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A 5-Year Strategic Plan to Prevent Perinatal Addictions In New Jersey



*The Governor's Council On Prevention Of Mental
Retardation And Developmental Disabilities
And*

*The New Jersey Fetal Alcohol Spectrum Disorders
And Other Perinatal Addictions Task Force*

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JON S. CORZINE
Governor

JENNIFER VELEZ
Acting Commissioner

March 2007

Honorable Jon S. Corzine
Governor of the State of New Jersey
New Jersey State House
Trenton, New Jersey 08625-0001

Dear Governor Corzine:

The use of alcohol, illicit drugs and cigarettes by pregnant women is a serious public health problem in New Jersey. Fetal Alcohol Spectrum Disorders (FASD) are the most preventable causes of mental retardation and other developmental disabilities; and, the associated costs to the state are very high. The Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities has organized a standing committee, the Fetal Alcohol Spectrum Disorders and other Perinatal Addictions Task Force, to coordinate services and educate the public about the dangers of these prenatal exposures.

Accordingly, I am submitting the report of the FASD Task Force, which summarizes the progress that New Jersey made over the past five years to address the problems associated with prenatal substance abuse. In addition, a strategic plan that the report proposes will be undertaken by the task force in the coming years to strengthen systems to ameliorate the effects of prenatal exposures.

In the interest of ensuring that the children of New Jersey have every opportunity to grow and to flourish, I respectfully submit this report to you.

Sincerely,

A handwritten signature in blue ink, appearing to read "Jennifer Velez".

Acting Commissioner

I. Introduction

New Jersey has a long history of working collaboratively to prevent perinatal addictions. The first Fetal Alcohol Syndrome (FAS) Task Force was organized by the Department of Health and Senior Services (DHSS) in the early 1980's. In 1985, the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities published its first report, *Programs to Prevent the Causes of Mental Retardation*, which addressed the importance of educating people about the effects of prenatal exposure to alcohol and drugs. The report included recommendations to decrease maternal use of these substances.

In 1989, acting upon some of the recommendations of the Governor's Council on Prevention, the DHSS established the Risk Reduction System whereby trained Alcohol and Drug Counselors were placed into prenatal care clinics and hospitals. Women who were at-risk of abusing substances during pregnancy were referred to the Risk Reduction Specialists for further assessment and, when needed, referral to substance abuse treatment programs.

In 1998, the Mercer County Council on Alcohol and Substance Abuse invited the DHSS, the Governor's Council on Prevention and community agencies to co-sponsor a statewide conference on Fetal Alcohol Syndrome (FAS). The keynote speaker was Ann Streissguth, Ph.D., a nationally-known expert on the primary and secondary disabilities associated with FAS. In addition, Dr. Streissguth hailed from the state of Washington, which had recently enacted legislation to establish diagnostic and treatment centers for persons affected by prenatal exposure to alcohol.

Following the conference, Dr. Streissguth met with the New Jersey FAS

Task Force, which became a committee of the Governor's Council on Prevention, to provide guidance to strengthen the state's efforts.

Acting upon Dr. Streissguth's advice, the Task Force assessed the status of FAS prevention and education efforts in New Jersey and, in 2001, submitted a report to Acting Governor Donald T. DiFrancesco: "*The Truth and Consequences of Fetal Alcohol Syndrome: Why New Jersey Should Be Concerned.*" The report documents the progress that New Jersey had taken to prevent prenatal exposures to alcohol, tobacco and illicit substances. It also provided recommendations for actions that could be undertaken to expand prevention programs and to strengthen systems to ameliorate the effects of prenatal exposure to alcohol. The report may be accessed at:<http://www.state.nj.us/humanservices/OPMRDD/ofp.html>

As a result of the report, Acting Governor DiFrancesco appropriated \$450,000 to the DHSS to support the establishment of regional Fetal Alcohol Spectrum Disorders Diagnostic Centers. Currently, there are six centers based in Child Evaluation Centers that are located throughout the state. Key staff from each of the FASD Regional Diagnostic Centers attended the training program at the University of Washington to be educated about the proper procedures to be used to diagnose any individual with suspected prenatal alcohol exposure. Besides diagnostics, the Centers are required to do outreach, information and referral to services, case management and community and professional education. In addition, the FASD Regional Diagnostic Center located at UMDNJ-NJ Medical School, has received a grant from the Centers for Disease Control and Prevention (CDC) to serve as one of four regional FAS Training Centers. Medical and allied health students, and professionals are the primary target audiences for the trainings. This center has also established an FASD Surveillance System.

During this same period, the DHSS greatly modified its hospital-based FAS Risk Reduction System and established the Perinatal Addictions System. Now, most Risk Reduction Specialists are Certified Alcohol and Drug Counselors (CADC/CARN) who are based in the six Regional Maternal and Child Health Consortia (MCHC). The MCHCs are responsible for implementing a system of uniform prenatal screening of pregnant women for alcohol and drug use in all hospital based, public and private prenatal settings in their regions. In addition, the



Perinatal Addictions Specialists from the MCHCs work closely with hospitals, public and private providers to educate them about the effects of prenatal exposure to alcohol as well as educating community agencies, including Addictions Treatment Centers that serve women.

