



Report to the President

The Promise of Research and Prevention

2008

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

I forward for your consideration the President's Committee for People with Intellectual Disabilities' 2008 *Report to the President: The Promise of Research and Prevention*.

This report addresses two issues of vital importance to preventing and ameliorating the effects of intellectual disabilities: speeding the discovery of cutting edge treatments and services through translational research and research consortiums, and defeating the single most preventable cause of intellectual disabilities—fetal alcohol spectrum disorders (FASD).

The members of the President's Committee applaud and embrace the goals in the New Freedom Initiative (NFI) and believe that through implementation of the recommendations contained in the report, people with intellectual disabilities will be better able to participate in their communities.

It should be noted that although some of the information and data contained in this report were contributed by authorities in the fields of disability, research and fetal alcohol spectrum disorders, the personal opinions that such contributors may hold or choose to express outside of this report do not necessarily reflect the views of the President's Committee for People with Intellectual Disabilities, the United States Department of Health and Human Services, or other Federal Government agencies.

Sincerely,

Michael O. Leavitt

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the President's Committee for People with Intellectual Disabilities (PCPID), I wish to express appreciation for the honor of serving your Administration and the American people. The members of the President's Committee are committed to the fulfillment of the Committee's mission to improve the quality of life of people with intellectual disabilities and their families. For many of us, it is a personal relationship with an individual with intellectual disabilities that inspires our dedication to the Committee and its important work.

In discussing the prospective topics for the 2008 Report to the President, the Committee was particularly struck with two distinct, yet interrelated topics: research and prevention. In the area of research, the Committee recognized that while much research is being conducted in both the public and private sectors with regards to intellectual disabilities, much of the benefit from these significant investments is lost when the results do not reach beyond the laboratory setting and into clinical practice where it can result in improved health care and services. With regards to prevention, the Committee recognized the awesome potential for improved life and health outcomes by defeating the single most preventable cause of intellectual disabilities: fetal alcohol spectrum disorders (FASD). We are pleased to share with you the results of our exploration of these two vital areas of concern.

Mr. President, the members of the President's Committee for People with Intellectual Disabilities appreciate the opportunity to submit for your consideration, *Report to the President: The Promise of Research and Prevention*. The intended outcome of this report is to promote further understanding of the inherent value of people with intellectual disabilities and the potential for improved life and health outcomes through the realization of the recommendations outlined herein. We are hopeful that this report will facilitate the further realization of the Committee's mission to improve the quality of life of people with intellectual disabilities and their family members.

Sincerely,

Dallas "Rob" Sweezy
Chair

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Committee Profile

Although there is no national census of the incidence and prevalence of intellectual disabilities, authorities in the field estimate that the number may be as high as two percent of the population, six million individuals. One in 10 families in the United States is directly affected by a person with intellectual disabilities. In order to ensure the right of a “decent, dignified place in society” for people with mental retardation (intellectual disabilities), President Lyndon B. Johnson established, in 1966, the Committee on Mental Retardation (PCMR), now the President’s Committee for People with Intellectual Disabilities (PCPID), to focus on this critical subject of national concern.

Since that time, the President’s Committee has served in an advisory capacity to the President and the Secretary of Health and Human Services on a broad range of matters relating to persons with intellectual disabilities and the field of intellectual disabilities. Since its inception, the President’s Committee has led the charge to improve the lives of people with intellectual disabilities, most recently embracing the vision and supporting the plan that is at the heart of President George W. Bush’s New Freedom Initiative (NFI) to tear down barriers that prevent people with intellectual disabilities from enjoying a quality of life that promotes independence, self-determination, and full participation as productive members of society. The NFI includes, but is not limited to: increasing access through assistive and universally designed technology; expanding educational opportunities for youth with disabilities; and promoting full and lifelong access to all aspects of community life.

The Committee consists of 21 citizen members appointed by the President and 13 ex officio heads of Federal Government departments and agencies designated by the President. The 13 ex officio members include: the Attorney General, Secretary of the Interior, Secretary of Commerce, Secretary of Labor, Secretary of Health and Human Services, Secretary of Housing and Urban Development, Secretary of Transportation, Secretary of Education, Secretary of Homeland Security, President and Chief Executive Officer of the Corporation for National and Community Service, Commissioner of the Social Security Administration, Chair of the Equal Employment Opportunity Commission, and Chair of the National Council on Disability. The President’s Committee for People with Intellectual Disabilities is led by an Executive Director, also appointed by the President, and supported by a team of Federal employees.

Executive Summary

In fulfillment of the Executive Order to prepare an annual report to the President, the President's Committee for People with Intellectual Disabilities submits its 2008 report, *Report to the President: The Promise of Research and Prevention*.

