could come through the justice system, schools, clinics, shelters and other sites. Develop school-to-work transition programs for teenagers with fetal alcohol syndrome or fetal alcohol effects to prepare them for appropriate long-term employment. Create partnerships with employers to provide apprenticeships or job training specifically for people with fetal alcohol syndrome or fetal alcohol effects. Encourage schools to teach independent living skills to teenagers with fetal alcohol syndrome or effects.
- > Fund a model long-term residential job training program for youth and adults with fetal alcohol syndrome or effects.
- > Provide training and support to family services programs, children's mental health programs, Interagency Early Childhood Intervention teams and other local efforts so they can better address the needs of children with fetal alcohol syndrome or effects.
- > Train youth and adults with fetal alcohol syndrome and effects to be their own advocates. Encourage communities to recruit and train volunteer advocates for people with fetal alcohol syndrome or effects.
- > Work through school-based clinics to provide early assessment, counseling and referral services to youth with fetal alcohol syndrome or fetal alcohol effects before they are placed in alternative school programs or referred to the courts for truancy.
- > Recruit and train volunteer mentors for teenagers with fetal alcohol syndrome or effects.
- > Provide summer activity and enrichment programs designed for youth with fetal alcohol syndrome or effects to develop their skills in areas of strength, including theater, music, visual arts, individual sports and computers.
- > Review delinquency and child protection laws to determine the feasibility of allowing the court to order family intervention where it deems appropriate.
- > Establish a juvenile assessment center in each judicial district to provide central intake and comprehensive assessment of all youth entering the juvenile corrections system. Direct judicial districts to follow up on juveniles who are identified as having fetal alcohol syndrome or fetal alcohol effects, so that the effectiveness of different strategies and approaches can be evaluated. Conduct preliminary screening for fetal alcohol syndrome and fetal alcohol effects at a person's first entry into the court system. Refer for diagnosis those suspected of having fetal alcohol syndrome or effects. The intake interview should establish the family's history of alcohol use and identify signs of learning and behavior problems, growth deficiency or birth defects.
- > Develop a diversionary program for first-time offenders who are identified as having fetal alcohol syndrome or fetal alcohol effects. Link these youth with trained advocates or mentors.
- > Conduct fetal alcohol syndrome and effects screening of adult and juvenile inmates in state correctional facilities. Use the screening to improve chemical dependency treatment and the transition of inmates into communities.

Medical personnel should receive intensive training and help with learning how to screen for fetal alcohol syndrome and effects.

**PUBLIC HEALTH NURSE,
DULUTH**

There should be mandatory training for education, health, justice, and other professionals.

**DRUG EDUCATION
INSTRUCTOR, DULUTH**

**SUFFER THE
CHILDREN:
THE
PREVENTABLE
TRAGEDY OF
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SYNDROME**

FINDING: A child's condition worsens without timely help for the problems associated with fetal alcohol syndrome or fetal alcohol effects.

When children with fetal alcohol syndrome and effects are not diagnosed, they are often misunderstood and not dealt with properly, which then can lead to secondary disabilities. Secondary disabilities are problems that develop when a child's special needs are not met. With fetal alcohol syndrome and fetal alcohol effects, secondary disabilities can include mental health problems, trouble with the law, problems in school and inability to manage money or live independently. These problems create additional burdens for those with fetal alcohol syndrome or effects and their families.

Behaviors associated with fetal alcohol syndrome or effects can seem willful. The standard approach has been to change the child rather than change the environment to better meet the child's needs. For example, punishing the child for not being able to remember what he or she was told to do yesterday. Over time, children develop defensive behaviors as a result of being punished for their disability, and secondary disabilities continue to increase. Minnesota must support efforts to prevent secondary disabilities in children with fetal alcohol syndrome and fetal alcohol effects.

RECOMMENDATIONS

- > Evaluate current efforts to prevent secondary disabilities and expand successful strategies through public and private agencies and organizations.
- > Develop effective substance abuse prevention tactics for children with fetal alcohol syndrome or fetal alcohol effects.

FINDING: Professionals in key fields have too little knowledge of fetal alcohol syndrome and fetal alcohol effects.

For the most part, professionals such as physicians, psychologists, teachers, school administrators, judges, county attorneys, public defenders, probation officers and social workers are poorly informed about fetal alcohol syndrome and fetal alcohol effects. A Department of Health survey of health care providers also found a need for more training and education.

