



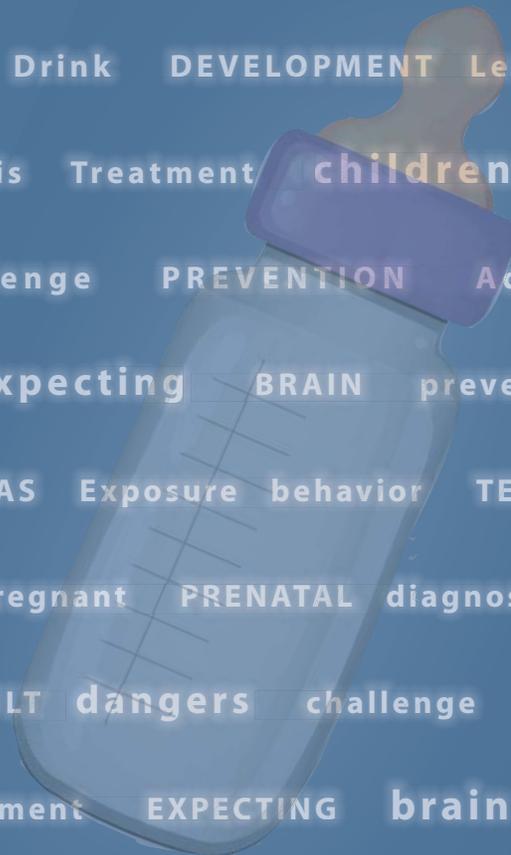
Be in the Know

A 5-Year Strategic Plan
to Prevent
Perinatal Alcohol Exposure
and Other Addictions
in New Jersey



The Governor's Council on the
Prevention of Developmental Disabilities
and
The New Jersey Fetal Alcohol Spectrum Disorders
and Other Perinatal Addictions Task Force

BRAIN Prevent alcohol baby FAMILY disability FAS exposure
behavior TEACH Drink DEVELOPMENT Learn Stigma pregnant
PRENATAL diagnosis Treatment children Responsibility ADULT
dangers challenge PREVENTION Adolescents Dangerous
TREATMENT Expecting BRAIN prevent ALCOHOL FASD
FAMILY disability FAS Exposure behavior TEACH Drink DEVELOPMENT
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Responsibility ADULT dangers challenge PREVENTION Adolescents
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in New Jersey



State of New Jersey
Chris Christie, *Governor*

Kim Guadagno, *Lt. Governor*

Department of Human Services
Jennifer Velez, *Commissioner*

**The Governor's Council on the
Prevention of Developmental Disabilities
and
The New Jersey Fetal Alcohol Spectrum Disorders
and Other Perinatal Addictions Task Force**

The New Jersey Task Force on Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions



MISSION

Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) are the nation's leading causes of preventable birth defects and developmental disabilities. The mission of the New Jersey Task Force on FASD and other Perinatal Addictions is to prevent FASD and to promote effective, life-long interventions for those affected by prenatal exposure to alcohol and other substances.

The authority for the New Jersey Task Force is derived from Public Law 1987, Chapter 5, as amended by Public Law 2000, Chapter 82, which establishes the Governor's Council on the Prevention of Developmental Disabilities. The New Jersey Task Force on Fetal Alcohol Spectrum Disorders and other Perinatal Addictions is a standing committee of the Council.

GOALS

1. To advise and foster coordination among state and local agencies on issues related to preventing alcohol and other substance use.
 2. To promote communication and education statewide on the adverse conditions associated with prenatal use of alcohol and other substances.
 3. To identify and encourage the implementation of effective strategies for preventing and treating FASD.
 4. To determine what services are currently available and to identify gaps in needed services for women at risk and for individuals affected by prenatal exposure to alcohol and other drugs.
 5. To encourage the availability and accessibility of appropriate diagnostic and treatment services for women at risk of having alcohol-exposed pregnancies and for individuals with FASD
 6. To encourage the inclusion of training about the effects of prenatal exposure to alcohol and other perinatal addictions in medical, allied health, and school curricula, as well as in continuing education venues.
 7. To serve as a source of assistance to families and state and regional agencies regarding FASD.
 8. To disseminate current research data regarding the effects of prenatal exposure to alcohol and other substances.
 9. To promote the reporting of the incidence of FAS/Partial FAS (pFAS) to the Birth Defects Registry so as to improve surveillance in the state of New Jersey.
 10. To provide education about prenatal exposure to alcohol and other substances to all New Jersey public school district personnel.
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2012 Fetal Alcohol Spectrum Disorders Task Force



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JENNIFER VELEZ
COMMISSIONER

August, 2012

Honorable Chris Christie
Governor of the State of New Jersey
New Jersey State House
Trenton, New Jersey 08625-0001

Dear Governor Christie:

The use of alcohol, illicit drugs and tobacco by pregnant women continues to be a serious public health problem in New Jersey. Fetal Alcohol Spectrum Disorders (FASD) are the most preventable causes of intellectual and other developmental disabilities in the United States and the associated costs to the state are very high – lifetime costs could be as high as 4.2 million dollars per individual. The Governor's Council on the Prevention of 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. This Task Force has been active in New Jersey for over 30 years.

Accordingly, I am submitting the third report from the FASD Task Force, which summarizes the progress that New Jersey has made over the past five years to address the problems associated with prenatal alcohol and substance abuse. In addition, they have developed a new strategic plan for New Jersey to ameliorate the effects of prenatal exposures over the next five years.