Research

According to the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the lag between scientific discovery and integration of those discoveries into practice is unnecessarily long – about 15 to 20 years. During this lag time, valuable opportunities are lost to improve the lives of individuals who could most benefit from the cutting edge discoveries that do not make it out of the laboratory setting and into clinical practice in a timely manner.

In order to address the lag time from discovery to practice, the Committee recommends that the President urge the private sector to create condition-specific research and clinical consortiums aimed at improving communication and encouraging collaboration in the fields of intellectual disabilities. The Committee further recommends that, where appropriate, the President encourage the formation of public/private partnerships to ensure the most efficient use of government research and resources.

Prevention

Fetal Alcohol Spectrum Disorder (FASD) is the single most preventable cause of intellectual disabilities and results from prenatal exposure to alcohol. Some of the primary and secondary disabilities associated with FASD include intellectual disabilities, adaptive functioning deficits, mental health problems, problems with the law, disrupted school experience and alcohol and drug problems.

According to the Substance Abuse and Mental Health Services Administration, two effective means of preventing FASD include increasing public awareness of the potentially harmful effects of prenatal alcohol exposure, and targeting those at risk for engaging in high risk alcohol consumption while pregnant. The Committee recommends that the President urge the private sector to establish a research and clinical consortium on FASD, and instruct the appropriate Federal agencies to conduct research to obtain more accurate data regarding the incidence and prevalence of FASD in the United States. The Committee further recommends that the President promote the prevention of FASD through early education, increased screening and prevention in clinical settings, and renewed dedication to public awareness of FASD through Federal health initiatives such as Health People 2010 and Healthy People 2020.

Section 1

Translational Research: Getting the Best Return on Our Investments in People with Intellectual Disabilities

Basic research is fundamental to improving the lives and health of people with intellectual disabilities. Research advances can improve health status, functional ability and quality of life. Better health outcomes lead to better life outcomes, including successful community integration and increased employability.

The United States of America affirms its belief in the value of people with intellectual disabilities by investing in research. However, in order to maximize the return on this investment we must also ensure that the results of the efforts in the laboratory reach the clinical and community level in a timely manner. Far too often, successful interventions and services that are based on rigorous clinical research remain unknown and untried rather than being used effectively in the community. The Institute on Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, describes the lag between scientific discovery and integration into practice as unnecessarily long – about 15 to 20 years.¹

Ideally, basic research discoveries are quickly translated into drugs, interventions, or methods of prevention. Such discoveries typically begin in the laboratory with basic research – where scientists study disease at a molecular or cellular level – then progress to clinical trials in humans and eventually to the community or service delivery level. Efforts to facilitate this continuum are called translational research. Translational research transforms scientific discoveries arising from laboratory studies into clinical applications that can be used to improve the lives of people with intellectual disabilities.

In 1962, *A Proposed Program for National Action to Combat Mental Retardation* was submitted by the President's Panel on Mental Retardation to President John F. Kennedy. The report states:

The phenomenal growth of research activity and consequent additions to knowledge that have taken place in the last 20 years have not been matched by significant innovations in the techniques of communication. The number of journals and other media now reporting the results of research make it impossible for investigators and practitioners to keep abreast of developments even within the spheres of their own immediate interest.²

¹ Institute of Medicine, Committee on Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, DC: National Academy Press, 2001), 145.

² The President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation* (Washington, DC 1962).

This problem has never been more acute than it is today. The accelerated pace of discoveries in the life sciences has prompted a need for their more rapid translation into practice. Yet, even at a time when technology has made possible instant communication, the rate of new scientific discoveries has overwhelmed our current ability to communicate these discoveries effectively.

Current approaches for bringing new scientific discoveries to the community level are often uncoordinated, inefficient, wasteful and sometimes counterproductive. Lag times in publication can be long and dissemination of research results incomplete. Data are sometimes unnecessarily duplicative because researchers are either not aware or do not have access to previous findings. Critical research gaps exist due to fragmented communication between investigators and clinicians.

While the United States has one of the best discovery engines in the world, we often fail in moving discoveries from research to practice. As a result, valuable opportunities to have a positive impact on the lives of people with intellectual disabilities are lost. Despite significant Federal and private investments that have expanded the scientific knowledge base in intellectual disability and that have led to many effective biomedical and behavioral innovations, people with intellectual disabilities are not fully benefiting from the results of these efforts.

In response to this shortfall, and the increasing importance of speedy access to state-of-the-art treatments, members of the research community have built condition-specific consortiums aimed at creating a shared knowledge base of current research, clinical best practices and service delivery procedures and policies.