Minnesota must ensure that all professionals who work with pregnant women and children with fetal alcohol syndrome or effects receive adequate education about these conditions and the successful methods for helping these women and children. Those who design programs serving individuals affected by fetal alcohol exposure should also have thorough, current knowledge of the fetal alcohol syndrome and effects.

RECOMMENDATIONS

- > Train professionals and government employees who work with people who have fetal alcohol syndrome or effects, or who design programs that serve these people. Key professions include health care, social services, chemical dependency, education, justice, law enforcement, corrections, mental health and child care. Employers, employee assistance counselors and human resources personnel should also learn how to work with individuals who have fetal alcohol syndrome or fetal alcohol effects.
- > Make fetal alcohol syndrome and effects training a continuing education requirement for licensing in key professions, including all that deal with chemical dependency.
- > Expand substance abuse education, including education on fetal alcohol syndrome and fetal alcohol effects, in medical schools and nursing schools.
- > Make staff education on fetal alcohol syndrome and effects a state licensing requirement for facilities that serve people with fetal alcohol syndrome or effects. Also require staff education at facilities and programs that contract with the state.
- > Review the adequacy of education in key professions and determine whether students in these fields are adequately prepared to deal with fetal alcohol syndrome and fetal alcohol effects.

FINDING: Lack of coordination hampers prevention, diagnosis and services.

Many children with fetal alcohol syndrome or fetal alcohol effects receive services from several public and private systems, including health, social services, child protection, education and juvenile corrections. Better collaboration and communication among professionals and programs in these fields would result in better services for families and better outcomes for children. Minnesota must coordinate statewide efforts and funding for prevention, diagnosis and services related to fetal alcohol syndrome and fetal alcohol effects.

There has to be an integration of all the sectors of the service delivery systems so that we are all on the same path.

DIRECTOR, COMMUNITY SERVICES, ROCHESTER



RECOMMENDATIONS

- > Create a state board, using state and private funding, to coordinate fetal alcohol syndrome activities. This office would manage a statewide public awareness campaign, assist local initiatives, create and maintain a World Wide Web site and implement other recommendations of the Governor's Task Force on Fetal Alcohol Syndrome. Require the office to prepare periodic reports to the Governor and the Legislature about its activities and results, and the status of fetal alcohol syndrome and fetal alcohol effects in Minnesota.
- > Explore creating a college- or university-based institute on fetal alcohol syndrome and fetal alcohol effects.
- > Provide resources to support and expand community coalitions that deal with fetal alcohol syndrome and fetal alcohol effects or assist children and families in dealing with the condition.
- > Establish a surcharge on all alcohol-related court fines, with proceeds designated to fund prevention and education on fetal alcohol syndrome and fetal alcohol effects. Create a dedicated account within the Children's Trust Fund for fetal alcohol syndrome and effects activities. Establish a tax return check-off option for children's services, using a portion of the revenues for prevention and intervention activities.

SUFFER THE CHILDREN: THE PREVENTABLE TRAGEDY OF FETAL ALCOHOL SYNDROME

VOICES FROM THE FRONT LINES

Minnesotans who see firsthand the hardships caused by fetal alcohol syndrome or effects – at home or in their work – share many common experiences and insights. Yet each community and family has a unique story, giving rise to many different thoughts on how best to prevent and treat this lifelong burden.

To hear some of those stories and insights, the Governor’s Task Force on Fetal Alcohol Syndrome held public meetings in nine Minnesota communities during October and November 1997.

“I’m here today asking for help,” said one participant, a teacher overwhelmed by the needs at her small rural school serving many students with fetal alcohol syndrome or effects.

Her plea was echoed by dozens of others who testified of unmet needs, low awareness and misconceptions. Participants also shared examples of work that is making a difference for children and families.

Along with the concerns and needs unique to each local situation, common themes emerged across the state. Concerns focused not just on children but also on pregnant women and families, caregivers and service providers.