The NJ FAS Task Force has been successful in influencing major policies and programs in other areas as well. Educating adolescents about the dangers of consuming alcohol during pregnancy was identified as a primary objective in the 2001 report. To this end, the Task Force worked with the New Jersey Department of Education as it amended the Core Curriculum Standards for Physical and Health Education in 2003. Education about the ill-effects of prenatal alcohol consumption is now included in the standards.

In 2002, the Task Force began to address another of the objectives included in *The Truth and Consequences of FAS* report, namely to provide state-of-the-art information to the medical, allied health, social and educational communities. As it planned a state-wide conference, the CDC asked to be a partner with the New Jersey Task Force and to invite attendees from across the country. In October 2003, the New Jersey FAS Task Force welcomed 350 persons from 30 states and 6 countries to the 30th Anniversary Conference on Fetal Alcohol Syndrome.

The Task Force also recognized that perinatal exposure to alcohol and other toxic substances was not included in the educational process for CADC/CARNs. The Task Force joined forces with the New Jersey Certification Board and in 2004, New Jersey became the first state to offer a certification specialty in Perinatal Addictions. Distinct from the CADC certification, this program focuses specifically on the effects of alcohol and drug exposure during pregnancy. In 2006, the New Jersey Certification Board approved the requirement that all CADC/CARNs must take 6 hrs of the Perinatal Addictions course, with a concentration on FASD, as part of new and re-certification.

The purpose of this report is to document the progress that the Fetal Alcohol Spectrum Disorders* Task Force has made since the submission of its report in 2001. In addition, it delineates the actions that the state needs to take to reduce the risk of prenatal exposures while addressing the needs of those who have been affected.

*Note: In 2004, the term, Fetal Alcohol Spectrum Disorders (FASD), was accepted by the three major federal agencies that address prenatal exposure to alcohol: the National Institute of Alcoholism and Alcohol Abuse (NIAAA), the Centers for Disease Control and Prevention (CDC), and the Substance Abuse and Mental Health Services Administration (SAMH-

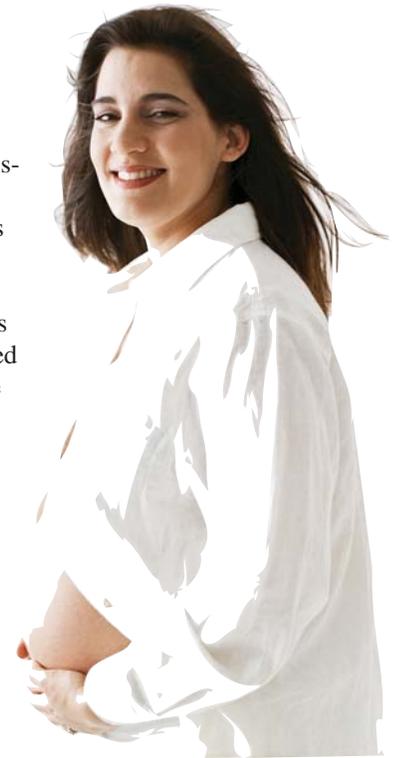
SA). FASD recognizes that prenatal exposure to alcohol results in a broad array of disabilities and incorporates other common terms such as Fetal Alcohol Effects (FAE), Alcohol-Related Neurodevelopmental Defects (ARND) and Alcohol-Related Birth Defects (ARBD). The New Jersey Task Force has similarly adopted the new term as part of its title.

A. How Common is Alcohol and Drug Use?

Recent national surveys attest to the continued and growing presence of alcohol use as a part of the American culture. According to the 2004 National Survey on Drug Use and Health (NSDUH), administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), an estimated 51% of all Americans aged 12 or older reported being current drinkers of alcohol (1). Almost 23% reported participating in binge drinking (5 drinks or more on one occasion) once in the 30 days prior to the survey and 6.9% reported that they were heavy drinkers (five or more drinks on the same occasion on at least five different days in the past 30 days). The prevalence of current alcohol use increased with age from 2.0% at age 12 to 36.2% at age 17. The rate reached a peak of 70.9% for persons 21 years old.

In comparison with the pervasive use of alcohol, illicit drug use is much lower in the general population. However, approximately 8.3% of all Americans aged 12 or older, reported that they were current illicit drug users in the NSDUH. Marijuana was the most commonly used drug, with a rate of 6.2%, followed by psychotherapeutic drugs, taken non-medically, e.g., pain relievers, tranquilizers, stimulations and sedatives (2.6%), heroin (1.6%), and cocaine (0.9%).

Alcohol abuse and illicit substance use are highly correlated. Almost 75% of all illicit drug users reported drinking alcohol as well. In contrast, level of drinking is correlated to illicit drug use with 32.6% of heavy drinkers reporting being current illicit drug users. For binge drinkers who were not heavy drinkers, 16.6% reported past month illicit drug use while occasional drinkers had a rate of 5.8%.





Drinking levels are also associated with tobacco use and serious mental illness (SMI). Over 61% of heavy alcohol drinkers smoke cigarettes while 21.8% of non-binge current drinkers and 17.7% of non-drinkers were cigarette smokers. SMI was reported among adults who reported heavy alcohol use and substance abuse (23.2%).

The Behavioral Risk Factor Surveillance System (BRFSS), used by the Centers for Disease Control and Prevention (CDC) to monitor national trends in public health, has documented a consistent rate of alcohol use among pregnant women. In 2001, 12.5% of pregnant women reported some alcohol use, with 1.6% reporting frequent drinking and 4.6% reporting binge drinking (2). The

NSDUH documented that 3.3% of pregnant women between the ages of 15 to 44 reported using illicit drugs in the month prior to their interview. This rate was significantly lower than the rate among women of the same age who were not pregnant (10.3%). Over 17% of pregnant women smoked cigarettes compared with 31.1% of non-pregnant women aged 17 to 44.

