

# COMPREHENSIVE APPROACHES TO THE DIAGNOSIS, SCREENING AND PREVENTION OF FETAL ALCOHOL SYNDROME IN NEW JERSEY

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## ABSTRACT

Integrated efforts by state, academic and private organizations in New Jersey to improve the diagnosing and prevention of fetal alcohol syndrome disorders (FASD) that have developed over the past ten years are reviewed and discussed. The recent funding and development of State funded FASD Diagnostic Centers throughout New Jersey and Centers for Disease Control and Prevention (CDC) funded Northeast Regional FAS Education & Training Center located at the New Jersey Medical School has led to improvement of efforts to survey and educate health professionals regarding FAS. This has also lead to improved referrals for FASD related diagnosis and treatment. The creation of a patient referral database for the State Diagnostic Centers is discussed and initial data presented for the year 2002 in New Jersey, supporting previous CDC estimates of FAS prevalence.

**F**etal Alcohol Syndrome (FAS) is the leading preventable cause of mental retardation and other disabilities in the United States. The estimate of its prevalence varies from 0.5 to 3.0 per 1,000 live births with higher levels in specific socioeconomic groups.<sup>1</sup> In New Jersey, with an average birth rate of 110, 000, assuming 1 per 100 births, this can translate to approximately 50 - 100 children a year with FAS. FAS is a recognized birth defect and one of the Fetal Alcohol Syndrome Disorders (FASDs) that may result from prenatal alcohol exposure.

Given the extent of potential neurological damage alcohol can induce, children with FAS have been seen to display many symptoms in relation to learning and memory, executive functioning, attention disorders and motor control difficulties.<sup>2</sup> They also have a variety of impaired social abilities that affect their ability to function in social settings throughout their lives.<sup>3</sup> The social, educational, and financial impact of this disorder can be staggering. In 1995, the total cost to the economy due to FAS was estimated to be greater than \$2,500,000,000; for one child with FAS, the health care costs can be over \$1,400,000.<sup>4</sup> The prevention of FAS is thus a public health imperative.

Compared to the nation as a whole, New Jersey is more racially and ethnically diverse. According to the 2000 Census, 74.4% of the residents were white, 13.9% were black, 5.9%

were Asian or Pacific Islander, and 2.6% reported two or more races. In terms of ethnicity, 13.6% of the population were Hispanic. The racial and ethnic mix of New Jersey mothers, infants and children were more diverse than the overall population composition as well. In 2000, 20.1% of mothers delivering infants in New Jersey were Hispanic, 70.6% were white, 18.2% were black, and 7.8% were Asian or Pacific Islanders.<sup>5</sup>

New Jersey's commitment to preventing FASD and taking serious actions began in 1982 when the State organized its original FAS Task Force. In 1989, as a result of a report published by the Governor's Council on the Prevention of Mental Retardation, the New Jersey Department of Health and Senior Services (DHHS) funded and implemented the initial Risk Reduction System that was charged with identifying women at high risk for substance abuse and who received prenatal services in public clinics.

In 1996, New Jersey enacted its point of sale FAS Warning act. In 1998, the FAS Task Force was re-organized and, in 2001, submitted a report to the Acting Governor regarding the status of prevention, diagnosis and treatment of FAS. This action resulted in an appropriation to the DHSS to establish FASD Diagnostic Centers that are located throughout the state. In 2002, DHSS enhanced the Risk Reduction System by transforming it to the Perinatal Addictions System and incorporating it into the Maternal and Child Health Consortia (MCHCs). In 2003, New Jersey became the first

state to implement a Perinatal Addictions Certification Program for health related professions.

In spite of these realities, FAS and FASDs in general remain under-diagnosed and under-reported conditions. In New Jersey, prior to the establishment of the FASD Diagnostic Centers, only 137 diagnosed cases of FAS had been reported to the New Jersey Birth Defects Registry since 1990, with only 36 of these cases reported from 1995-1999. Given an expected prevalence of at least 0.5 to 3.0 per 1000 births, this is a very low reported value since there are approximately 100,000 live births per year in NJ, implying the number of expected FAS cases to be in the range of fifty to one hundred cases.

Recent work by the CDC<sup>6,7</sup> has shown that binge drinking, time of exposure in terms of fetal development, mother's ethnicity and age are important contributing factors to the likelihood of a child being born with FAS. The rate at which alcohol is metabolized and the stage of fetal development seem to play a large role and are the subject of much animal model research.<sup>8</sup> In formulating policies that combat FAS and FASD, it is necessary to emphasize that prevention involves both limiting addictive behavior among women of child bearing age and limiting potential damage to the fetus. This implies interventions and services of varying types for different sets of at risk sub-populations.