The research and clinical consortium model is widely recognized as an advantageous structure to optimize and accelerate research progress and ultimately provide improved care. Consortiums integrate numerous disciplines, serve as a magnet for basic, translational and clinical research and bring together investigators, community clinicians, professional societies, industry and advocates.

Research and Clinical Consortium Models

A number of collaborative models of varying scope and purpose exist in the intellectual disability research community. These consortiums were developed to create a shared knowledge base of effective interventions and to establish a structure for facilitating collaborative efforts.

The examples below illustrate that research-based consortiums can be developed wholly in the private sector, the public sector, or through public/private partnerships. They represent varying missions and operating structures, and each demonstrates that

increased collaboration and improved communication can accelerate the translation of basic research and improve the quality of life for the populations they serve.

- The Fragile X Clinics and Research Consortium is sponsored by the National Fragile X Foundation. The consortium was developed in 2006 and now includes 18 clinics nationwide. The consortium provides a communication network organized to provide evidence-based services, develop best practice guidelines and accelerate the process by which promising new interventions, including new medications, can be evaluated, approved and disseminated for individuals with Fragile X syndrome.
- The National Institutes of Health (NIH) Down Syndrome Working Group was established in 2005 within the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The group, consisting of leading scientific staff from across NIH, was formed to share expertise and better coordinate ongoing NIH-supported research related to Down syndrome. They also foster collaborations between NIH and other agencies and groups representing the interests of individuals with Down syndrome and their families.
- The National Down Syndrome Society Research Coalition (DSRC) was launched in 2005 with a goal of increasing public and private funding of Down syndrome research. The coalition is comprised of institutions, researchers and parents with an interest in Down syndrome and aims to improve communication, coordination and collaboration among stakeholders.
- The Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network was established following passage of the Children's Health Act of 2000. The Act directed the Centers for Disease Control & Prevention to establish regional centers of excellence for autism spectrum disorder and other developmental disabilities. Five research sites make up the CADDRE Network.
- The University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) were established by Congress in 1963 as centers of excellence for research in intellectual and developmental disabilities. They represent the nation's first and foremost sustained effort to prevent and treat disabilities through biomedical and behavioral research. UCEDDs evaluate the effectiveness of biological, biochemical, and behavioral interventions; develop assistive technologies; and advance prenatal diagnosis and newborn screening. The network consists of 67 UCEDDs.
- The Interagency Committee on Disability Research (ICDR), established by the Rehabilitation Act of 1973, is organized under the U.S. Department of Education.

The Committee promotes coordination and cooperation among Federal departments and agencies conducting rehabilitation research programs. Its mission includes, but is not specific to intellectual disability. An annual report is submitted to the President on recommendations with respect to coordination of policy and the development of objectives and priorities for all Federal agencies related to disability and rehabilitation research.

In addition to the examples above, several consortiums not specific to intellectual disabilities can serve as models for future collaborations.

- The National Veterans Administration (VA) Parkinson's Disease Consortium, sponsored by the VA Healthcare System, supports the provision of optimal care and education for veterans diagnosed with Parkinson's disease and related movement disorders through professional education, collaboration and advocacy.
- The Multiple Myeloma Research Consortium, sponsored by the Multiple Myeloma Research Foundation, works to accelerate the development of cutting-edge treatments for patients afflicted by multiple myeloma by catalyzing, promoting and facilitating collaborative research between industry and academia. This bench to bedside research is solely directed to provide new and more effective treatments for multiple myeloma patients and fast forward progress toward the ultimate cure of myeloma.
- The Child Care Policy Research Consortium, sponsored by the United States Department of Health and Human Services, Administration for Children and Families, Child Care Bureau, helps the Child Care Bureau increase national capacity for sound child care research, identify and respond to critical issues, and link child care research with policy and practice.

Benefits of Condition-Specific Consortiums

Research application has a critical role to play in promoting full access to community life for Americans with intellectual disabilities.

The benefits of translational research can be measured in a number of areas including academics, personal skill-building, health and wellness, employment, independence, self-confidence and self-determination. For example, research in the neurosciences that promotes increased skills or improved function expands educational and employment possibilities. Research in pathophysiology that results in better symptom management or reduced co-morbidity leads to improved quality of life.

- When the lag time between discovery and delivery is reduced, access to the most efficacious service and care models and potential for the best individual outcomes can occur.
- When research discoveries are routinely available at the community level, longstanding disparities in health, education and employment can begin to narrow.
- When research findings are efficiently translated into practice, a knowledgeable and timely delivery network can apply the latest breakthroughs in medicine, behavioral intervention or education.
- When the gap closes between what is known and what is practiced, increasing possibilities can emerge for post-secondary education, employment and independent living.

