



Changes and Challenges:
Securing Our Children's Future

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

June 2005

THE GOVERNOR'S COUNCIL ON THE PREVENTION OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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Changes and Challenges: **Securing our Children's Future**

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

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RICHARD J. CODEY
Acting Governor

JAMES M. DAVY
Commissioner

June 10, 2005

The Honorable Richard J. Codey
Governor of the State of New Jersey
New Jersey State House
Trenton, New Jersey 08625-0001

Dear Governor Codey:

Twenty years ago, the State of New Jersey set out to demonstrate that the old maxim, "an ounce of prevention is worth more than a pound of cure," was true. In 1985, the Governor's Council on Prevention of Mental Retardation presented its initial report, ***Preventing the Causes of Mental Retardation***, to Governor Thomas Kean. This report investigated the policies and programs that needed to be established or strengthened in order to reduce the incidence of mental retardation and related developmental disabilities in New Jersey.

Today, on behalf of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities, I am pleased to submit to you this 20th Anniversary edition, ***Changes and Challenges: Securing Our Children's Future***. This report documents the progress that New Jersey has made toward realizing our goal. It provides a status report on actions taken to establish legislation, policies and programs that have resulted in reductions in developmental disabilities. Of equal importance, the report offers recommendations for action by the Governor's Council on Prevention and by the state for the next ten years.

It is in the interest of ensuring that the children of New Jersey have the opportunity to grow and to flourish that I respectfully submit this report to you.

Sincerely,

A handwritten signature in cursive script that reads "James M. Davy".

James M. Davy
Commissioner



This 20th anniversary report, *Changes and Challenges:*

Securing Our Children's

Future, is dedicated to the memory of four long-standing members of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities. Each of these individuals made unique and lasting contributions to the health and well-being of our children through their participation on the Governor's Council on Prevention as well as through their professional and personal lives.

John Alexander, M.D.
Elizabeth Monroe Boggs, Ph.D.
Barbara Norton, R.N.
Ilana Robbins Zarafu, M.D.

We remember them with much affection and appreciation.

A Prevention Poem

PREVENTION is caring
about human outcomes.
It is pre-term babies
supported
viruses foiled
alcohol avoided
thyroid replaced
phenylalanine suppressed
lead eliminated
vitamins embraced
genes coded
but especially it is food and transportation and housing and
respite and clean environments
little children guided and stimulated
mothers who are challenged, getting help
babies born who are wanted, expected, and valued
wrestling with inequities and striving for justice.

**Printed with the permission of
Allen C. Crocker, M.D., Preventing Childhood Disabilities,
Baltimore, Maryland, May 23, 1988**



Prevention Measures

This map provides a snapshot of the history of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities and a road map of the major pieces of legislation enacted and regulations promulgated over the past two decades.

- 
- 1983 Creation of the Governor's Council on the Prevention of Mental Retardation by Governor Thomas Kean
- 1984 Legislation to mandate seatbelt use in automobiles enacted
- 1985 Governor's Council publishes report, ***Programs for Preventing the Causes of Mental Retardation***
- 1987 Public Law 1987, Chapter 5 enacted creating the Governor's Council on the Prevention of Mental Retardation and the Office for Prevention of Mental Retardation and Developmental Disabilities
- 1988 March - Elizabeth M. Boggs, PhD, named Acting Director of Office for Prevention of Mental Retardation and Developmental Disabilities (OPMRDD)
- July - Deborah E. Cohen, PhD, comes on-board
- August - First awards for public education projects
- September - Center for Disease Control and Prevention cooperative agreement for Disability Prevention Program awarded to OPMRDD
- September - Interagency Task Force on the Prevention of Lead Poisoning re-established and becomes a committee of the Governor's Council on Prevention
- Department of Health and Senior Services (DHSS) initiates Fetal Alcohol Syndrome Prevention Program
- Perinatal Task Force (PTAC) formed, resulting in the DHSS institutionalizing regional Maternal Child Health consortia system and promulgation of new regulations
- 1990 PL 1991c323(1) Bicycle Helmet Tag Law enacted
- Hemoglobinopathies added to newborn screening
- 1991 PL 1991c465 New Jersey becomes first state to enact Bicycle Helmet Law for all children younger than 14.
- 1992 PL S.B.408 Emergency Medical Services for Children Law enacted
- PL 1992c92 (2) New Jersey Seat Belts in School Buses Law enacted
- N.J.S.A. 33:12- Point-of-Sale Alcohol Warning Sign Law enacted
- Department of Health and Senior Services enacts regulations requiring use of External Cause of Injury (E-codes) and Place of Injury (Z-codes) as part of hospital discharge data
- 1993 PL 1993c288 Lead Hazard Control Bill enacted
- 1995 Changes and Challenges: Building Our Children's Future published
- PL 1995c316 Health Insurance Coverage for Immunizations and Lead Screening for Children enacted
- PL 1995c328 Universal Childhood Lead Screening enacted
- N.J.S.A.55:13A-7.12 Landlord Window Guards Legislation enacted