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".

Commissioner Jennifer Velez

Introduction and History



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 (DOH) in the early 1980's. In 1985, the Governor's Council on the Prevention of Intellectual and Developmental Disabilities published its first report 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 DOH 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 these "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 DOH, 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 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 the Governor: "**The Truth and Consequences of Fetal Alcohol Syndrome: Why New Jersey Should Be Concerned.**" The report documents the progress that New Jersey took to prevent prenatal exposures to alcohol, tobacco and illegal 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 www.beintheknownnj.org.

As a result of the report, in 2002, the Governor appropriated \$450,000, to the DOH to support the establishment of regional Fetal Alcohol Syndrome Diagnostic Centers. Currently, there are six centers based in Child Evaluation Centers that are located throughout the state. Key staff from each of the FAS Regional Diagnostic Centers attended the training program at the University of Washington to gain expertise in the use of the Four Digit Coding system, a standardized procedure used to diagnose an individual with

suspected prenatal alcohol exposure. Besides diagnostics, the Centers also are required to do outreach, information and referral to services, case management, and community and professional education.

In addition, the FAS Regional Diagnostic Center located at UMDNJ-NJ Medical School, received a grant from the Centers for Disease Control and Prevention (CDC) to serve as one of the original four Regional FAS Training Centers. A curriculum was developed, targeting medical and allied health students for the trainings. This center also had established an FASD Surveillance system.

During this same period, the DOH 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) who are based in the Regional Maternal and Child Health Consortia (MCHC).

The MCHCs (see listing in appendix) 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. Representatives from both the FAS Regional Centers and the MCHC PAPPs are members of the FASD Task Force. This participation has greatly enhanced communication and coordination between the state and community agencies that are addressing Perinatal addictions.

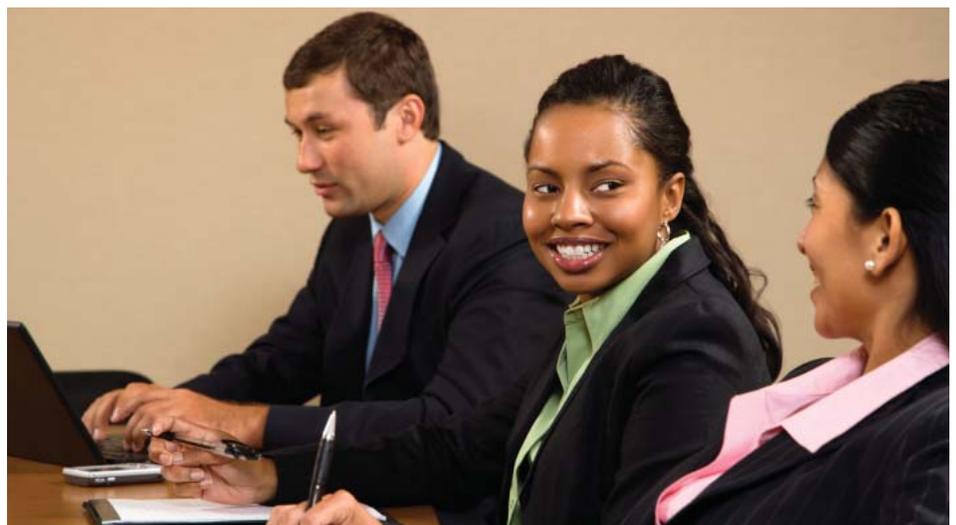
The NJ FASD Task Force has been successful in influencing major policies and programs in other areas as well. Educating adolescents about the dangers of consuming alcohol during pregnancy was identified as a primary objective in the 2001 report. To this end, the Task Force worked with the New Jersey 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 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 was planning 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 six countries to the 30th Anniversary Conference of the first US article 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 CADCs.

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 CADCs must take 6 hours of the Perinatal Addictions course, with a concentration on FASD, as part of recertification.

In 2004, the term: "*Fetal Alcohol Spectrum Disorders (FASD)*" was accepted for use 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 (SAMHSA). FASD recognizes that prenatal exposure to alcohol results in a broad array of disabilities and incorporates other common diagnostic terms, such as Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Neurodevelopmental Defects (ARND), and Alcohol-Related Birth Defects (ARBD). The New Jersey Task Force then followed suit, and similarly adapted the new term as part of its title.



In 2007, as part of a statewide multimedia public education campaign, the FASD Task Force launched its website: www.beintheknownj.org. The website includes information and referral sources regarding prenatal substance use and developmental issues, with a focus on alcohol. Starting with only 326 visits in 2007, the site now has grown to over 74,000 visits in 2011, with a total number of 219,612 visits in the period of 2007 to 2012. It is expected that the website will continue to play an important role for the Task Force, as more and more people use social media and other on-line educational tools for their trainings and information.

Also, in 2007, the Task Force co-sponsored a conference: *"Women's Health: Addiction, Trauma and Hope"*, in partnership with the Governor's Council on Prevention, the DOH, and the Department of Human Services' Division of Addiction Services. Approximately 300 CADCs and other Allied Health Specialists attended this educational initiative. Some notable speakers from the field were Luther Robinson, MD, a noted dysmorphologist working with the NIAAA global FASD studies, Norma Finklestein, Ph.D, known for her work in trauma and addiction in women, and Kathy Tavenner



Mitchell, LCADC, Vice President and the National spokesperson for the National Organization on Fetal Alcohol Syndrome. The two day conference was very well received, and people were turned away at the door, for lack of space.