By establishing condition-specific research and clinical consortiums to work toward these milestones, we affirm the value of every person with an intellectual disability and demonstrate our commitment to improving their health and quality of life outcomes.

Recommendations

The President’s Committee recommends that the President encourage the private sector to establish condition-specific consortiums dedicated to the coordination of research and the cooperative dissemination of knowledge among researchers, professionals and public policy makers in the various fields of intellectual disabilities. Such consortiums should, at a minimum, focus on the following critical areas:

1. Identify and recruit the consortium membership – particularly clinics that specialize in, or provide services to, the condition-specific community
2. Develop and begin the implementation of consortium goals and objectives
3. Inform the community of parents and professionals
4. Enhance clinics’ services and coordination
5. Engage relevant researchers across multiple disciplines to coordinate research efforts
6. Engage government institutions for implementation of translational Research and public health goals and objectives

The President’s Committee further encourages the President to promote, where appropriate, public/private partnerships to further the goals of the consortiums to accelerate the translation of basic research.

Establishing consortiums dedicated to the various conditions of intellectual disabilities will:

- Provide leadership to bridge the gap between discovery and delivery
- Facilitate expansion of evidence-based practices in the field
- Encourage adoption of proven evidence-based interventions
- Promote application of research results to appropriate populations of people with intellectual disabilities
- Help translate research into practice within specific intellectual disability populations
- Encourage commonalities in research questions, methods and measurements
- Develop state of the art screening and intervention
- Identify neglected research issues
- Encourage information exchange among the research community
- Serve as a sounding board for current research ideas and methodological issues
- Discourage inefficient duplication of research efforts
- Facilitate cross-disciplinary collaborations
- Facilitate cross-organizational collaborations
- Facilitate public-private partnerships to test educational, behavioral, pharmaceutical or therapeutic interventions
- Recommend research priorities to governmental and non-governmental agencies with responsibilities for funding intellectual disability research
- Connect evolving needs of families and individuals with intellectual disabilities to ongoing research agendas
- Support communication between the research community and the larger community of families and organizations supporting the interests of people with intellectual disabilities
- Recommend best strategies for dissemination of new discoveries
- Identify potential diffusion and dissemination partners to aid decision-making for families, practitioners and policy-makers
- Promote dissemination of knowledge to researchers, public policy-makers and the intellectual disability community
- Augment the quality and productivity of the overall intellectual disability research enterprise

Research consortiums can speed the discovery of cutting-edge research, treatments and services, and help to bring them to the community level in a timely manner. As a result, Americans with intellectual disabilities will be able to access the evidence-based best practices needed to improve their lives and health outcomes.

Section 2

Defeating the Single Most Preventable Cause of Intellectual Disabilities in the United States: Fetal Alcohol Spectrum Disorders

FASD and the Effects of Prenatal Alcohol Exposure

Fetal alcohol spectrum disorders (FASD) result from prenatal exposure to alcohol through maternal alcohol consumption during pregnancy and include several conditions including fetal alcohol syndrome (FAS), fetal alcohol effects (FAE) and alcohol related birth defects (ARBD). The most severe end of this spectrum is fetal alcohol syndrome with nearly 50 percent of the FAS population experiencing intellectual disabilities.³

FASD is the leading known preventable cause of intellectual disabilities⁴ and is *completely preventable*. The only way a child will suffer from FASD is through prenatal exposure to alcohol. In other words, if a woman abstains from alcohol use during pregnancy, there is no possibility for her child to be born with FASD.

According to the *Institute of Medicine Report to Congress*, “of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus, resulting in life-long permanent disorders...”⁵ including intellectual disabilities, adaptive functioning deficits, growth failure, behavioral problems, and problems with impulse control and memory function. FASD “is a permanent, lifelong condition that affects every aspect of a child’s life and the lives of the child’s family.”⁶

Individuals with FASD can also experience a broad range of secondary disabilities including mental health problems, trouble with the law, disrupted school experience, alcohol and drug problems, confinement (via incarceration, enrollment in drug and alcohol rehabilitation, or commitment to a mental health facility), inappropriate sexual

³ Committee To Study Fetal Alcohol Syndrome, Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine, *Fetal alcohol syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*, eds. Kathleen Stratton, Cynthia Howe and Frederick Battaglia, (Washington, DC: National Academy Press, 1996).

⁴ Kennedy Krieger Institute, “Fetal Alcohol Syndrome and Related Disorders,” Kennedy Krieger Institute, http://www.kennedykrieger.org/kki_diag.jsp?pid=1085, Accessed May 12, 2008.