Prevention Measures

- 1996 (7) Spinal Cord Injury Advisory Board established
- PL 1997c229 Governor's Council on Adolescent Pregnancy established
- Johnson & Johnson Head Start - Lead Project Initiated
- 1997 PL 1997c278 Brownfield and Contaminated Site Remediation Act enacted
- PL 1997c411 Amendment to PL1991c465 to mandate use of helmets when roller-skating, skateboarding and in-line skating enacted
- 1998 FAS Task Force re-formed
- 1999 Traumatic Brain Injury (TBI) Advisory Board established by Executive Order #84 SB#1707(1R) 2001/AB 2884(1R)
- Public Law 1999c105 the NJ Infantile Autism Biomedical Research Act was enacted and established the Governor's Council for Medical Research and Treatment of Infantile Autism
- HUD grant awarded to OPMRDD for Get a Head Start on Lead
- 2000 PL 1999c 422(1):P.L. 2001c244 (2) Enforcement of car safety belt use as a primary offense enacted
- PL 2000c82, amended PL 1987c5 to expand the title and responsibilities of the Governor's Council on Prevention to include developmental disabilities
- Lead Exploratorium inaugurated as a cooperative project of OPMRDD and UMDNJ-SOM
- Black Infant Mortality Report released
- 2001 *Truth and Consequences of FAS* submitted to Acting Governor Donald DiFrancesco, which resulted in \$450,000 being appropriated for FAS Diagnostic Centers
- \$400,000 appropriated for lead education with Governor Codey serving as a prime sponsor
- P L 2001c373 The Universal Newborn Hearing Screening Act passed
- PL c244(1) 8 Years and 80 Pounds Booster Seat Law enacted
- PL N.J.S.A.26:2-110 Newborn Screening Law expanded
- 2002 PL 2001c376 New Jersey Office of Women's Health
- 2003 PL 2003c311 The Lead Hazard Control Assistance Act passed
- 2004 PL 1997c278 Supplemental Newborn Screening Act expand the program from 6 mandated metabolic disorders to 20
- Strictest mercury and arsenic standards in the nation adopted
- PL2003c314 Legal blood alcohol content when driving is lowered from .10 to .08
- The New Jersey Perinatal Addictions Certification Program was initiated as the first in the nation
- 2005 PL S144 Requires Cultural Competency Training for New Jersey physicians in order to obtain or renew a medical license from the State Board of Medical Examiners

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

In 1983, Governor Thomas H. Kean visited an institution for persons with mental retardation with Mr. John Scagnelli, then Director of the Association of Retarded Citizens of New Jersey (now The Arc of New Jersey). During this tour, Mr. Scagnelli informed the Governor that some types of mental retardation could be prevented, but acknowledged that a concise survey of existing programs and resources had never been conducted. The Governor responded to this lack by issuing an Executive Order that established the original Governor's Council on the Prevention of Mental Retardation. The Council was charged with the mission of assessing the status of prevention programs in the state. Funds were awarded to The Arc of New Jersey to support this endeavor.