B. How Common is FASD and Prenatal Substance Abuse Exposures?

Because of lack of education about FASD, difficulties in diagnosing, and physicians' reluctance to discuss alcohol use with patients, the prevalence of FAS is unknown. However, CDC has conducted studies in four states -- Alaska, Arizona, Colorado, and New York -- as well as in Atlanta that document rates ranging from 0.2 to 1.5/1,000 live births (3). New Jersey's annual birth rate is an estimated 115,000 live births. This translates to a conservative estimate of 100 infants with FAS being born each year in the state. Research estimates that, for every one child born with FAS, an additional five are born with some FASD effects. This translates to an estimated 500 children with FASD born in New Jersey each year.



While New Jersey's Birth Defects Registry (BDR) includes FAS as a reportable disorder, reporting of birth defects was required only to age one and, because they are difficult to diagnose at birth, most children are not diagnosed until they are older. As a result, few children with FAS have been reported to the BDR. Data to determine the prevalence of FAS in the state are being collected by the FASD Regional Diagnostic Centers. Since the FASD Centers opened their doors in 2002, over 12,600 children have been screened for FASD. Diagnoses have been confirmed for 340 individuals. However, the mandated age of reporting birth defects to the Registry was increased to age five in 2006. It is thus expected that the number of reports to the BDR of children diagnosed with FAS will increase.

C. What are the Consequences of Prenatal Exposures?

In order for children to be diagnosed with FAS, they must meet three diagnostic criteria:

Facial Dysmorphism - smooth philtrum (the groove between the nose and the upper lip, thin vermilion ridge (upper lip) and small palpebral fissures (length of the eyes)

Pre- or Postnatal Growth Retardation

Neurological impairments - reduced volume in parts of the brain as evidenced by MRIs, mental retardation, other developmental disabilities and/or behavioral problems

Often the effects found in individuals with FASD are not significantly different from those with FAS. However, the children with FASD may not have the facial dysmorphism or meet the growth retardation standard. Persons with other FASDs may exhibit some neurodevelopmental and medical problems that are as serious as those found in those with FAS and that remain throughout the lifespan. Physical malformations that may result in expensive health care costs have been observed in some alcohol-exposed individuals.

The degree of growth retardation and intellectual impairment has been directly related to the degree of cranial abnormalities (4). As a result, children diagnosed with FAS and other alcohol-related birth defects often have significant physical abnormalities (e.g., heart defects) that result in expensive medical procedures requiring on-going health as well as mental and behavioral health and social service needs.

With respect to what has been termed "secondary disabilities," long-term research of almost 500 individuals with FASD has documented:



Secondary Disabilities Associated with Prenatal Exposure to Alcohol

- 65% had serious mental health problems, including depression and bipolar disorder (5)
- 61% had experienced disrupted school problems (6)
- 60% experienced trouble with the law (6)
- 50% had been confined in prison, drug or alcohol treatment centers or a mental health institution (6)
- 49% had exhibited inappropriate sexual behavior, often at precocious ages (6)
- 35% had alcohol and drug problems and a high proportion were unable to live independently (6)
- 80% had difficulties sustaining employment (6)

Children who are exposed to other substances in utero may have some or all of these disabilities. However, research on

prenatal exposure to heroin, methadone and/or cocaine has documented that these substances were not associated with decrements in intelligence, as measured by standardized tests. As has been found for children with FASD, the greatest mitigating factors for school success for children who have been exposed to illicit drugs have been stable and loving home environments, early identification and diagnoses, and access to services, e.g., preschool enrichment and no exposure to violence (7, 8). As noted earlier, a great proportion of the children exposed to drugs are likely to be exposed to alcohol and tobacco as well.

The costs associated with prenatal exposure to alcohol are enormous. Recent analyses project the lifetime health and social costs of raising a child with FAS to range from \$850,000 to \$3 million (9). These preventable expenses included extraordinary medical and mental health care, special education, juvenile and criminal justice costs, child welfare and protective services costs, addiction treatment, and adult social service needs.

Protective Factors for Prenatally Exposed Children

- Loving, stable family
- Diagnoses at an early age
- Access to services

II. Primary Prevention through Education

A. Professional Education

Northeastern FASD Regional Education and Training Center

In 2002, the New Jersey Medical School in Newark was the recipient of a grant from CDC to serve as one of four regional FASD Training Centers. The purpose of the grant was to develop a standard curriculum to train medical and allied health students and practitioners about the teratogenic effects of alcohol. The curriculum has a modular design and is based on a “train-the-trainer” model. The Regional Training Centers are using the curricula to provide information and training to medical and social service professionals throughout the New England and Mid-Atlantic Regions.



Northeast FASD Regional Education and Training Center FASD Modules:

- 1) The Foundation of FAS
- 2) Screening and Brief Interventions with Women
- 3) Models of Addiction
- 4) Biomedical Effects of Alcohol on the Fetus
- 5) Screening, Diagnosis and Assessment of FAS
- 6) Case Management through the Life Cycle
- 7) Social, Legal and Ethical Issues

Since its inception, the Northeast FASD Regional Education and Training Center has conducted numerous trainings within the medical, allied health, child protection, juvenile and criminal justice, education fields, and with families throughout New Jersey, the Northeast and Puerto Rico which has resulted in over 3500 professionals being trained.