⁵ CALFAS, “Basic Facts About Fetal Alcohol Spectrum Disorder (FASD) and Fetal Alcohol Syndrome,” California Fetal Alcohol Spectrum Organizations, <http://www.calfas.org/fasdfacts.htm>, Accessed March 5, 2008.

⁶ CDC, “FASD: Preventing Alcohol-Exposed Pregnancies,” Centers for Disease Control and Prevention, <http://www.cdc.gov/ncbddd/fas/fasprev.htm>, Accessed March 5, 2008.

behavior, lifetime dependent living and problems with employment.⁷ Children with FASD are more likely to live in foster care or adoptive homes. They “are also placed in an unusually high number of different foster homes”⁸ – perhaps as a result of the special challenges that face children with FASD that many foster families are unprepared to accommodate.

The Incidence and Prevalence of FASD

In the United States, varying sources report widely divergent data on the estimated incidence and prevalence of FASD, in large part because of a critical need for more research and awareness. Some experts estimate that up to 10 times as many individuals are affected with the learning, behavior and neurological problems associated with FASD than are diagnosed with FAS⁹ due to significant under-diagnosis and underreporting. For just the single condition FAS, the prevalence is estimated at between 0.5 and 2 cases per 1000 live births.¹⁰

Reliable, accurate data about the incidence and prevalence of FASD are essential in order to ensure the success of programs and services aimed at the prevention and treatment of FASD.*

The Costs Associated with FAS and FASD

Several different health economists have estimated the cost burden in the United States due to FAS. Averaging the estimated costs from five different studies and correcting for 2002 dollars, the best estimate is that in 2002 dollars FAS alone costs the United States \$4 billion per year, and over \$2 million per individual with FAS (over the lifespan).¹¹ Healthy People 2010 states that some estimates reach as high as \$9.7 billion each year.¹² According to *Costs of Fetal Alcohol Spectrum Disorders*, “one prevented case of FAS saves

⁷ Ann P. Streissguth, Helen M. Barr, Julia Kogan and Fred L. Bookstein, *Understanding the Occurrence of Secondary Disabilities in Clients with FAS/FAE. Final Report (1996)*. (Seattle: University of Washington Press, 1999), 30-33.

⁸ Ann P. Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities* (Baltimore: Paul H. Brooks Publishing Co., 1997), 179.

⁹ Paul D. Sampson et al., “Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-Related Neurodevelopmental Disorder,” *Teratology*, 56, no. 5 (1998): 317-326.

¹⁰ Phillip A. May and J. Phillip Gossage, “Estimating the Prevalence of FAS: A Summary,” *Alcohol Research and Health* 25, no. 3 (2001): 165, <http://pubs.niaaa.nih.gov/publications/arh25-3/159-167.htm>, Accessed May 12, 2008.

* For a discussion of the incidence and prevalence of FASD in special populations see Appendix I.

¹¹ Chuck Lupton, Larry Burd and Rick Harwood, “Cost of Fetal Alcohol Spectrum Disorders,” *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 127C no. 1 (2004): 49.

¹² U.S. Department of Health and Human Services, *Healthy People 2010*, 16-5, can be viewed at: <http://www.healthypeople.gov/Document/pdf/Volume2/16MICH.pdf>.

almost \$130,000 in the first 5 years, \$360, 000 in 10 years, \$587,000 in 15 years, and more than \$1 million in 30 years.”¹³

The above figures represent only the costs of the single condition FAS, not the entire spectrum of disorders known as FASD which, as discussed above, may include as many as 10 times the number of individuals diagnosed with FAS. These estimates also do not include the costs of many public services including special education, vocational services, drug abuse treatment and the costs associated with the juvenile and criminal justice system – all of which are disproportionately utilized by people with FAS and FASD.¹⁴ Furthermore, most experts agree that there is a significant gap in available services for individuals with FASD and that this gap only serves to increase the occurrence of secondary disabilities, thus increasing the costs associated with treating them.

Given the billions spent to address the outcomes of this *completely preventable* condition and its attendant secondary disabilities, the potential benefits of prevention programs and services extend beyond just the quality of life of the individual and their families – a good in and of itself – but to the whole of society as well. At a time when many public benefits programs are facing significant funding challenges, the savings associated with each prevented case of FASD represents additional resources available to serve other beneficiaries at risk of losing much-needed benefits.

Prevention and Early Intervention of FASD

FASD is *completely preventable* and, as indicated above, there are several opportunities for education and intervention that can have an impact on a woman’s decision to engage in high risk drinking during pregnancy – at school, at the doctor’s office and through better societal and cultural understanding of the risks associated with alcohol consumption during pregnancy.