Two years later, in 1985, a report, *Programs for Preventing the Causes of Mental Retardation*, was submitted to former Governor Thomas Kean by the Honorary Chairperson of the Governor's Council on the Prevention of Mental Retardation, Deborah Bye Kean, and Chairperson Richard Goldberger, at a special conference held in December. This document provided the baseline information needed to begin to measure the effectiveness of prevention efforts in the State.

In 1986, a special-purpose grant was awarded to The Arc of New Jersey by the Department of Human Services, Division of Developmental Disabilities to begin the task of mobilizing community efforts. In the spring of 1986, three regional conferences were held to introduce the report findings to the public and to organize networks to assist in the implementation of some of the recommendations contained in the report.

By summer, these networks began to meet as a large group and became what is now known as the New Jersey Coalition for Prevention of Developmental Disabilities, a project of The Arc of New Jersey. The Coalition was designed to mobilize individuals and agencies to work collaboratively to educate the public about the causes of developmental disabilities and ways in which they might be prevented. The areas for prevention initiatives, as defined by the Governor's Council, included:

- 1. Genetic and teratologic services**
- 2. Exposure to environmental contaminants**
- 3. Prenatal consumption of alcohol**
- 4. Substance abuse**
- 5. Adolescent pregnancy**
- 6. Health insurance for the medically needy**
- 7. Ensuring full-term births**
- 8. Follow-up services for infants with birth defects**
- 9. Immunization for infectious disease**
- 10. School-based health services**
- 11. Nutrition and breast feeding**
- 12. Lead poisoning**
- 13. Improved vehicular safety**
- 14. Childhood injury prevention**
- 15. Child abuse and neglect**
- 16. Pediatric HIV/Aids (The Council added Pediatric HIV/Aids to its sphere of responsibilities in 1989.)**

In February, 1987, Mr. Scagnelli was invited by the President's Committee on Mental Retardation to present New Jersey's plan to prevent mental retardation. The plan was recognized as the best and most complete at a national conference in Washington, D.C.

Orchestrated under the Coalition for Prevention leadership, Barbara Norton and Glenna Gundell, The Arc, governmental entities, as well as many community agencies and organizations worked with the Legislature to enact Public Law 1987, Chapter 5. After the law was signed by Governor Kean in March, 1987, New Jersey was propelled to the forefront of the prevention world. A permanent Governor's Council on the Prevention of

Mental Retardation was established and an administrative arm, the Office for Prevention of Mental Retardation and Developmental Disabilities, was created. Subsequently, Public Law 2000, Chapter 82 was enacted to expand the Governor's Council on Prevention sphere of responsibilities to include all developmental disabilities, including cerebral palsy, spina bifida, epilepsy and other seizure disorders, and traumatic head injury. A copy of the most recent legislation is found in Appendix A.

P.L. 1987, c. 5 still stands as model legislation that other states may emulate. The law stipulates the boundaries for Governor's Council on Prevention actions: service delivery is not included in the mandate but is the responsibility of other agencies. The Governor's Council on Prevention is mandated to provide leadership in:

- **coordinating prevention initiatives, programs and activities among state agencies;**
- **developing, monitoring, and updating the strategic Prevention Plan for Developmental Disabilities;**
- **educating communities about ways in which developmental disabilities may be prevented;**
- **stimulating, encouraging, and supporting research into the causes of developmental disabilities;**
- **disseminating information to the public about new research results that may prevent developmental disabilities.**

Philip Ziring, M.D., from the Department of Pediatrics at Morristown Memorial Hospital, and Mr. Scagnelli worked under the guidance of Assemblyman Rodney Frelighuysen to secure an appropriation to provide funds to support the activities of the Governor's Council on Prevention and the Office for Prevention.

In March, 1988, former New Jersey Department of Human Services Commissioner Drew Altman hired Elizabeth Boggs, PhD., to serve as the Acting Director of the Office for Prevention. Dr. Boggs began to design a system to disburse state appropriations to support prevention education programs that would meet the intent of the

legislation. Notably, Dr. Boggs initiated the Small Grant Public Education Program. This program provided, after competitive review, support to community agencies, schools, hospitals, and other non-profit organizations to engage in educational efforts about the causes of and prevention of developmental disabilities.