The Task Force also launched a media campaign (described elsewhere in this plan) which continues to this day. Using Public Service Announcements (PSAs), brochures, posters and radio spots, the Task Force has been able to spread its prevention message all across the state. A television ad campaign was developed with seven ads (in English and Spanish) which have been running for the last four years throughout New Jersey's Cable network COMCAST. Data from May 14th - June 17, 2012 found the banner ads had been seen by 542,629 people, with 578 "checks" to the *beintheknownj* website (personal correspondence, J Palumbo, COMCAST, June, 2012). The developed ads can be found on the *beintheknownj* website and *YouTube*.

From 2007-2011, the Task Force worked diligently to address the objectives of its first five year plan. Results included increased screening

for women, increased screening of children for prenatal alcohol exposures and increased informational trainings and media activities throughout the state. New Jersey is considered to be one of the East Coast's premier states regarding its services and educational programs for prenatal alcohol and other substance use due to its implementation of many of the recommendations contained in its first *Five Year Plan, Be In The Know*, available at www.state.nj.us/humanservices/opmrdd/fasd/index.html.

However, not all objectives were met in its most current plan- New Jersey still needs to educate more teachers and mental health staff, for example, on the disabilities associated with FASD.

The purpose of this report is to document the progress that the Fetal Alcohol Spectrum Disorders Task Force continues to make since the submission of its last report in 2007 (the original report can be found at the website: www.beintheknownj.org). In addition, it delineates the actions that the state still needs to take to reduce the risk of prenatal exposures while addressing the needs of those who have been affected.

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 Health statistics from the National Health Interview Survey, 2010⁽¹⁾, 50.9% of adults over 18 years of age and over are current regular drinkers (12 drinks in the past year), with 13.6% considered “infrequent drinkers” (1-11 drinks in the past year). The number of alcohol liver disease deaths totaled 15,183, with an additional 24,518 deaths being alcohol-induced. These exclude deaths due to accidents and homicides which are strongly associated with alcohol consumption. Also in 2010, research documented that Caucasian women consume more drinks per person, and are more likely than Latino or African American women to consume five or more drinks a day or to drink to intoxication⁽²⁾.

When one looks at the prevalence of illegal drug use, the statistical data is much different. 8.7% of persons 12 years of age and older used drugs in the past month; 6.6% used marijuana in the past month, and 2.8% used any nonmedical psychotherapeutic drug in the past month.

For New Jersey, results from the Behavioral Risk Factor Surveillance System (BRFSS), 2010⁽³⁾ data show that for adults who have had at least one drink of alcohol within the past 30 days is 56.2%. Heavy drinkers (adult males –more than two drinks a day; females more than one drink a day) were found to be at 4.3%. “Excessive drinking” rates, from the 2012 County Health Rankings and Roadmaps ranking states⁽⁴⁾ found the rates for NJ to be higher. The highest rates -18%- were found for the counties of Sussex, Hunterdon, Gloucester, Atlantic and Cumberland. The lowest rate of 13% was found in Middlesex County. Overall, the rate of binge drinking (males-five or more drinks on one occasion; females four or more drinks on one occasion) was found to be 13.8%. However, considering only the rate for women, a serious pattern emerges. The

BRFSS 2008 data found estimates of alcohol use (any use and binge drinking) for NJ women to be at 52.3%.

The rates and the resulting problems for pregnant women are much more frightening. SAMSHA’s most recent report from their 2002-2010 National Survey on Drug Use and Health⁽⁵⁾ found the rate of alcohol use by pregnant Black and White women to be almost the same- 12.8% and 12.2%, respectively, and were much higher than Latino women at 7.4%. Latino women also were less likely to use cigarettes (21.8% of White women and 14.2% of Black women who were pregnant, ages 15-44, smoked cigarettes). SAMSHA Director, Pamela Hyde stated that: “...when pregnant women use alcohol, tobacco or illicit substances, they are risking health problems for themselves and poor birth outcomes for their babies...”

In August, 2011, the American College of Obstetricians and Gynecologists (ACOG) published a committee opinion paper, stating that alcohol use by women has a disproportionate effect on their health and lives, including reproductive function and pregnancy outcome. In the same paper, they strongly state that all obstetrician-gynecologists give “compelling and clear advice” to avoid alcohol use and to provide assistance to achieve abstinence⁽⁶⁾.

The most recent CDC Morbidity and Mortality Weekly report⁽⁷⁾ looked at the 2006-2010 alcohol use and binge drinking pattern for women of childbearing age (18-44) in the US. They found that 7.6% of pregnant women (1 in 13) and 51.5% of non-pregnant women (1 in 2) reported drinking alcohol in the past 30 days. Among pregnant women, the highest estimates were for women aged 35-44 (14.3%), white women (8.3%), college graduates (10%) and employed women (9.6%). 1.4% of pregnant women still reported binge drinking within the last 30 days. Among binge drinkers, the average frequency and intensity of binge episodes were similar – about three times a month and approximately six drinks on occasions for those women who were pregnant or not.

Thus, as more and more women are drinking, and the resulting effects more evident, the *Five Year Plan for NJ* includes goals and objectives for ensuring that more women are educated about prenatal alcohol effects, and that more women will be screened for their alcohol use during pregnancy.