AMONG SPECIFIC CONCERNS WERE THESE:

- > Women often stop using alcohol during pregnancy but not until they know they are pregnant. Referral for chronic alcohol use often happens late in pregnancy.
- > Women who want to stop drinking during pregnancy must have immediate and thorough support.
- > Prenatal intervention should not be punitive. A judgmental attitude will sabotage prevention and treatment.
- > Many women with alcohol problems move frequently, making it difficult to follow through with services.
- > Transportation and childcare are barriers for women seeking help. Many alcohol treatment centers are too far away for a successful transition after treatment.
- > Prevention efforts must not overlook males, middle- and high-income people, and children as young as preschoolers.
- > The cost to local governments is high, especially in larger counties.
- > Fetal alcohol syndrome is often part of a package of other serious problems such as abuse, depression and poor nutrition.
- > Many children with fetal alcohol syndrome or effects have IQ levels too high to qualify for services they need.
- > Fetal alcohol syndrome is easy to see, but fetal alcohol effects is not.

- > Services for children with fetal alcohol syndrome or effects are better in early childhood than during their school years, when the focus of public services shifts from health and development to educational ability.
- > Labeling children may add to their shame, guilt and anger.
- > Some children are the third generation of fetal alcohol syndrome or effects.
- > Many children and youth in foster care and group homes have been affected by alcohol.
- > Children with fetal alcohol syndrome are more likely to have contact with child protection, legal and corrections systems.
- > Teen drinking and teen pregnancy are closely related and on the rise, according to public health workers.
- > The chemical dependency field and legal system need a better understanding of fetal alcohol syndrome. Public awareness is also low.
- > Mandatory reporting covers illicit drugs but not alcohol. Yet alcohol use is more common and more damaging during pregnancy. Physicians may be hesitant to report suspected alcohol use because of concerns about data privacy or damaging their relationship with patients. Child protection workers have no legal authority to report alcohol abuse by pregnant women.
- > Knowing about all available resources is a critical, unmet need for families and professionals.

Agencies need to see fetal alcohol syndrome and effects as the underlying cause of many problems. There isn't much contact between social services and public health.

CITIZEN, DULUTH

There are problems with accessibility of [chemical dependency] services, especially in rural areas, for women with children.

**OBSTETRIC NURSE,
WILLMAR**

NEEDS RAN THE GAMUT FROM PREVENTION AND AWARENESS, TO SUPPORT SERVICES, TRAINING AND FUNDING. MANY IDEAS ADDRESS THE CONCERNS DESCRIBED ABOVE.

- > Early, accurate diagnosis and reliable standards for assessment
- > Local prevention, treatment and training to meet certain needs, along with other training through state, regional and national resources
- > Ongoing support and reliable information for those who care for, teach or otherwise serve children with fetal alcohol syndrome or effects
- > Immediate, thorough support for pregnant women who want to stop drinking, with forced commitment to a treatment program for women who cannot stop drinking during pregnancy as a last resort
- > Long-term support groups and respite services for birth, adoptive and foster parents who are raising children with the syndrome or effects, especially teenage or adult children
- > Outreach clinics and better access to resources and experts, especially in rural areas
- > Follow-up care for teenagers after alcohol treatment

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- > Child care and transportation for women seeking treatment for alcohol, along with chemical dependency treatment programs that allow women to bring their children and include training in parenting, relationships and life skills
- > Solutions that keep families intact
- > Inclusion of both fetal alcohol syndrome and effects among the developmental disabilities listed in state law
- > A consistent and clear prevention message repeated in many creative ways to different audiences
- > Use peers for prevention training
- > Inclusion of fetal alcohol syndrome or effects information in sex education classes
- > A media campaign emphasizing it is not "cool" to drink
- > Efforts from the liquor industry that go beyond the required warning labels, such as a percentage of liquor sales designated for prevention work
- > Involvement of local government, reservation leaders and bar owners
- > More emphasis on fetal alcohol effects
- > Better collaboration between social services, public health nurses and child protection
- > Advanced training and curriculums for health professionals and preschool, elementary and special education teachers
- > Training for law enforcement and corrections personnel, along with juvenile justice practices that lead to immediate consequences rather than long-term involvement with the system
- > Long-term assisted living or transitional help for people with fetal alcohol syndrome or effects as they reach adulthood
- > Incentives and rewards for women who participate in prevention programs before and during pregnancy
- > Statewide coordination and health insurance coverage for prenatal intervention and treatment services
- > More funding for preventing unplanned pregnancies
- > Funding for research on the most effective actions to take after diagnosis
- > Grants that require collaboration among agencies

ACTION STEPS FOR PROFESSIONALS

Many skills are needed to prevent fetal alcohol syndrome and fetal alcohol effects. The task force on fetal alcohol syndrome compiled these action steps that may be taken by professionals in a variety of fields.