Regional Perinatal Addictions Conferences

As part of their contract with the DHSS, each MCHC is required to sponsor a biannual regional conference on perinatal addictions. The consortia have used these conferences as an opportunity to educate allied health and social service professionals about women and addictions as well as the impact of prenatal exposures upon fetal development. Conferences have been tailored to address the most pressing needs of the service region.

B. Community Education

Targeted Media Campaign

The FASD Task Force is currently undertaking a targeted media campaign to educate specific communities about the effects of perinatal exposures to alcohol, drugs and cigarettes. The campaign, “Be in the kNOw” is concentrating on reach-

ing residents of Newark and Atlantic City during the first year of implementation. In future years, the campaign will target Paterson, New Brunswick, Trenton and Camden. A variety of media outlets are being employed and include: placards and posters in New Jersey transit buses and trains; billboards; radio Public Service Announcements, local newspaper advertisements, and posters and brochures placed in local stores, churches, beauty and nail salons and other venues. All materials are available in English and in Spanish. Individuals concerned about their use of alcohol, cigarettes or illicit substances during pregnancy are encouraged to call the New Jersey Family Health Line or visit the FASD Diagnostic Centers website. Since the campaign began in July 2006, the number of persons who have visited New Jersey’s FASD website has tripled. In addition, preliminary analysis of the data collected by the New Jersey Family Health Line indicates that more people have contacted the Health Line during the first quarter of Fiscal Year 2007 to inquire about perinatal addictions than had called cumulatively during the prior year.

Pregnant women need to
BE IN THE kNOw

✓ **NO** Alcohol
✓ **NO** Smoking
✓ **NO** Drugs

Think about it...
Every time you drink alcohol, smoke or use drugs,
so does your baby. Alcohol, cigarettes and drugs
can harm your unborn child!

For more information, call the New Jersey Family Health Line at
1-800-328-3838 or www.fasnj.org

New Jersey Family Health Line
Fetal Alcohol Spectrum Disorders

Community Education

Many members of the New Jersey FASD Task Force engage in educational and training activities. To begin to assess the spread of educational efforts and knowledge, the Task Force established a Training and Education Surveillance System in 2005. A total of 141 presentations were given by members of the FASD Task Force in 2005. A total of 5028 attended these FASD educational sessions.

During the first six months of 2006, a total of 109 presentations were made by members of the FASD task force. According to the presentation reports, a total of 3306 participants were educated on some aspect of FASD and/or perinatal addictions from the 109 presentations that were given

throughout the state. A wide range of audience participants attended the trainings, including physicians, nurses, family members, alcohol and drug treatment providers, high school teachers and allied health professionals. As a result, the FASD Task Force has been successful at providing perinatal addictions education to a broad audience.

As indicated by the training surveillance system, members of the FASD Task Force are gaining entrance to special populations. Various training models and approaches have been developed to reach these groups:

Substance Addiction Treatment Centers

Women who are in substance abuse treatment programs are at a higher risk for drinking alcohol than the general population

and for drinking during future pregnancies. Cerebral Palsy of New Jersey has been providing prevention education about FASD to women who are clients in substance abuse treatment programs and to the professional staff of the programs. Over 250 women and 90 staff in eighteen treatment centers have been educated about the risks associated with alcohol consumption during pregnancy.

Middle and High School Students

The Arc of Warren County has sponsored a “Teen Summit” for over 60 students from Warren County Middle and High Schools to heighten awareness and train peer mentors about the prevention of FASD.

The Hudson Perinatal Consortium has educated school personnel, who have then educated over 3,000 11th and 12th grade Jersey City public school students about Fetal Alcohol Syndrome (FAS). Thirty staff, including health teachers, school nurses, substance awareness coordinators and administrators have received six hours of education on the characteristics of FAS, prevention and ways to incorporate the curriculum into other health education efforts.

The Arc of Atlantic County works with high schools throughout the county to present programs to students about the effects of prenatal exposure to alcohol. This program also serves as a consultant and resource to other NJ agencies and community based organizations involved in the prevention, education and diagnosis of FAS and FASD to assure that they have access to up to date and comprehensive information. The consultant provides training, consultation and technical assistance in program and resource development.

Juvenile and Criminal Justice System

The Northeast FASD Regional Education and Training Center has made reaching both the justice and legal system a priority. Because of the high incidence of individuals with FAS/FASD being involved at some point in their lives, with the justice and legal systems, workshops have been provided in partnership with the The Arc of New Jersey’s Developmental Disabilities Offenders Program (DDOP) for state troopers in all regions of the State. In addition, the Regional Center has also provided trainings for family court personnel and probation officers. The information given includes general information on prenatal alcohol use, its effect on brain development and primary and secondary disabilities that arise through the life span. In addition, specific information needed by justice and legal personnel is provided. This includes how to recognize individuals with alcohol exposure, how to interview them, and how to provide appropriate services. Future trainings will include lawyers and judges.



The Arc of New Jersey, represented by the Director of the DDOP, served on an advisory board to the NJ Department of Law and Public Safety regarding the development and implementation of a new law enforcement and prosecutor training program. In this capacity, the DDOP Director provided FASD content for this three-year law enforcement training, funded by the US Department of Justice. The goal of the training program was to sensitize law enforcement personnel to issues affecting people with disabilities who are victims of sexual violence; to illustrate specific case examples/ role-plays; and, to provide them with a binder of materials, articles and resources for their use back at their criminal justice sites.