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

Because of lack of education about FASD, difficulties in diagnosing, and often 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.⁽⁸⁾ However, newer case studies, by  Philip May documents the FAS rates at closer to 2-7/1000, and those for FASD 2-5%, in "typical, mixed-racial and mixed socio-economic populations."⁽⁹⁾

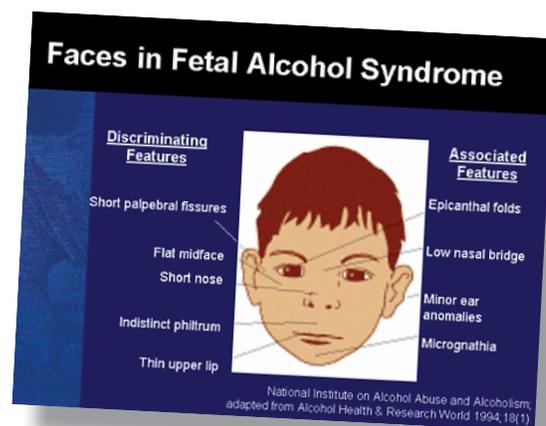
New Jersey's annual birth rate is an estimated 110,331 live births.⁽¹⁰⁾ This translates to a conservative estimate of 2,207 -5,517 infants with prenatal alcohol exposure being born each year in the state. Many adolescents and adults exposed to prenatal alcohol may never have been diagnosed, or may have been misdiagnosed.

While New Jersey's Birth Defects Registry (BDR) includes FAS as a reportable disorder, reporting of birth defects is required only to age five and many children are not diagnosed until they are older. Only 163 children have been reported to the Birth Defects Registry, since 2000. Data to determine the prevalence of FAS in the state are being collected by the FASD Regional Diagnostic Centers. Since 2007, the FASD Centers have screened over 894 children. FAS diagnoses have been confirmed for  individuals; FASD has been found for 329 individuals assessed. Given the birth rate for New Jersey, and the national estimates, this number is much lower than expected.

C. What are the Consequences of Prenatal Exposures?

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

1. **Facial Dysmorphia** - smooth philtrum (the groove between the nose and the upper lip), thin vermilion ridge (upper lip) and small palpebral fissures (length of the eyes).
2. **Pre- or Postnatal Growth restriction;** and
3. **Neurological impairments** - reduced volume in parts of the brain as evidenced by MRIs, Intellectual Disability, 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 dysmorphia or meet the growth restriction standard. Persons with FASDs exhibit neurodevelopmental, growth and/or medical problems that are as serious as those found in individuals with FAS and that may remain throughout their lifespan. Disabilities that result in expensive health care and educational costs have been observed in individuals prenatally exposed to alcohol.

The degree of growth restriction and intellectual impairment has been directly related to the degree of cranial abnormalities⁽¹¹⁾. 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.

Still considered to be the most informative work regarding secondary disabilities, long-term research by Dr. Ann Streissguth found that individuals with FASD have the following lifelong issues:

- 65% had serious mental health problems, including Depression and bipolar disorder
- 61% had experienced disrupted school problems
- 60% experienced trouble with the law
- 50% had been confined in prison, drug or alcohol Treatment centers or a mental health institution
- 49% had exhibited inappropriate sexual behavior, often at precocious ages
- 35% had alcohol and drug problems and a high proportion were unable to live independently
- 80% had difficulties sustaining employment ⁽¹²⁾.

But Dr. Streissguth also described four important “protective factors” that may influence the long-term development outcomes for Prenatally Exposed Children:

- a loving, stable family,
- diagnoses at an early age,
- no exposure to violence and
- access to needed services.

Children who are exposed to other substances in utero also 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 always 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 ⁽¹²⁾. 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 \$870,000 to \$4.2 million ⁽¹³⁾. 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.

It is increasingly apparent that, with the multitude of problems and disabilities often associated with prenatal alcohol exposure, a multi-modal, multi-systemic approach is needed for assessment and management. Medical, education, social welfare, psychology, occupational and speech therapy, and legal advocacy all may be needed to ensure a healthy and safe environment for an individual exposed prenatally to alcohol ⁽¹⁴⁾.



II. Primary Prevention through Education

A. Professional Education



Northeastern FASD Regional Training Center/New Jersey FASD 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 had a modular design and was based on a “train-the-trainer” model. The modules developed for training include:

- 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

(The curriculum- FASD Competency-Based curriculum Development Guide for Medical and Allied Health Education and Practice- can be downloaded from www.cdc.gov)

The Northeast Regional Training Center used the curricula to provide information and training to medical and allied professionals throughout the New England and Mid-Atlantic Regions, as well as Puerto Rico. 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 8,500 professionals being trained. Upon completion of



the CDC grant in 2009, the Northeast Center received a contract for 2010-2011 to continue its work through the NJ Office for the Prevention of Developmental Disabilities (OPDD). The Center was then renamed: *The New Jersey Education and Training Center*, and continued to provide consultation and trainings throughout New Jersey. Since 2008, the Center has provided 50 trainings to 1339 attendees from various professional, medical and community groups in New Jersey. In addition, the Center continues to have yearly webinars and podcasts through the UMDNJ department of continuing education. The Center also provides on-going consultations for NJ families and agencies, as needed. Finally, the Center also continues to work with various federal agencies and Northeastern states to provide consultation and trainings in prenatal alcohol and FASD.