Two important methods to prevent FASD include:

- Increasing public knowledge about FASD through general education, public service announcements, media attention, alcohol warning labels, posters, pamphlets and billboards; and
- Targeting women at risk by screening pregnant women and women of childbearing age for high risk alcohol use, and by providing interventions to those identified as high risk drinkers.¹⁵

¹³ Lupton et al., “Cost of Fetal Alcohol Spectrum Disorders,” 45.

¹⁴ Ibid., 48.

¹⁵ Adapted from SAMHSA, “Preventing FASD: Healthy Women, Healthy Babies,” Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, http://fascenter.samhsa.gov/documents/WYNK_Preventing_FASD.pdf, Accessed March 4, 2008.

Increasing Public Knowledge Through Early Education

There is no known safe level of alcohol consumption while pregnant. Since every case of FASD is the result of prenatal alcohol exposure, a mother can guarantee that her child will not be born with FASD if she abstains from drinking alcohol while pregnant.

The Office of the Surgeon General first published a public health advisory warning of the dangers of alcohol consumption during pregnancy in 1981 making the United States the first nation to “have a national policy recommending that women not drink during pregnancy or when planning a pregnancy.”¹⁶ Since that time, public awareness of the negative effects on the fetus of prenatal alcohol exposure has increased, as well as the awareness of the existence of FASD. However, studies have shown that while 73% of women have heard of FASD, only 29% of women of childbearing age can identify it as a birth defect. Many women believe that it is a condition in which babies are born addicted to alcohol (similar to babies born addicted to illegal substances such as cocaine and heroin).¹⁷ Such misinformation demonstrates the vital need for increased public education and awareness about the risks associated with prenatal alcohol exposure and the life and health outcomes for people born with FASD.

The opportunity to educate not only women, but all people, about the dangers of prenatal alcohol exposure begins as early as elementary school when children first begin to study biology and human development. Concentrated public education programs – such as those dedicated to educating school-aged children about the health risks associated with smoking – have proven effective at influencing decisions that can have a lifelong impact on future high risk behaviors and health outcomes.¹⁸ In addition to curriculum-based strategies, FASD education can also be integrated into alcohol and drug awareness programs and public awareness campaigns.

Early education and interventions are key to ensuring that the dangers of prenatal alcohol exposure become common knowledge amongst current and future generations.

Screening and Intervention in the Clinical Setting

In order to prevent FASD, it is imperative that women who drink during pregnancy, or are at risk of drinking during pregnancy, are identified early and are provided with the necessary interventions. According to the most recent *Surgeon General's Advisory on Alcohol Use in Pregnancy*, “data suggest that the rates of binge drinking and drinking seven or more drinks per week among both pregnant women and non-pregnant women of childbearing age have not declined in recent years. Many women who know they are

¹⁶ Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities*, 48.

¹⁷ Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities*, 253.

¹⁸ CDC, “Preventing Tobacco Use Among Young People: A Report of the Surgeon General,” 8 http://profiles.nlm.nih.gov/NN/B/C/F/T/_/nbcft.pdf, Accessed 5/07/08.

pregnant report drinking at these levels.”¹⁹ Various studies place the number of women that drink at least some alcohol during pregnancy between 10 and 20 percent,²⁰ and the number of women who report frequent drinking during pregnancy has increased from 0.8 percent in 1991 to 3.5 percent in 1995.²¹

Routine screenings of all pregnant women for high risk alcohol consumption must become part of the standardized prenatal exam in order to ensure early identification and intervention for those at risk of having a child with FASD. In 1987 only 34% of obstetricians screened their patients for alcohol abuse.²² Further complicating early identification of high risk alcohol consumption is the finding that pregnant women are “likely to deny or minimize their drinking during pregnancy out of embarrassment.”²³ Clinically developed screening tools administered in a clinical setting have proven more effective than self-reporting at identifying those engaging in high risk behaviors. However, inconsistent screening practices by obstetricians result in too many women falling through the cracks.²⁴

Once a woman has been identified as engaging in high risk alcohol consumption, intervention and treatment must be the next step. For example, studies have shown that an intervention strategy known as a brief intervention²⁵ can have a positive impact

¹⁹ U.S. Department of Health and Human Services, *Surgeon General's Advisory on Alcohol Use in Pregnancy*, can be viewed at: <http://www.hhs.gov/surgeongeneral/pressreleases/sg02222005.html>.

²⁰ 10%--CDC, “Alcohol Consumption Among Women Who Are Pregnant or Who Might Become Pregnant,” <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5350a4.htm>, Accessed 5/07/08; 13%--CDC, “Alcohol Use Among Women of Childbearing Age,”

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5113a2.htm>, Accessed 5/07/08; 20%--Grace Chang, “Alcohol-Screening Instruments for Pregnant Women,” *Alcohol Research and Health* 25, no. 3 (2001): 204.