PROFESSIONALS	ACTION STEPS
PHYSICIANS AND NURSES	<ul style="list-style-type: none">> Be diligent in asking about alcohol use by both biological parents. Use a screening tool to identify women who drink during pregnancy.> Participate in efforts to improve the identification of chemically dependent women and the provision of treatment for them.> Work to incorporate fetal alcohol syndrome information into basic academic curriculums.> Discuss family planning with women who are of childbearing age and use alcohol.> Be more aware of fetal alcohol syndrome and effects and learn to recognize the signs early on. Become knowledgeable about prevention, intervention and assistance resources.> Caution mothers to abstain from alcohol when they are nursing.> Educate practitioners who work with families, children and women via continuing education programs.> Make public statements through professional associations and newsletters that define fetal alcohol syndrome as a social problem of significant proportion that calls for heightened awareness and action.
HEALTH CARE PLAN PROVIDERS	<ul style="list-style-type: none">> Promote and facilitate education and training on fetal alcohol syndrome for physicians and other health care providers. Offer continuing education classes and develop videos to train staff in local health care clinics.> Help develop and promote the adoption of best practices for treating pregnant women for chemical dependency. Provide sample questionnaires and assessment tools along with training.> Help gather and analyze data on the incidence and costs.> Participate in broad-based public education efforts.> Help seek political and legislative support and funding for fetal alcohol syndrome programs.
SCHOOL BOARDS AND EDUCATION PROFESSIONALS	<ul style="list-style-type: none">> Screen school children for prenatal exposure to alcohol and other drugs.> Develop plans, including an information campaign, to help children with fetal alcohol syndrome and their teachers.

PROFESSIONALS

ACTION STEPS

*School boards and
education professionals (cont.)*

- > Provide educational opportunities for district personnel.
- > Work cooperatively with other agencies and inform school staff about referral procedures.
- > Establish a fetal alcohol syndrome task force, resource center and support team.
- > Create a mentor program for children with fetal alcohol syndrome or effects.

TEACHERS

- > In the classroom, maintain a calm, structured and orderly environment.
- > Establish clear, consistent rules. Follow a routine.
- > Use concrete, simple instructions.
- > Teach functional and social skills in the classroom.
- > Communicate closely with the parents.

JUSTICE SYSTEM PROFESSIONALS

- > Work with probation services and psychologists within court services to thoroughly assess juveniles.
- > In ongoing training sessions, present factors for identifying individuals with fetal alcohol syndrome or effects with whom law enforcement personnel are likely to come into contact.
- > Establish appropriate diversion programs for juveniles who have fetal alcohol syndrome or fetal alcohol effects.
- > Make law enforcement personnel aware of alternatives to the criminal justice system for individuals with fetal alcohol syndrome or fetal alcohol effects.
- > Educate justice system professionals, including judges, county attorneys, public defenders, probation officers and corrections officials.

REPRESENTATIVES OF THE
ALCOHOL INDUSTRY

- > Provide information for service staff and customers on the harmful effects of alcohol during pregnancy.
- > Provide training for service staff in checking identification, recognizing intoxication, monitoring patron drinking and refusing service when appropriate.
- > Sponsor advertising that promotes the responsible use of alcohol.

SOCIAL WORKERS AND CHILD
PROTECTION PERSONNEL

- > Train social workers in child welfare to identify, assess and intervene effectively with substance-abusing women and their families.

EFFORTS UNDERWAY IN MINNESOTA

Government agencies, advocacy groups and local public health agencies have undertaken a wide variety of efforts aimed at reducing and responding to fetal alcohol syndrome and fetal alcohol effects.