OPDD has been an active member of the FASD Task Force, since its inception. Working under the guidance of the Governor’s Council on the Prevention of Developmental Disabilities, OPDD

provided grants to support on-going FASD prevention education. In the past, these initiatives, which have involved members of the Task Force included:

The Arc of New Jersey

The Arc of New Jersey has been an active member of the Task Force, and instrumental in many of the activities and conferences. In addition, they participated in the  Arc chapter, CDC funded project of The Arc of the US entitled: “*Sharing Stories, Finding Hope.*” They have sponsored over 370 Pregnant Pause events in the state, covering all 21 counties with an estimated 48,000 participants. The NJ Coalition for Prevention of Developmental Disabilities from The Arc of NJ also has presented at the most recent criminal justice conference  the African American Health Association Roundtable, and at various health fairs, child care centers and high schools. As noted previously, the Coalition also presently has a media campaign throughout NJ.

B. Community Education

The Arc of Atlantic County



The **Arc of Atlantic County** provided much leadership in the development of the “*beinthekNOW*” campaign, using a variety of marketing strategies to educate the general community. The Arc of NJ also provided many educational sessions to a number of communities in the southern part of the state. These efforts resulted in over 1,100 high school students and other individuals being educated about the importance of not consuming alcohol during pregnancy.

The Arc of Atlantic County worked with regional middle 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 regional 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. They provide training, consultation and technical assistance in program and resource development

Targeted Media Campaign

The FASD Task Force continues its media campaign to educate communities about the effects of perinatal exposures to alcohol, drugs and cigarettes. The campaign, “*Be in the kNOW*”

(about alcohol and drugs) has now been used in all 21 counties of New Jersey.

Materials are available in English and in Spanish on the website. 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 *beintheknownj* website. Since 2007, the number of people who have visited the website has increased from 326 visits in 2007 to 74,880 in 2010, and 32,763 in the first 5 months of 2012. In

addition, preliminary analysis of the data collected by the New Jersey Family Health Line indicates that, each year, more people are now contacting the Health Line to inquire about perinatal addictions.

In conjunction with the *beinthekNOW* campaign, the New Jersey Coalition for Prevention of Developmental Disabilities, through The Arc of NJ, has just begun a poster and magazine ad campaign. The ads have been seen in montly magazines, such as *NJ Monthly*, and in weekly papers, such as the *Star Ledger*.

Other Task Force Partners

Many members of the New Jersey FASD Task Force engage in educational and training activities. Presentations are given by various members of the FASD Task Force, including staff from all of the FASD Diagnostic centers, MCHs and The Arc of NJ.

Participants are educated on some aspect of FASD and/or perinatal addictions. A wide range of audience participants attend the trainings, including physicians, nurses, social workers, legal and justice representatives, child welfare, family members, alcohol and drug treatment

providers, educators and allied health professionals. As a result, the FASD Task Force has been successful at providing perinatal addictions education to a broad audience.

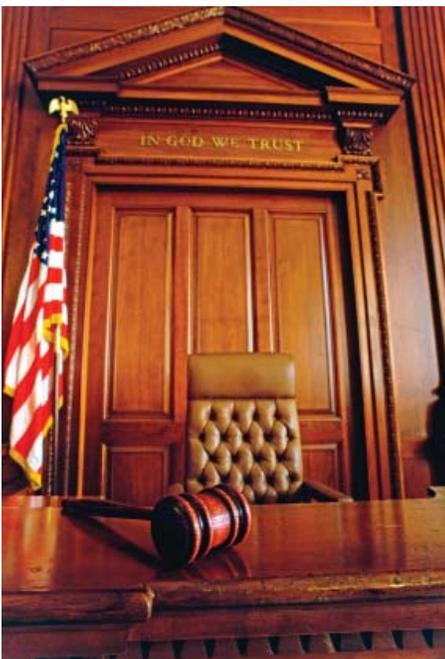
Substance Addiction Treatment Centers

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.

In FFY 2011, DMHAS contracted with 211 for an Addictions Hotline. 211 provides pre-treatment screening, motivational counseling and case management/care coordination over the phone, which can better engage and support individuals who reach out in search of help. 211 can be a resource to prenatal care providers when pregnant women who screen positive on the 4Ps Plus are in need of substance abuse screening



and a “warm hand-off” to a licensed substance abuse treatment provider (The 4 Ps Plus is a standardized brief questionnaire to be used by obstetricians to identify women at risk of substance abuse and/or domestic violence during pregnancy.) The DOH worked successfully with DHS’ DMAHS to have Medicaid Contracts use the 4 Ps Plus to screen pregnant women.



Juvenile and Criminal Justice System

The New Jersey FASD Education and Training Center has made reaching  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. The NJ Center has provided trainings for family court personnel, probation officers and child welfare workers. 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 the United States, through their Criminal Justice Advocacy Program sponsored a conference in 2012 which included information on FASD.

Families and Foster Care - Saving Stories, Finding Hope

Families of children with Fetal Alcohol Spectrum Disorders in New Jersey have been instrumental in the development of an FASD curriculum, developed by The Arc of the United States, 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. The Northeast FASD Regional Education and Training Center/NJ FASD Education and Training Center has provided general information on prenatal alcohol use and FAS to case workers of the Department of Children and  Family (DCF) 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. The Arc of the United States and the NJ FASD Education and Training center is presently working with the Child Welfare Initiative from Stockton State, Rutgers University, and Montclair State University to provide a one-day elective course for all child welfare workers on FASD. The curriculum was developed by Brian Illencik from The Arc of the United States.



III. Identification of Women and Children

A. The Perinatal Addictions Prevention Project (PAPP)

The major goals of the PAPP 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. The Risk Reduction Coordinators in each Maternal Child Health Consortia (see Appendix for listing of all MCHCs) are responsible for implementing this project.