The FASD segment, which was presented by the Director of the Northeast FASD Regional Education and Training Center and the Director of The Arc’s Coalition for Prevention of Developmental Disabilities was part of a day-long workshop focused on other developmental disabilities, and included mini-lectures; videos; and, role-play. The audience included troopers, police officers; investigators; human service police; and, sheriff’s officers from across the state in three different workshops, in the north, central and southern parts of New Jersey. In addition, a fourth event focused exclusively on the needs of prosecutors and was held at the Hughes Justice Complex in Trenton. The Arc’s Coalition for Prevention has continued to provide on-going FASD technical assistance and consultation to DDOP concerning the juvenile and adult consumers with FASD in their caseload. Information about The Arc of New Jersey and the DDOP can be found at www.arcnj.org

Families and Foster Care - Saving Stories, Finding Hope

Families in New Jersey with a child with Fetal Alcohol Spectrum Disorders have been instrumental in the development of an FASD curriculum for parents, teachers and public health workers used nation-wide. The three-part curriculum provides current and relevant information on FASD; demonstrates how families affected by FASD can obtain support from families facing similar issues; and, shows how to obtain services and supports for children and families affected by FASD. Several New Jersey families participated in initial interviews; quotes from them were used in the *In Their Own Words* segment suggested by The Arc of New Jersey’s Coalition for Prevention of Developmental Disabilities. In addi-



tion to conducting the surveys, the Coalition for Prevention was also part of the seven-member curriculum development team/ chapter trainers organized by The Arc of the United States, which was awarded a 3-year grant by the Centers for Disease Control and Prevention to develop the curriculum. The Coalition was invited to conduct Parent/ Professional

Workshops and Train-the-Trainer Workshops in four states, as well as the panel presentation at the National Convention of The Arc of the United States. Though CDC funding has ended, invitational workshops have continued across the state and in the region with foster parents, child care workers, and teachers, all of whom have evaluated the curriculum, as a foster parent described it, as “the best workshop I had this year.”

The Northeast FASD Regional Education and Training Center has provided general information on prenatal alcohol use and FAS to case workers of the Division of Youth and Family Services (DYFS) through regional conferences. In addition, the Center has worked locally with various District Offices and foster parent groups to provide general training, as well as individual guidance for the children in their care.

III. Identification of Women and Children

A. The Perinatal Addictions Prevention Project

As one of its highest recommendations for action, the National Task Force on FAS/FAE recommended the identification of women at risk for having an alcohol-exposed pregnancy (1). In addition, because of the common use of alcohol in our society, the United States Preventive Services Task Force recently issued a report in the *Annals of Internal Medicine* that recommended primary care clinicians screen all adults and pregnant women for alcohol misuse and refer them for counseling, if necessary (10). Among the many health ills linked to alcohol, the Task Force noted that “...alcohol use during pregnancy can cause fetal alcohol syndrome, which can cause growth retardation, facial deformities, and central nervous system dysfunction” (10).

The major goals of the Perinatal Addictions Prevention Project include providing professional and public education, encouraging all prenatal providers to screen their patients for substance use/abuse and developing a network of available resources to aid pregnant substance abusing women. During the 2005 grant year, 2025 professionals participated in the 130 education programs provided throughout the state. There were 160 programs held to make information available to the public. Examples of places where this education occurred are community health fairs and displays and talks on college and high school campuses. Over 6400 people participated in these trainings.