### **An Important Step: State Funded FASD Diagnostic Centers**

Efforts to improve the diagnosis and treatment of FASD and FAS are ongoing in New Jersey. State Regional Fetal Alcohol Syndrome Diagnostic Evaluation and Services Centers were established in 2002 and mandated to develop regional diagnostic and education services for FAS and to provide early treatment and supportive services to children and families.

The State funded FASD diagnostic centers, six in all, opened their doors in Fall 2002 to begin diagnosing children. They have helped provide the Northeast Education and Training Center with resources and support. They have a website, [www.njfas.org](http://www.njfas.org). Their resources include expertise in the development of teaching materials, access and development of mailing

lists of all pediatricians currently practicing in New Jersey, nurses and child development specialists involved in aspects of FASD related diagnosis and prevention.

The State Centers are spread throughout New Jersey with two centers in Northern New Jersey, two in central and two in southern New Jersey. All centers are set up in a similar fashion: they are part of Child Evaluation Centers, funded by the state DHSS. Each regional center is a multi-disciplinary diagnostic center. Each has a developmental pediatrician, a psychologist, social worker, nurse, speech therapist, and a physical and/or occupational therapist. All centers can receive referrals from anyone in the state. The purpose of the centers is to provide a thorough diagnosis for any child suspected of having FASD. In addition, audio-visual equipment and materials are available to aid in the diagnosis of FAS.

### **FAS Diagnostic Tools**

Several diagnostic tools have been developed to aid in the proper diagnosis of FAS. One is the FAS Facial Photographic Screening Tool. This tool determines facial phenotype; short palpebral fissure lengths, smooth philtrum, and thin upper lip.<sup>9</sup>

Another diagnostic tool is the 4-Digit Diagnostic Code. The code is composed of four scores: growth, face, brain and alcohol that are each rated on a scale of 1-4.<sup>10</sup> These tools were developed at the University of Washington and are quickly becoming standard diagnostic assessment tools in relation to FAS. All NJ FASD regional centers staff received training in the diagnostic coding developed by the University of Washington and use an adapted form of their coding system for diagnosis.

When physicians screen patients and detect a potential case of FAS, they refer to one of the regional centers for a full diagnostic work-up. After the work-up is completed, the children will be referred to appropriate services and/or intervention. All centers work with their regional Maternal Child Health Consortia to sponsor area trainings and workshops, as well as to develop regional resource directories.

### **NJ FAS Client Referral Database**

To improve the understanding of the underlying epidemiology of FAS cases in New Jersey and help identify any risk factors and secondary patterns in

regard to these cases, the State FASD Centers are developing a comprehensive patient referral database. Currently, the New Jersey Birth Defects Registry collects data on infants who are reported to the registry on a volunteer basis when the diagnosed child is over one year of age. Collected information includes demographics, insurance, hospital of birth, prematurity, plurality, pediatrician and diagnosis. It does not collect information regarding child development, and the services needed and received by the child throughout the life span.

To improve understanding of referral patterns and information on cases of FASD, each Center is developing a patient database that will provide historical and long-term information on patient access to special and social services, benefits of the services and pharmacological interventions, and comorbidities or secondary conditions that are likely to emerge throughout their life span.

An initial study of referrals abstracted fifty-three year 2002 cases at the Newark FASD Center. These included 60.4% males and 39.6%

females. The majority (53.8%) of the subjects were African American. As a group, the entire sample had 64.2% (34 cases) living in foster care. The age range was one to eighteen years. The majority of cases were referred through foster care related sources. Prenatal alcohol exposure was confirmed in 45.3% of the cases. In 37.7% of the subjects, prenatal alcohol exposure presumed but unconfirmed. In the remaining cases (17%), information regarding prenatal alcohol exposure was missing. Formal diagnoses yielded 41.5% (22 cases) having Static Encephalopathy (alcohol related disorder), 18.9% (10 cases) with FAS and 18.9% (10 cases) with Neurobehavioral Disorder.

#### Initial NJ FAS Epidemiologic Data

While accurate statistics for FASD (FAS/ARND) are difficult to obtain, and usually based on self-report, work by the CDC<sup>6,7</sup> shows that higher rates of drinking behavior more likely to result in FAS exists among non-white, unmarried women. This identified, at-risk population is present in large numbers in several New Jersey counties, for example Essex County.