The State has endorsed the 4 Ps Plus screening tool. This tool was developed by Dr. Ira J. Chasnoff and designed for the prenatal care setting. It quickly identifies OB patients in need of in-depth assessment or follow up monitoring. The questions are broad based and sensitive, requiring only a “yes” or “no” answer. This tool was revised in 2011. There now are questions that screen pregnant women for domestic violence and possible mood disorders. During the last five years, the number of NJ women who were screened has increased to approximately 34% in 2011. The 4 Ps Plus can be found in the Appendix.

As part of their contract with the DOH, each MCHC is required to work with their regional FAS Diagnostic center to provide education in their region. In addition, the MCHCs 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. The MCHs have reached 89,958 individuals through their educational programs, from 2007-2011.

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. There were 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.

B. Substance Abuse Services for Women

The Division of Mental Health and Addiction services (DMHAS) provides approximately \$16 million annually in Federal Block Grant Women’s Set Aside and state funding to a statewide network of 45 licensed substance abuse treatment providers in all modalities of care. This funding is for gender specific substance abuse treatment for pregnant and parenting women, and women and their children under the supervision of the Division of Children and Family Services (DCF). Programs are gender responsive and designed to meet the specific needs of women and their children.



C. FASD Diagnostic Centers

In 2001, the FAS Task Force submitted its report, *The Truth and Consequences of Fetal Alcohol Syndrome*, to the Governor. The establishment of Diagnostic Centers was included among the recommendations. Funds were included to support these centers - an appropriation of \$450,000 was given to the Department of Health (DOH), which continues to this day.

In 2002, through a competitive bidding process, the DOH awarded grants to six Child Evaluation Centers to administer the FASD Centers. In order to insure accuracy and consistency in diagnostic procedures, key staff from all Diagnostic Centers attended the FASD 4 Digit Code training at the University of Washington. This model is used for diagnosis in all six NJ Centers. The mandate for each Center is to regionally diagnose and provide case management services for individuals





who come through their Centers. Each Diagnostic Center has an appropriate team of professional and ancillary personnel (neuro-developmental pediatrician, psychiatrist, psychologist, social worker, learning disabilities specialist, geneticist, etc.).

The Centers also serve as regional resources for training/professional education regarding early detection and treatment, working with the Perinatal Addiction Programs to ensure the availability of resources so that care providers within the regions understand and can disseminate information and literature that addresses the effects of prenatal alcohol exposure. Information regarding the FASD Diagnostic Centers can be found at our website: www.beintheknownj.org



Cultural Competence in Prevention

- ✓ A physician recommends contraception to a woman to treat and relieve severe monthly menstrual cramps. The patient is a devout Catholic and does not believe in taking any form of contraception. She refuses the treatment plan and the physician documents “non-compliance” on the medical record.
- ✓ A person who is blind receives a written letter to attend an important meeting
- ✓ A mother from an Eastern European country never has sought prenatal care for any of her deliveries. All were home births, attended by a midwife. She delivers and is diagnosed with Gestational Diabetes. The baby is in distress. Staff are annoyed she neglected to attend prenatal care.

All of the above examples remind us that cultural competency is an intrinsic reality for all individuals. In order to encourage dialogue and inspire trust from the communities we serve, we must consider that cultural awareness is a two-fold process:

1. It requires a continual evaluation of New Jersey residents’ life views and experiences; it purposefully seeks to understand and integrate feedback from constituents it serves in order to enhance outreach efforts;
2. Cultural competence requires providers to monitor existing paradigms in order to ensure a response that adapts to the cultural needs of communities they are serving.

The literature suggests that a culturally competent substance abuse prevention program requires educators to have a thorough grasp of the language, values, belief systems and challenges faced by the targeted recipient population ⁽¹⁵⁾.

Any program should incorporate a representative level of relevant cultural elements and draw images and themes from popular culture likely to resonate with a wide variety of consumers.

By offering a broad range of culturally relevant material and allowing consumers to bring their own cultural perspectives into group discussions, a program can achieve cultural competency ⁽¹⁵⁾.

The present five year strategic plan will make every effort to ensure that all recommended activities and written materials developed will be culturally and linguistically appropriate.



IV. FASD FIVE YEAR STRATEGIC PLAN- 2012-2017

OVERALL GOAL: To make the majority of New Jersey residents knowledgeable about FASD and Prenatal Substance Abuse, by 2017.

A. Education and Training

Goal:

To increase education and awareness of the risk for FASD and other prenatal substance exposure.

Objective:

By 2013, re-establish a list of speakers for the interdisciplinary Speaker's Bureau.

Activity:

- Confirm a list of 10-15 speakers for the Speaker's Bureau.
- Seek possible interested speakers from the FASD Task Force to train for the Speaker's Bureau.

Objective:

Decide on core presentations from a list of at least 10 topics that will be covered by the Speaker's Bureau. These include, but are not limited to: screening of pregnant women, brain damage from alcohol and prenatal substance use, screening for and diagnosis of FAS and FASD, primary and secondary disabilities associated with prenatal alcohol use, case management through the lifespan, and legal/ethical issues.

Activity:

- Develop core presentations from above list, which will be utilized by all speakers in the Speakers' Bureau
- Train chosen speakers, from the chosen topic list.
- Presentations will be adapted to various professional and paraprofessional groups, such as medical personnel, allied health, child welfare, legal and justice, adoption, education and state organizations.