MINNESOTA DEPARTMENT OF HEALTH

The department is involved in fetal alcohol syndrome prevention and intervention activities in four major areas:

- 1. Assessment.** The department conducts a statewide telephone survey of women of childbearing age to examine knowledge, attitudes and beliefs related to alcohol and tobacco use in general and during pregnancy. It also reviews regional and statewide data sources on the prevalence of alcohol use during pregnancy; trains Head Start staff, educators and nurses to conduct screening of preschool children; comprehensively reviews the patterns and economic costs of alcohol use in Minnesota; and researches the best practices for screening, counseling, making referrals for and following up on services for pregnant women who use alcohol. The department conducts diagnostic clinics outside the seven-county metropolitan area to assess children who may have special health needs, including fetal alcohol syndrome and effects. For more information, call 612-623-5338.
- 2. Professional education and training.** The agency develops and implements training programs for health care providers on screening and counseling pregnant women on alcohol use; adapts and refines a tool to screen pregnant women for chemical use and violence; and adapts and tests a screening tool to identify children who need referral to diagnostic clinics. Call 612-623-5337 for more information.
- 3. Media campaign.** In collaboration with a variety of groups, the agency helped plan, implement and evaluate a statewide broadcast media campaign in 1994 and 1995. It develops resource materials to help link groups working to prevent fetal alcohol syndrome with their local media; designs, tests and distributes to all alcohol points-of-sale in the state a mandated warning sign that includes information on the risks of drinking during pregnancy; and produces color posters in six languages to increase public awareness of these risks. For more information, call 612-215-1301.
- 4. Community and coalition involvement.** The agency staffs the statewide Fetal Alcohol Syndrome Work Group, which is involved in prevention, screening and diagnosis, and services. The department also works closely with local public health agencies and community-based collaborative efforts such as the Interagency Early Childhood Intervention teams. A question-and-answer service provides information about children with chronic illness and disabilities, including fetal alcohol syndrome and effects. Call 612-623-5150 or 800-728-5420 (toll free).

We support prevention efforts; this is the key. We should reach the women when they are pregnant.

**SPECIAL EDUCATION
COOPERATIVE STAFF
MEMBER, FERGUS FALLS**

**SUFFER THE
CHILDREN:
THE
PREVENTABLE
TRAGEDY OF
FETAL ALCOHOL
SYNDROME**

MINNESOTA DEPARTMENT OF HUMAN SERVICES

The department funds chemical dependency treatment for low-income women, including specialized women's programs that provide child care, transportation and other services. It also conducts research on the incidence and prevalence of prenatal drug and alcohol exposure, along with follow-up studies of children who were prenatally exposed to drugs; administers grants to local and statewide coalitions working to prevent fetal alcohol syndrome; and funds maternal child substance abuse projects in Hennepin and Ramsey counties. Human Services oversees the state's child protection system and Medical Assistance program. Call 612-296-4610 for more information.

MINNESOTA DEPARTMENT OF CHILDREN, FAMILIES AND LEARNING

The Department of Children, Families and Learning is involved with several programs that are designed to reduce the incidence of fetal alcohol syndrome and fetal alcohol effects. The Early Childhood Screening Program, Family Services Collaborative, Interagency Early Intervention Committees, Head Start, Early Childhood Special Education and Special Education provide services, training and technical assistance to communities on a wide array of issues. Research is conducted by the department with the Minnesota Student Survey. The department has provided leadership in the interagency prevention work group coordinated by the Department of Health. Contact the Department of Children, Families and Learning at 612-296-6104.

Several interagency agreements have been implemented and community-based grants have been awarded, including Department of Correction's screening programs at juvenile assessment centers; Pathfinder Resources Inc. for the Healthy Roots project; Arc Duluth; Thunder Spirit Lodge; and the Department of Health's information services about finding resources and developing parent support groups through Minnesota Children with Special Health Needs. Call 612-623-5150 or 800-728-5420 (toll free).

MINNESOTA DEPARTMENT OF PUBLIC SAFETY

The department reports to the Minnesota Legislature on strategies for reducing prenatal alcohol consumption and helped develop the legislatively mandated warning sign that must be posted in establishments that sell liquor. For more information, call 612-296-6430.

LOCAL PUBLIC HEALTH AGENCIES

Local public health agencies are involved in a number of collaborations, coalitions and task forces addressing alcohol-related issues such as fetal alcohol syndrome.

NONGOVERNMENTAL ORGANIZATIONS

A variety of private and nonprofit organizations are involved in prevention activities, including Minnesota Healthy Roots Coalition, the Minnesota chapter of the March of Dimes, the Guardian Support Group of Cloquet, Thunder Spirit Lodge and Arc of Minnesota, among others. Their efforts include producing and distributing informational materials on fetal alcohol syndrome; developing educational programs and curriculums; teaching families, teachers and others strategies for working with children with fetal alcohol syndrome; and providing support, guidance and referrals for families.

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