**TABLE 1** NJ County Data; Confirmed FAS Cases, Total Births (2002)

County	Essex	Sussex	Salem	Warren	Atlantic	Cumberland	Gloucester	Total
<b>Total Live Births</b>	12,246	1,776	767	1,304	3,441	1,996	3154	24,684
<b>Confirmed FAS Cases</b>	11	4	1	1	1	4	6	28

The New Jersey FASD Centers together examined diagnosed FAS cases in a subset of counties having a total population of 25,000. The validated set of cases supports current CDC estimate of an FAS prevalence rate of approximately 1/1000 live births.<sup>6</sup> A difficulty here is the need for better case ascertainment through education and training of health professionals in New Jersey in regard to FASD and specifically the FASD Diagnostic Centers.

Undercounting of FAS cases is a consideration in these initial values. For example, Essex County mothers were the most likely in a previous MCHC (Gateway) Region Fetal and Infant Mortality Review to report alcohol use. Mothers in Newark were twice as likely as New Jersey mothers in general to have used alcohol while pregnant. See Table 2. These populations are typically underserved in terms of resources and access to health care and opportunities for referral.

**TABLE 2** Gateway Region & New Jersey Maternal Alcohol Exposure (1998)

	<b>Essex County</b>	<b>Newark</b>	<b>E. Orange</b>	<b>Irvington</b>	<b>Orange</b>	<b>Middlesex</b>	<b>Perth Amboy</b>
<b>Alcohol Exposure</b>	315	201	44	23	12	91	18
<b>% Reported Live Births Exposed</b>	2.7	4.2	3.8	2.1	2.1	0.9	2.1

These findings have serious implications both for the continued education of health care professionals with respect to FASD and FAS in New Jersey as well as the need for inclusion of the foster care system in the screening and diagnosis process for at risk populations.

**Coordinated FAS Education & Prevention Efforts in NJ**

The efforts toward prevention of prenatal alcohol use in an attempt to deter FAS are continually increasing. The Institute of Medicine has proposed a comprehensive intervention program encompassing an array of approaches.<sup>11</sup> Universal prevention targets the entire population group. It includes methods such as health advisories, public service announcements, and health brochures. Selective prevention targets specific high-risk groups. Indicated prevention targets individuals known to be at a high risk, such as a person with a past history of drinking. Methods for indicated prevention include counseling and case management.<sup>12</sup>

Efforts to educate both health care practitioners and potential mothers in New Jersey to aid in the prevention of FAS have a long history in NJ. The Arc of NJ, the Maternal and Child Health consortia and the State Departments of Health and Senior Services and Department of Human Services all have ongoing training and intervention programs. Recently, as part of the CDC National Center for Birth Defects and Developmental Disorders, funded effort focused on FAS, a CDC Regional Center for FAS Education and Training was formed to help educate pediatricians, child developmental specialists, nurses and other allied health professionals in screening and diagnosing FAS.

**CDC NJ/Northeast FAS Regional Education & Training Center**

In 2002, the CDC funded the Northeast Regional FAS Education & Training Center, located in the University of Medicine and Dentistry of New Jersey, along with three other Regional Centers (UCLA, Meharry - Morehouse, U. Missouri). The objectives of the educational program developed by the regional center are several and comprise distinct, quantifiable goals. These include identification of the level of existing knowledge in regard to the identification and diagnosis of fetal alcohol syndrome among health care professionals and students in New Jersey.

This effort is being conducted through the surveying of health professionals across the U.S. in collaboration with the Academy of Pediatrics. The results from the initial knowledge survey will be used as a basis for development of core curriculum for various student and practitioner groups.<sup>13</sup> Improvement of the knowledge base is important among pediatricians, medical students, residents and other health professionals in New Jersey in regard to identifying and diagnosing fetal alcohol syndrome is needed. This lack is being addressed through the development and implementation of educational workshops focusing on fetal alcohol syndrome.

The Northeast Center is focused on ensuring that the educational program developed is accessed by practitioners and residents at multiple sites within the UMDNJ family of medical schools. This is accomplished through the support of Schools and Departments within the University of Medicine and Dentistry of New Jersey, the New Jersey State DHSS, and other community based organizations. Existing networks of professionals affiliated with the State funded FAS diagnostic centers have been urged to participate in workshop sessions.

### **Initial National Pediatrician Survey Results for Northeast region**

Initial results from a recent FAS knowledge related survey of pediatricians, carried out under the auspices of the Academy of Pediatrics are useful to consider in relation to health professional education efforts.<sup>13</sup> We focus here on the Northeast region and report only findings relevant to general FAS related knowledge.

Of 879 pediatricians surveyed, 28% were from the Northeast. Only 52% were able to accurately estimate the prevalence of FAS (1/1000) with 38% viewing it as much less prevalent (less than 1/10000). Thirty percent of respondents believed FAS to be similarly prevalent in all socio-economic groups and only 20% agreed that FAS occurs at similar prevalence levels in all ethnic and cultural groups.