Objective:

By 2014, identify new venues and expand existing venues to provide education.

Activity:

- Develop a list of new audiences to receive education.
- Share information and contacts with the NJ FASD Task members



Objective:

By 2017, 80% of all New Jersey schools will incorporate FASD education into their health curricula, as mandated by the NJ Educational Core Curriculum standards.

Activity:

- Work with the Department of Education to ensure that all schools are aware of the core curriculum standards for Fetal Alcohol Spectrum Disorders.
- Share "10 Key Points", developed by the NJ Task Force members on FASD and perinatal exposure, with all educational groups, for their use.
- Develop simple powerpoint presentation on prenatal alcohol and substance use, for use by the school system, as it relates to their core curriculum standards.

B. Prenatal Screening for Alcohol and Substance Use

Goal:

By 2017, to continue and increase universal screening and Brief Intervention of women for alcohol, tobacco, substance use, mental health issues, and domestic violence, as a standard of prenatal care.

Objective:

By 2015, 50% of all pregnant women will be screened for alcohol, tobacco and other drug (ATOD) use/abuse.

Activity:

- Recruit and support prenatal care providers to screen patients using either the 4Ps Plus or the PRA.



Goal:

By 2015 increase access to appropriate referrals for assessment, following women who are screened and identified with risk factors



Objective:

By 2015, assist Obstetrics providers to increase the use of directories to refer women for appropriate services.

Activity:

- Update and distribute regional directory of services that are available for women with community groups to ensure resource lists are current and comprehensive.

Goal:

By 2017 identify a process and steps to move toward a more comprehensive approach in the management and treatment of women of childbearing age.

Objective:

By 2014, convene groups including ACOG, ASAM, AAP, DAMHS, and NJ judiciary and legal groups to facilitate collaboration.

Activity:

- For medical groups- review and address the detox process for pregnant women at treatment centers. Develop best practices in this area.
- For all other groups- create advocacy opportunities.

C. Treatment and Services

Goal:

By 2017, continue and increase universal screening of infants and children for prenatal alcohol, tobacco and substance exposure, as a standard of pediatric care.

Objective:

Continue to expand the established system for the identification of prenatally exposed infants.

Activity:

- Task Force members will continue to educate physicians, nurses and medical clinics on the importance of screening all infants and children for possible prenatal substance exposure.



- By 2015, surveillance systems documenting maternal prenatal use will be linked to electronic birth certificates
- By 2017, the screening tool currently utilized by the NJ FAS Diagnostic centers will be disseminated at all educational programs for use by medical and allied health personnel. This tool will be used to screen and then refer any child needing a diagnostic workup to the NJ FAS Diagnostic Centers.

Goal:

By 2015, increase the use of a single point of entry for information and referral of pregnant women and individuals with prenatal alcohol exposure.

Objective:

Identify the appropriate toll-free NJ telephone number to serve as a single point of entry for information and referral for families of substance exposed individuals.

Activity:

- Ongoing training for personnel who will be manning the toll free 800 and 211 numbers. Include the 800 and 211 numbers on all brochures , pamphlets and and public education information.

Goal:

By 2014, disseminate information regarding existing services for families.

Objective:

Increase awareness of and disseminate resource directories of existing services available to families throughout the state.

Activity:

Identify existing services for women and children throughout the State for women and families of substance exposed children.

Distribute the directory through the **Beintheknownj.org** website and through regional agencies.

Ensure that the majority of children diagnosed with FAS are referred to the NJ Birth Defects Registry.

Goal:

By 2014, establish and train a group of professionals who will treat individuals with FASD

Objective:

Create a state-wide directory of medical and allied health professionals, in a variety of settings (clinics, hospitals, forensics, private practice) who will treat individuals with prenatal alcohol exposure.

Activity:

- Identify medical and other allied health professionals who can provide appropriate services and treatment to persons with FASD.
- Train those professionals in the latest research and clinical information regarding health and mental health issues associated with prenatal alcohol exposure over the life cycle.
- Create a health care directory, specifically for prenatal alcohol exposure, of trained professionals in the state of NJ, for distribution.
- Disseminate directory through the ***Beintheknownj.org*** website, and through state and regional agencies.
- Educate insurance providers on FASD, and the importance of including FASD in their coverage.

D. The Use of Media

Goal:

By 2017, to increase the use of media in order to provide education and to disseminate information regarding FASD and other Perinatal addictions.

Objective:

By 2013, identify the five to ten most commonly spoken languages (after English) in NJ, into which culturally competent prevention information will be translated and disseminated. Translations will take into account cultural issues and wording, religious beliefs, etc.

Activity:

- Find and contact the appropriate New Jersey agencies who will be able to assist in the translation process.

- Develop an online and hard copy needs assessment, to be used in various NJ regions, with diverse populations (urban, rural, different ages and cultural groups) regarding alcohol and prenatal use, and their beliefs, disbeliefs, misconceptions and needs for a targeted media campaign and/or trainings.

Goal:

By 2017, increase the use of media and the websites- beintheknownj.org and [alcohol free pregnancynj.org](http://alcoholfreepregnancynj.org) to spread the prevention message of no substance use during pregnancy.