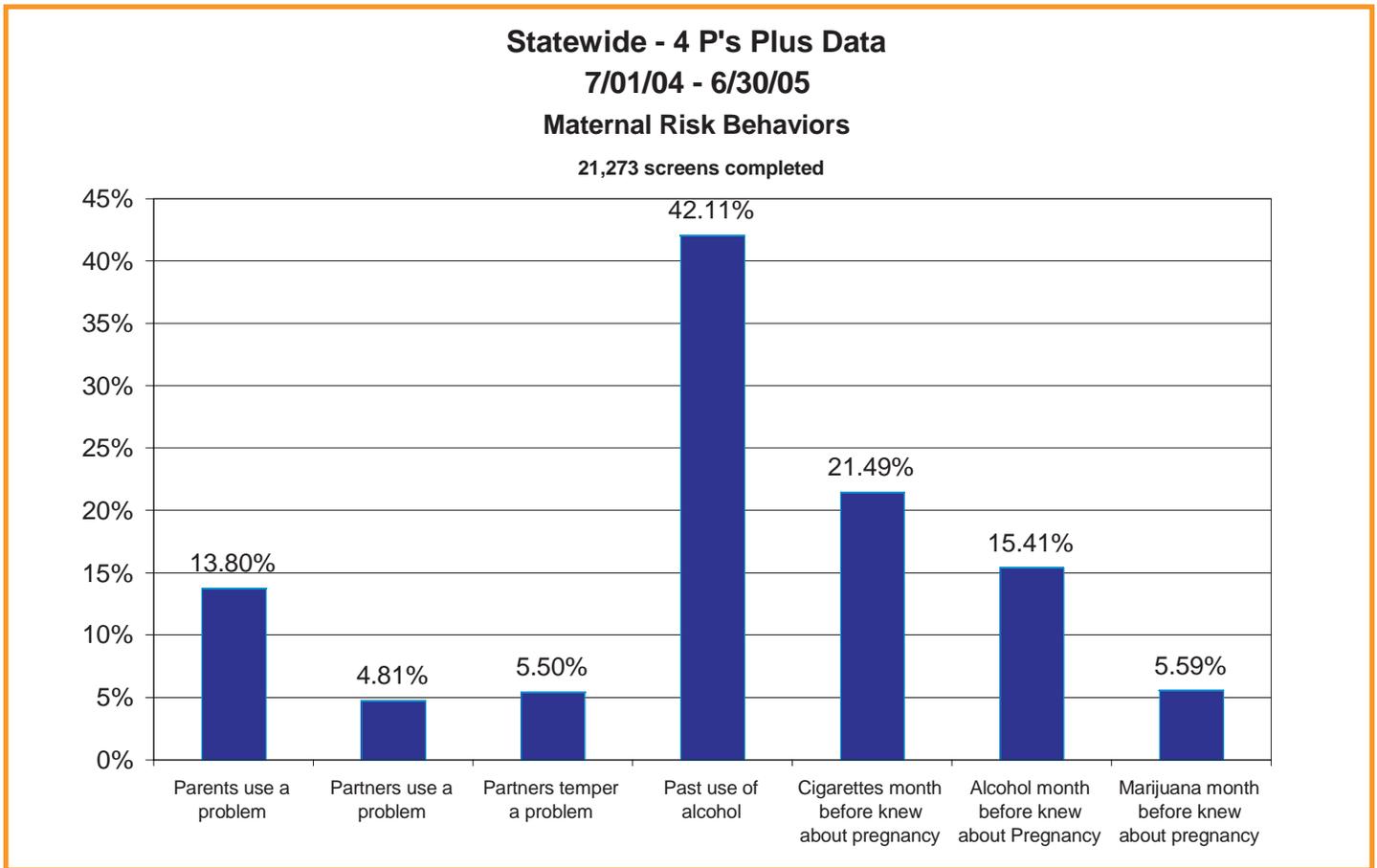
To help address the challenges associated with identifying women at risk of drinking or using illicit substances during pregnancy, the Family Health Initiatives, a subsidiary of one of the MCHC, the Southern New Jersey Perinatal Cooperative (SNJPC), received a grant from the Robert Wood Johnson

Foundation, New Jersey Health Initiatives. The purpose of the grant is to augment the prenatal screening system by developing a common database to collect and analyze aggregate information about the women screened and their treatment needs. All six MCHC/Perinatal Addictions Prevention Programs participating in this effort are using the 4 Ps Plus Screening and Referral Tool. This tool was developed by Dr. Ira J. Chasnoff, founder of the National Training Institute, and designed for the prenatal care setting. It is a 6-question screen that quickly identifies OB patients in need of in-depth assessment or follow up monitoring. The questions are broad based and highly sensitive, requiring only ‘yes’ or ‘no’ responses.

Since the implementation of the Screening Initiative in 2001 Camden City Healthy Start engaged 5 Camden prenatal provider sites. In 2002 the DHSS expanded the project statewide. In 2003, the Robert Wood Johnson Foundation New Jersey Health Initiatives provided funding to SNJPC’s subsidiary organization, Family Health Initiatives for the Window of Opportunity for Children project. A Window of Opportunity for Children in collaboration with DHSS and the six MCHC began coordinating the uniform implementation data collection and analysis for the statewide effort. During the grant year July 2004 through June 2005, 21,273 4P’s Plus Screens were completed.



The table below illustrates initial indications:



B. Substance Abuse Services for Women

Based on treatment admission data reported to the Division of Addiction Services (DAS) and the percentage of female clients, New Jersey recognizes the complexities associated with treating the female addict. The Division approximates funding through the Federal Substance Abuse Block Grant Women's Set Aside on an annual basis to fund a continuum of care. This continuum provides specialized treatment to pregnant women and women with dependent children.

-  Primary medical care for women including referral for prenatal care;
-  Primary pediatric care including immunization for their children;
-  Gender specific substance abuse treatment and other therapeutic intervention for women that may address issues of relationships, sexual and physical abuse and parenting (childcare must be provided while the women are receiving services);
-  Therapeutic interventions for children in custody of women in treatment which may, among other things, address the developmental needs, their issues of sexual and physical abuse and neglect; and sufficient case management and transportation to ensure women and their children have access to these services.



The Block Grant funds a statewide network of agencies that includes 5 Residential Programs (women and children), 4 Residential (women only), 4 Residential (Pregnant Women - 28 day programs), 11 Outpatient/Intensive Outpatient and 18 Methadone Maintenance Programs. Programs are required to provide or arrange for the provision of services that address the specific needs of this population such as:

In addition to the Block Grant, state dollars are allocated to fund treatment programs for women and their children under the supervision of the DYFS or at high risk of abusing sub-

stances and high risk of child abuse and neglect. Statewide treatment programs include 7 Residential programs for women and children (approximately six month length of stay); 13 Outpatient Variable Level of Care programs for women with children; and 7 Methadone Variable Level of Care programs for women with children. The overall treatment goal will be the sustainable recovery of each woman that will in turn impact the healthy reunification with her children. Programs are required to provide enhanced services including treatment, counseling, life skills training, parenting skills training, Strengthening Families curriculum, assessment and treatment for co-occurring disorders, referrals for children to medical (including immunizations) and/or psychological care as needed. Child care, transportation, case management and referral to services in the community are provided to each client in an effort to eliminate barriers to treatment.