Seventy-seven percent of pediatricians surveyed believe that pregnant women should abstain from alcohol consumption. Among those pediatricians who believe that occasional drinking during pregnancy is not harmful (23%), 27%, 50% and 98% believed that drinking during the first, second and third trimesters of pregnancy is safe, respectively (categories not mutually exclusive, respondents checked all that applied). In regard to defining heavy drinking for pregnant women in a given week, 22% set this at 0-2 drinks, 38% at 3-5 drinks and 40% higher than 5 drinks. In terms of defining heavy drinking for a pregnant woman at a single occasion, 1 drink (5%), 2 drinks (29%), 3 drinks (43%) and more than 3 drinks (23%) were the responses. Disturbingly, many (45%) of respondents rarely or never provide their adolescent female patients consultation or education regarding the consequences of drinking during pregnancy. Only 18% of surveyed pediatricians reported that they received excellent formal training on FAS, with 20% reporting poor training. Further, only 16% make use of a formal diagnostic schema for FAS in their practices.

The efforts of the Northeast Regional FAS Education & Training Center will, in tandem with State and private educational efforts, focus on improving the FAS related training of health professionals, both pediatricians and others.

### **Online Educational Outreach**

Given the variety of health professional audiences needing access to FAS educational materials, accessible online materials are an obvious outreach endeavor. Initial funding to develop an online course aimed at UMDNJ health professional and student audiences has been provided by the CDC and a local UMDNJ Educational Training grant. A CME accredited version of the course will soon be available for health professionals. The materials in these courses will closely reflect recently developed CDC approved FAS educational materials.<sup>13</sup>

### **NJ Department of Human Services, OPMRDD and NJ FAS Task Force**

Located in the Department of Human Services, the Office for Prevention of Mental Retardation and Developmental Disabilities (OPMRDD) is charged with educating the public about ways to prevent developmental disabilities and to stimulate prevention research. The Office accomplishes these mandates through its Small Grant Prevention Education Program that provides resources to community entities to implement prevention efforts. Approximately half of these programs are directed towards preventing FAS. In addition, OPMRDD funds the New Jersey Coalition for Prevention of Developmental Disabilities, a project of The Arc of New Jersey.

**TABLE 3 Educational Projects to Prevent FASD in New Jersey Funded by the NJ Office for Prevention of Mental Retardation and Developmental Disabilities (1992 – 2002)**

Organization	Program
The Arc of New Jersey, Coalition for Prevention of Developmental Disabilities	Support for staff, resource library and for Pregnant Pause events
Hudson County Perinatal Consortium	Education of high school students and staff (health education teachers, nurses, substance abuse counselors) in Jersey City about FAS.
Prevention First – Alcohol/Substance Abuse Training Model	Addresses middle school students regarding the risks and effects of prenatal alcohol.
The Arc of Hunterdon County	Implementation of the Fair Chance Program (Fetal Alcohol Information and Referral) for high school students.
The Arc of Atlantic County	Education of high school students and outreach and referral to FAS Diagnostic Centers
Cerebral Palsy of New Jersey	Training of women in recovery and staff of addiction services about FAS.
The Arc of Warren County	Educating high school students about FAS.
Central New Jersey Maternal and Child Health Consortium – REmeDy	The FAS Resource Center of NJ provides community, professional and paraprofessional education regarding FAS and distribution of FAS materials at point of seeking marriage licenses.
Preferred Children’s Services	Education for staff, treatment providers, adolescents and high-risk children and their families about FAS in Monmouth and Ocean Counties.
UMDNJ – New Jersey Medical School – Prescription for a Healthy Pregnancy	Educated providers regarding FAS and encouraged distribution of preconceptual health information.
Southern New Jersey Perinatal Cooperative	Educating adolescents about FAS.

OPMRDD organized and staffs the NJ FAS Task Force that is composed of representatives of the MCHC-based Perinatal Addiction System, each of the FAS Diagnostic Centers, practitioners and genetics, as well as community agencies. The Office, in partnership with the agencies represented on the NJ FAS Task Force

and the CDC, sponsored the 30th anniversary FAS Conference. Held in NJ, 350 participants from across the country attended. Keynote addresses were given by nationally known experts in FAS, including Kenneth Lyons Jones, MD, author of the original FAS research.

OPMRDD and the NJ FAS Task Force also work cooperatively to address policy issues related to prenatal exposure to alcohol. Assessing the feasibility of prenatal screening for alcohol, tobacco and drugs becoming a standard of obstetrics care for all Medicaid providers is an example of these initiatives.