Objective:

Increase the use of social networking, social bookmarking and on-line educational programming to promote the prevention message through the websites ***Beintheknownj.org*** and ***alcohol free pregnancynj.org***

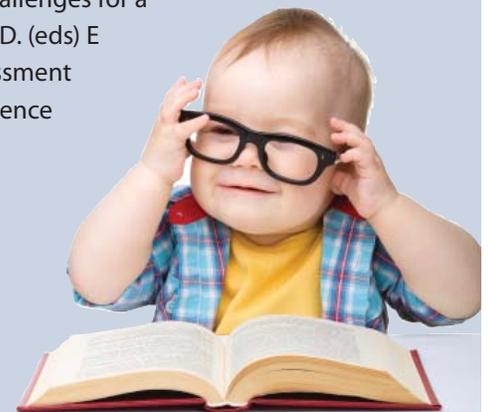
Activity:

- Incorporate social media strategies, such as social networks (Facebook, Twitter, YouTube, Pinterest), social bookmarking (Diggs and Stumbleupon) to allow for wider access of prevention messages.
- Increase general media outlet use-PSAs, radio station ads, banners, billboards, TV spots, general signage on transportation outlets, and website awareness campaign.
- Increase the use of webinars and podcasts to increase the audience base for prevention messages.



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RESOURCES

FASD Regional Diagnostic Centers

Northern Regional Centers

Northern New Jersey FAS Diagnostic Center
UMDNJ-NJMS
Department of Pediatrics
30 Bergen Street, ADMC 1608
Newark, NJ 07107
973-972-3817

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

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

Children's Specialized Hospital
6106 Black Horse Pike
Egg Harbor, NJ 08234
(888) 244-5373

Regional Perinatal Addictions Prevention Programs

The Partnership for Maternal Child Health of
Northern New Jersey
381 Woodside Avenue
Newark, NJ 07104
Maureen Ghali
Judy King
Yisel Alaoui
973-268-2280

Central Jersey Family Health Consortium
2 King Court, Suite B
North Brunswick, NJ 08902
Debbie Riscica -732-937-5437
Deena Cohen -732-363-5400

Southern New Jersey Perinatal Collaborative, Inc.
Kevon Office Center, Suite 250
2500 McClellan Avenue
Pennsauken, NJ 08109
Suzanne Kinkle and Quinn Ingemi
856-665-6000

Other Resources:

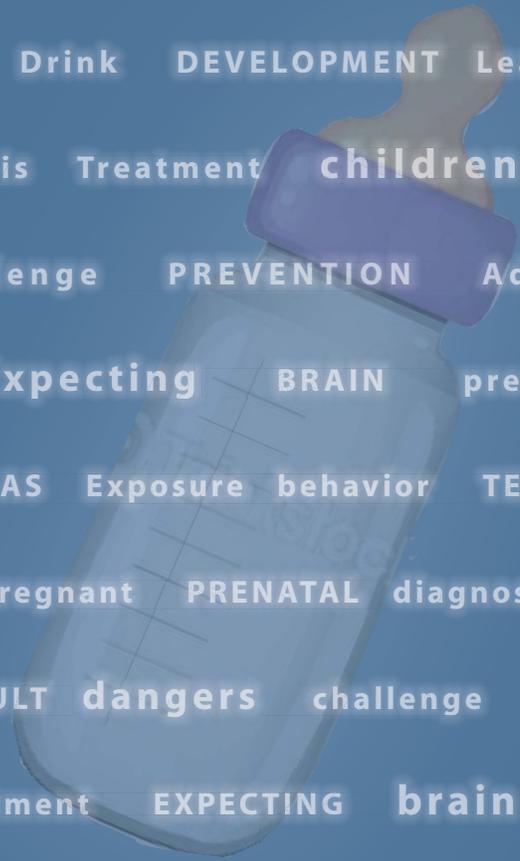
National Institute on Alcohol Abuse and Alcoholism
www.niaaa.nih.gov

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/fasd/documents

Fetal Alcohol Spectrum Disorders
www.fascenter.samhsa.gov

National Organization on Fetal Alcohol Syndrome
www.NOFAS.org





BRAIN Prevent alcohol baby FAMILY disability FAS exposure
behavior TEACH Drink DEVELOPMENT Learn Stigma pregnant
PRENATAL diagnosis Treatment children Responsibility ADULT
dangers challenge PREVENTION Adolescents Dangerous
TREATMENT Expecting BRAIN prevent ALCOHOL FASD
FAMILY disability FAS Exposure behavior TEACH Drink DEVELOPMENT
learn Stigma pregnant PRENATAL diagnosis Treatment children
Responsibility ADULT dangers challenge PREVENTION Adolescents
Dangerous treatment EXPECTING brain Alcohol FASD Prevent
BABY FAMILY disability FAS exposure BEHAVIOR TEACH Drink
DEVELOPMENT Learn Stigma pregnant PRENATAL diagnosis
Treatment CHILDREN Responsibility ADULT dangers
CHALLENGE PREVENTION Adolescents Dangerous TREATMENT
Expecting FAMILY brain prevent ALCOHOL FASD
disability FAS Exposure behavior TEACH Drink DEVELOPMENT
learn Stigma pregnant PRENATAL diagnosis Treatment
children Responsibility ADULT dangers challenge
PREVENTION Adolescents Dangerous treatment EXPECTING brain

**New Jersey Department of Human Services
Governor's Council on the Prevention of
Developmental Disabilities**

This report can be accessed on-line by visiting:
www.beintheknownj.org

Additional information regarding prenatal alcohol exposure,
FASD and perinatal addiction resources can be found at: www.beintheknownj.org, and alcoholfreepregnancyNJ.org