C. FASD Diagnostic Centers



In 2001, the FAS Task Force submitted its report, *The Truth and Consequences of Fetal Alcohol Syndrome*, to Acting Governor Donald DiFrancesco. The establishment of diagnostic centers was included among the recommendations. Acting Governor DiFrancesco included funds to support these centers in his Kids Needs Initiative. An appropriation of \$450,000 was given to the Department of Health and Senior Services (DHSS).

Through a competitive bidding process, the DHSS awarded grants to six Child Evaluation Centers to administer the FASD Centers. In order to insure accuracy and consistency in diagnostic procedures, key staff attended the FASD training at the University of Washington. The purposes of the initiative are:

-  establish regional centers to diagnose and provide medical maintenance services to children with FASD and, when appropriate and available, refer to services
-  ensure regional access to an appropriate team of professional and ancillary personnel (neurodevelopmental pediatrician, psychiatrist, psychologist, social worker, learning disabilities specialist, geneticist, etc.) for the diagnosis, treatment and education for FAS and FASD
-  serve as regional resource centers for training/professional education regarding early detection and treatment work with the Perinatal Addiction Programs to ensure the availability of resources so that primary care providers within the regions disseminate information and literature that addresses the effects of FAS/FASD
-  coordinate with the regional Maternal and Child Health Consortia (MCHC) regarding activities to influence and assist perinatal and family planning providers and primary healthcare providers to upgrade their ability to address substance abuse issues within their practice
Information about the FASD Diagnostic Centers can be found at their website: <http://www.beintheknownj.org>

IV. FASD Strategic Plan

GOAL: TO MAKE ALL NEW JERSEY RESIDENTS KNOWLEDGEABLE ABOUT FASD AND PRENATAL SUBSTANCE ABUSE

A. Education and Training

Goal: Develop an interdisciplinary speaker's bureau.

Objective:

-  Develop a list of at least 12 speakers for the interdisciplinary speaker's bureau.

Activity:

-  Develop a questionnaire for the FASD Task Force Members, The Arc, the Perinatal Addiction Projects, and Maternal Child Health in order to gather professional training experience and expertise among its membership.

Objective:

-  Identify a list of at least 10 topics that will be covered by the speaker's bureau.

Activity:

-  Develop a questionnaire that will also include areas of expertise including but not limited to: Screening of Pregnant Women, Case Management and Treatment, Screening and Diagnosis of FAS/FASD, Primary and Secondary Disabilities, Case Management and Treatment, Legal/Ethical Issues.

Goal: Increase education and awareness of the risk of FASD and prenatal alcohol exposure.

Objective:

- Identify at least 5 new venues to provide education.

Activity:

- Develop a list of target audiences to receive education.
- Conduct telephone calls to identify new venues.
- Share information and contacts with the NJ FASD Task Force members.

Objective:

- Distribute at least 3,000 flyers and brochures to consumers in New Jersey.

Activity:

- Partner with the Maternal Child Health Consortium, Diagnostic Centers, The Arc, and schools to distribute the information.

Goal: Conduct Regional Focus Groups on Prenatal Alcohol Exposure and FASD

Objective:

- Conduct at least 6 focus groups, 2 in each region within one year.
- Identify at least 6 target groups to participate in the focus group, including but not limited to the following communities; Consumers, Medical, Substance Abuse Treatment and Prevention, Boards of Social Services, Community Based Organizations, Education, Mental Health, Child Protection, and schools including early intervention and preschool.

Goal: Insure implementation of FASD education as required by the core curriculum standards for physical education and health.

Objective:

- By 2010, 80% of all New Jersey schools will incorporate FASD education into their health curricula.

Activity:

- Work with the Department of Education to insure that all schools are aware of the core curriculum standards for Fetal Alcohol Spectrum Disorders.
- Identify, assess, modify and recommend existing FASD curricula to be used by schools.
- Task Force members include school-based FASD education in their community education plans.

B. Prenatal and Child Screening

Goal: Institute universal screening of women for alcohol, tobacco and drugs as a standard of prenatal care



Objective:

- By 2010, 75% of all physicians providing prenatal care to women screen for substance abuse.

Activity:

- Partner with Medicaid to establish universal prenatal screening policy.
- Work with ACOG, Academy of Family Practitioners, and other medical academies to assimilate policy.
- Establish relations with relevant Schools of Nursing and professional nurses associations.

Objective:

- Establish system of identification of prenatally exposed infants.

Activity:

- By 2008, all prenatally exposed infants will be screened at birth and provided follow-up services.
- By 2008, surveillance systems documenting maternal prenatal use will be linked to electronic birth certificates.
- By 2008, an “Early Warning Signs” tool for use by professionals, e.g., Early Intervention Programs, DYFS Case Workers, Addiction Treatment Providers, Preschool Educators, etc., to screen children and refer them to FASD Diagnostic Centers for evaluation will be identified and adapted or developed.

C. Treatment and Services

Goal: Increase awareness of Diagnostic Centers.

Objective:

- Annually, distribute at least 5,000 brochures about the Regional Diagnostic Centers to schools, child study teams, pediatricians, family practitioners, psychologists, social workers, DDD, Foster & Adoptive Family Services, NJ ARCH etc.