The DHS also administers services that may be appropriate for persons affected by prenatal alcohol and their families.

These resources include: the Division of Mental Health, the Division of Developmental Disabilities, the Division of Medical Services (Medicaid), the Division of Family Development (TANF) the Division of Youth and Family Services, the Division of Addiction Services, and the Division of Prevention and Children's Services.

### **Maternal and Child Health Consortia (Gateway) Education & Prevention Efforts**

The New Jersey Maternal and Child Health (MCHC) service system is organized into seven regions. The MCHCs are an established network of maternal and child health providers (non-profit) with emphasis on prevention and community-based activities. They are funded through contracts with member hospitals and providers as well as federal and state grants. The MCHCs are charged with developing regional perinatal and pediatric systems, data analysis, and infant follow-up programs and each house a Perinatal Addictions Project.

Specific programs include the activities of eight Healthy Mothers/Healthy Babies Coalitions, preconception health counseling and facilitation of the Black Infant Mortality Reduction initiative. Relevant to FAS is the Beth Israel High-Risk Treatment Center for alcohol addicted women focusing on a high-risk population, providing treatment and interventions and provides useful experience in the practical development of interventions for high-risk women.

The MCHCs in New Jersey have played a leading role in education and related prevention efforts for many years. Through a grant from the Robert Wood Johnson Foundation to the Southern Perinatal Cooperative, the MCHC responsible for services in the southern part of the state, all the Perinatal Addictions Projects

are working with hospitals and public clinics to train health care providers to question all pregnant women about their alcohol, nicotine and drug use. Women who are at high risk of using these substances during pregnancy are referred to addiction treatment services. The MCHCs recognize maternal substance abuse as a significant public health issue and regularly assess resources available regarding treatment for women, particularly pregnant women and women with dependent children.

### **The Arc of New Jersey**

The Arc of New Jersey is a private organization that has worked closely with State related efforts in FAS education and prevention. Its efforts have focused primarily on childhood injury prevention, childhood lead poisoning prevention, and FAS prevention with a focus on training and development, community organizing, and dissemination of resources. In training and development, The Arc has presented at conferences for health, addictions and human service professionals; teacher in-service trainings with middle school faculty; and, workshops with pregnant and parenting women in community-based organizations, child care centers, and grass-roots agencies. The Coalition also created a *Network of Prevention Specialists* in 1999 to bring together the prevention staff in local chapters of The Arc across the state to share what works, resources, problem solve and network.

The centerpiece of The Arc's FAS efforts is local community organizing. The Coalition supplies FAS resources for agencies and organizations across the state from NOFAS, the March of Dimes, The Arc of the US, and for-profit health companies. The Coalition has published a quarterly newsletter since its inception and has included information on FAS in almost every issue. Further, the Coalition is a member of a nation-wide CDC grant awarded to The Arc of the U. S. to create a curriculum for families, teachers and others on FAS.

## **DISCUSSION**

### **An Ongoing Multi-Dimensional Struggle**

The prevention, diagnosis and treatment of FAS is a long term struggle. The incorporation and

acceptance of alcohol use by women of childbearing age is an established fact in North American culture. The fact that women may be pregnant for many weeks before becoming aware of their condition leaves many women and their children at risk for alcohol exposure and resulting FAS. While the risks from binge drinking are now documented, it is not common knowledge.

As shown by the FAS Northeast regional survey results discussed above, there remains much work to do in regard to educating New Jersey health professionals. It is important that issues regarding alcohol consumption while pregnant be discussed with mothers and families, with screening and diagnostic criteria be applied in a standard manner in all health care settings.

The struggle to prevent FAS is closely linked to the prevention of alcohol addiction and related behaviors among women of childbearing age. In New Jersey this has been very much a joint effort of State, private and state-private consortiums. Cooperation among the agencies is a pre-requisite to successful implementation and long-term beneficial effects of the various programs (see Table 3).

Practical experience and data collected in the New Jersey Diagnostic Centers has shown limitations and much remaining work to do. Few referrals are currently from pediatricians and many children who are referred are currently in the foster care system, often leading to little information regarding potential fetal exposure to alcohol, leading to difficulties in formal diagnosis of FAS and undercounting. This is a difficult hurdle for serious intervention and treatment regarding FAS and FASD in general. In conclusion, New Jersey, through the involvement of several state agencies, private organizations and CDC funding, has over time created a series of inter-related, ongoing multi-dimensional efforts to prevent fetal alcohol syndrome. Much of these efforts are being implemented through educational initiatives that help to insure that the serious dangers of fetal exposure to alcohol become better understood and prevented.

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