²¹ Chang, “Alcohol-Screening Instruments for Pregnant Women,” 204.

²² Ibid.

²³ Ibid.

²⁴ Ibid., 205.

²⁵ Nancy Sheehy Handmaker and Paula Wilbourne, “Motivational Interventions in Prenatal Clinics,” *Alcohol Research and Health* 25, no. 3 (2001), <http://pubs.niaaa.nih.gov/publications/arh25-3/219-299.htm>, Accessed May 12, 2008; U.S. Preventative Services Task Force, “Screening and Behavioral Counseling Interventions in Primary Care to Reduce Alcohol Misuses: Recommendation Statement,” *Annals of Internal Medicine* (2004) 140 (7):554-556; Evelyn P. Whitlock, Michael R. Polen, Carla A. Green, Tracy Orleans, and Jonathan Klein. Behavioral Counseling Interventions in Primary Care to Reduce Rucky/harmful Alcohol Use by Adults: A summary of the evidence for the U.S. Preventative Services Task Force. *Annals of Internal Medicine* (2004) 140(7):557-568; NIAAA, “Helping Patients Who Drink Too Much, A Clinician’s Guide. (2005 edition), NIH Publication No. 07-3769, U.S. Department of Health & Human Services, http://pubs.niaaa.nih.gov/publications/Practitioner/CliniciansGuide2005/clinicians_guide.htm, Accessed May 12, 2008.

on a woman's decision to engage in high risk alcohol consumption while pregnant²⁶ and can be easily incorporated into existing clinical settings and social services.²⁷

Increasing Societal and Cultural Understanding: Healthy People 2010

Given the incredible potential for both an improved quality of life for individuals at risk for FASD and intellectual disabilities, and the savings associated with each case prevented, it is no surprise that Healthy People 2010 – the health policy of the United States Government – includes reducing the occurrence of the single condition FAS as a priority area under the Maternal, Infant and Child Health priorities.²⁸ It also includes health objectives aimed at decreasing intellectual disabilities and low birth weight, and increasing prenatal care – all goals related to FAS.²⁹

While it is promising that FAS is specified as a priority of Healthy People 2010, FAS was also a priority in Healthy People 2000 and failed to show improved outcomes. In fact, FAS outcomes worsened and lost rather than gained ground toward Healthy People 2000 targets.³⁰ Healthy People 2010 is in jeopardy of similarly disappointing, or even worsening results. According to *Progress Toward Healthy People 2010 Targets*, the sub-objectives for FAS could not be assessed, and the sub-objectives for intellectual disabilities and low birth weight have moved farther away from their targets.³¹ By including FAS and intellectual disabilities as specific objectives in Healthy People 2010, the Federal government has signaled its dedication to decreasing the incidences of both conditions. However, given the disappointing results in reaching the FAS goals set over the last 15 years, it is clear that a more focused effort is needed.

Recommendations

The President's Committee recommends that the President:

1. Urge the private sector to establish a research and clinical consortium on FASD. As detailed in section one of this report, condition-specific consortiums serve to foster communication, research and clinical best practices.

²⁶ Grace Chang, "Screening and Brief Intervention in Prenatal Care Settings," *Alcohol Research and Health* 28, no. 2 (2004/2005), <http://pubs.niaaa.nih.gov/publications/arh28-2/80-84.htm>, Accessed May 12, 2008.

²⁷ Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities*, 268.

²⁸ U.S. Department of Health and Human Services, *Healthy People 2010*, Objective 16-18, can be viewed at: <http://www.healthypeople.gov/Document/pdf/Volume2/16MICH.pdf>.

²⁹ *Ibid.*, Objectives 16-6, 16-10 and 16-14.

³⁰ U.S. Department of Health and Human Services, "Healthy People 2000, Progress Review: Maternal and Infant Health," <http://odphp.osophs.dhhs.gov/pubs/hp2000/PROGRVW/materinfant/maternalprog.htm>, Accessed March 19, 2008.

³¹ U.S. Department of Health and Human Services, "Progress Toward Healthy People 2010 Targets," <http://www.healthypeople.gov/data/midcourse/html/focusareas/fa16progresshp.htm>, Accessed March 19, 2008.

2. Instruct the appropriate Federal agencies to conduct research to obtain more accurate data regarding the incidence and prevalence of FASD in the United States.
3. Promote renewed dedication to the prevention of FASD through early education, increased screening and prevention in clinical settings, and renewed dedication to public awareness of FASD through Federal health initiatives such as Healthy People 2010 and Healthy People 2020.