Activity:

- Partner with Maternal Child Health Consortium, The Arc, Division of Child Behavioral Health Services, Division of Developmental Disabilities, Division of Addiction Services, schools, medical & mental health professionals and early intervention programs to distribute brochures.

Goal: By 2010, create a single point of entry for information and referral for both women and children.

Objective:

- Identify an 800 telephone # to serve as a single point of entry for information and referral for women & children.

Activity::

- Train personnel who will be manning the 800 #.
- Include the 800 # on all brochures and public education information.

Goal: By 2010, create linkages to existing services for women and children.

Objective:

- Create a resource directory for existing services available to women and children throughout the State.

Activity:

- Identify existing services for women & children throughout the State.
- Create a resource directory describing the various services available to women and children in each county.

- Distribute the directory.
- Post the directory on the website.

Goal: By 2010, establish corps of trained professionals who treat individuals with FASD

Objective:

- Create a directory of physicians and other allied health professionals who treat persons with FASD in their private practices.

Activity:

- Identify physicians and other allied health professionals who will provide services and treatment to persons with FASD.
- Train physicians and other allied health professionals in health and psychological issues associated with FASD over the life cycle.
- Create a health care directory for distribution.



V. Bibliography

1. US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration. (2006). *Results from the 2005 National Survey on Drug Use and Health: National Findings* (Office of Applied Studies, NSDUH Series H-30, DHHS Publication No. SMA 06-4194). Rockville, MD.
2. US Department of Health and Human Services, Centers for Disease Control and Prevention. National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. Defining the national agenda for fetal alcohol syndrome and other pre-natal alcohol-related effects. *MMWR* 2002;51:9-12.
3. CDC. Fetal alcohol syndrome - Alaska, Arizona, Colorado, and New York, 1995-1997. *MMWR* 2002;51:433-5.
4. Mattson SN, Schoenfeld AM, Riley EP. Teratogenic effects of alcohol on brain and behavior. *Alcohol Research & Health* 2001; 25:3:185-191.
5. Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects (FAE). Final Report. University of Washington School of Medicine. September 1996.
6. Streissguth AP, Bookstein FL, Barr, HM, Sampson, PD, O'Malley, K, and Kogan Young, J. Risk Factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics*, 25,(4), 228-238.
7. Ornoy A, Segal J, Bar-Hamburger R, Greenbaum C. Developmental outcome of school-age children born to mothers with heroin dependency: importance of environmental factors. *Developmental Medicine Child Neurology*. 2001 October; 43(10): 668-75.
8. Hurt H, Brodsky NL, Roth H, Malmud E, Giannetta JM. School performance of children with gestational cocaine exposure. *Neurotoxicology and Teratology*. 2005 Marcy-April; 27(2): 203-211.
9. Lupton C, Burd L, Harwood R. Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. 2004.127C:1, 42-50.
10. US Agency for Healthcare Research and Quality. US Preventive Services Task Force Recommends that Primary Care Clinicians Screen and Counsel Adults to Prevent Misuse of Alcohol. Press Release: April 5, 2004. (Internet Citation)

FASD Regional Diagnostic Centers

Northern Regional Centers

Northern New Jersey FASD Diagnostic Center
UMDNJ-NJMS Department of Pediatrics
30 Bergen Street, ADMC 1608
Newark, NJ 07107
973-972-8930

CHATT - Child Evaluation Center
Newark Beth Israel Medical Center
Affiliate of Saint Barnabas Health Care System
201 Lyons Avenue
Newark, NJ 07112
973-926-4544

Central Regional Centers

Child Evaluation Center
At Jersey Shore University Medical Center
1944 Route 33, Suite 101-A
Neptune, NJ 07753
732-776-4178

Ambulatory Care Center
Children's Specialized Hospital
150 New Providence Road
Mountainside, NJ 07092
908-301-5511

Southern Regional Centers

South Jersey Healthcare
Child Development Center
1138 East Chestnut Ave, Bldg. 3B
Vineland, NJ 08360
856-696-1035

Children's Hospital of Philadelphia
Specialty Care Center in Atlantic County
4009 Black Horse Pike
Mays Landing, NJ 08330
609-677-7895

Regional Perinatal Addictions Prevention Programs

Northern New Jersey Maternal and
Child Health Consortium
17 Arcadian Avenue
Paramus, NJ 07632
201-843-7400

Gateway Northwest Maternal and
Child Health Consortium
381 Woodside Avenue
Newark, NJ 07104
973-268-2280

Hudson Perinatal Consortium
242 10th Street
Jersey City, NJ 07302
201-876-8900

Central New Jersey Maternal and
Child Health Consortium
2 King Court, Suite B
North Brunswick, NJ 08902
732-937-5437

Regional Perinatal Consortium of
Monmouth and Ocean Counties, Inc.
1255 Route 70, Suite 312
Lakewood, NJ 08701
732-363-5400

Southern New Jersey Perinatal Collaborative
2500 McClellan Avenue, Suite 250
Pennsauken, NJ 08109
856-665-6000



New Jersey Department of Human Services

Governor's Council on the
Prevention of Mental Retardation
and Developmental Disabilities

This report can be accessed on-line by visiting:
<http://www.state.nj.us/humanservices/OPMRDD/ofp.html>

Additional information about FASD and perinatal addiction resources
can be found at: www.beintheknownj.org