Conclusion

Every life has value and we affirm our belief in the value of people with intellectual disabilities through our commitment to improving their life and health outcomes. Cutting edge technologies and the rapid pace of scientific discovery provide nearly limitless opportunities to improve the quality of care available to those who need it most. But, we must work towards improving the pace of translational research through more collaborative efforts that ensure the most efficient use of our time and resources. Through the development of condition-specific research and clinical consortiums, we can realize our goal of more efficient, streamlined health care systems and people with intellectual disabilities will benefit from improved access to much-needed care.

We can also improve the life and health outcomes of people with intellectual disabilities by working toward the eradication of the completely preventable condition, fetal alcohol spectrum disorder (FASD). In order to attain the goals outlined in Healthy People 2010 we must: conduct the necessary research on the incidence and prevalence of FASD in the United States; promote educational opportunities at all levels on the effects of high risk drinking while pregnant; and promote the development of a research and clinical consortium on FASD.

The President's Committee for People with Intellectual Disabilities affirms its belief in the value of people with intellectual disabilities and urges the President to utilize the recommendations in this report to improve the quality of life for people with intellectual disabilities and their families through an increased commitment to research and prevention.

Appendix I

Special Populations

The occurrence of FASD is not limited to a single racial or ethnic population, nor is it limited to one particular socio-economic background. However, several risk factors consistently indicate an increased risk of heavy maternal drinking and the occurrence of FASD, including:

- Family social traits, including: alcohol misuse/abuse in the family, alcohol misuse/abuse by the woman's male partner, tenuous marital status (cohabitation, never married, separated, or divorced), and loss of children to foster or adoptive placement;
- Health factors, including: older than age 25 when FASD child is born, already has three or more children when FASD child is born, use of other drugs, including tobacco and illicit substances, morbidity, or premature mortality from alcohol-related causes;
- Socio-economic status, including: low socio-economic status, social transience, and unemployment or marginal employment;
- Drinking patterns, including: early age at onset of regular drinking, frequent binge drinking (defined as consuming five or more drinks per occasion, two or more days per week), frequent drinking (defined as drinking every day or every weekend), high blood alcohol concentration, and no reduction in drinking during pregnancy;
- Psychological profile, including: low self-esteem, depression, and sexual dysfunction; and
- Local culture and community factors, including: relative tolerance of heavy drinking.³²

In addition to the above risk factors, populations with particularly high prevalence rates of alcohol abuse and alcoholism also experience above average incidences of FASD. For example, among some native tribes the prevalence of FAS is well above the national average.³³ In Alaska, the prevalence of FASD is "5.6 per 1000 live births for American Indians/Alaska Natives, compared with 1.5 per 1000 in the state overall."³⁴

³² Phillip A. May and J. Phillip Gossage, "Estimating the Prevalence of FAS: A Summary," 165.

³³ SAMHSA, "FASD Among Native Americans," Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, <http://download.ncadi.samhsa.gov/Prevline/pdfs/SMA06-4245.pdf>, Accessed on March 4, 2008.

³⁴ Ibid.

Acknowledging and understanding the risk factors associated with maternal drinking and FASD provides an important opportunity to tailor programs and services to specific risk factors and make significant improvements in prevention efforts.

Appendix II

Federal Government Agencies and Collaboratives with Initiatives and Large Programs relevant to FASD

- NIAAA - National Institute on Alcohol Abuse and Alcoholism located at the National Institutes of Health (NIH), Department of Health and Human Services (HHS)
- SAMHSA - Substance Abuse and Mental Health Services Administration located at HHS
- National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention
- Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS)³⁵ – FY2008 membership includes:
 - Department of Justice, Office of Juvenile and Delinquency Prevention
 - Department of Education, Office of Special Education and Rehabilitation Services
 - Department of Health and Human Services
 - Agency for Healthcare Research and Quality (AHRQ)
 - Centers for Disease Control and Prevention (CDC)
 - Health Resources Services Administration (HRSA)
 - Indian Health Service (IHS)
 - Substance Abuse and Mental Health Services Administration (SAMHSA)
 - National Institutes of Health (NIH)
 - National Institute on Alcohol Abuse and Alcoholism (NIAAA)
 - National Institute of Child Health and Human Development (NICHD)
- Surgeon General’s Advisory
- Anti-Drug Abuse Act of 1988 - requiring warning labels on all alcoholic beverages

³⁵ The ICCFAS was established on the recommendation of the Institute of Medicine’s Committee to Study FAS. The ICCFAS is lead by and supported by NIAAA, NIH.

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