While the public education program was modified in 1994 to allow for multi-year programs and outcome evaluation, the essence of the program that Dr. Boggs designed remains as a lasting contribution. Descriptions of some of the educational programs that were implemented to address specific priority areas of the Governor's Council on Prevention are included in **Appendix B**. All of the original projects received no more than \$25,000 per year, and many were funded at considerably lower levels. In 1989, the Governor's Council amended its list of prevention areas to include the prevention of pediatric HIV/AIDS.

Dr. Boggs also organized the first meeting of the newly reconstituted Governor's Council on Prevention in May, 1988. The Governor's Council consists of six cabinet members and twenty-five New Jersey citizens who are appointed by the Governor. The state departments are the Department of Human Services which serves as host to the Governor's Council on Prevention, the Department of Education, the Department of Environmental Protection, and the Department of Health (now the Department of Health and Senior Services). Executive Order 223, signed in 1989, added the Public Advocate and Executive Order 30, signed in 1992, added the Department of Community Affairs. When the Public Advocate's office was eliminated in 1994, the Secretary of State joined the Governor's Council.

The Governor's Council on Prevention began to meet quarterly in May, 1988. Each meeting includes a presentation regarding an innovative program initiative, policy change, or research findings. In this way, members of the Governor's Council are able to remain well-informed of changes in the field.

In July, 1988, the first permanent director of the Office for Prevention, Deborah E. Cohen, Ph.D., was hired. As Dr. Cohen was beginning her tenure, the

Centers for Disease Control and Prevention (CDC) issued a Request for Proposals to participate in the Disabilities Prevention Program. New Jersey, through its Office for Prevention, became one of nine states selected to receive a cooperative agreement. The Governor's Council on Prevention served as the Advisory Board to the New Jersey Disabilities Prevention Program until the program was changed in 1997 and funding was no longer available.

The CDC funds provided support for staff of the office and for expanding the support available for community demonstration projects, research and evaluation. In addition, funds were used to support two epidemiologists in the Department of Health: one who conducted surveillance in developmental disabilities and the other in traumatic injuries. Finally, support was given in the form of grants and technical assistance for innovative community interventions and research efforts.

Also in July, 1988, the Interagency Task Force on Lead Poisoning Prevention re-convened. This group had been active participants in the writing of the 1985 Governor's Council report. In September, the task force became a recognized committee of the Governor's Council. Since that time, the task force has worked to develop policies and programs to reduce lead in the environment.

From 1991 to 1995, the Office for Prevention also collaborated with the University of Medicine and Dentistry - School of Osteopathic Medicine to host the Childhood Lead Poisoning Prevention Education Program (CLPPP). This program was supported with funds from CDC granted to the Department of Health. When these funds were no longer available, the Office for Prevention continued to support this effort through its state appropriation, and in 2002, through the lead appropriation given to the Department of Health and Senior Services.

In July, 1995, the Legislature appropriated \$200,000 to the Governor's Council to be used by the Interagency Lead Poisoning Prevention Task Force to implement statewide public educational programs about the prevention of lead poisoning. In August, 1995, the task force submitted its recommendations to Governor Christine Whitman about ways in which New Jersey can assure a

decrease in the amount of lead existing in our environment.

In 1998, the CLPPP was expanded to include training of individuals to become professional Community Lead Educators. In 2001, CLPPP, in partnership with the Office for Prevention and the Interagency Lead Poisoning Prevention Task Force, inaugurated the Lead Exploratorium during Childhood Lead Poisoning Prevention Week. The Lead Exploratorium is a touring mobile that educates preschool children, teachers and parents about ways to minimize exposure to this toxic metal.

In 2004, the Interagency Task Force on Lead Poisoning Prevention submitted its five year Strategic Plan to the Governor and the Legislature. In addition, the Task Force serves as the Advisory Board in the development of the Statewide Lead Elimination Plan which is required as part of a grant by CDC to the Department of Health and Senior Services.

In January, 1989, the Governor's Council on Prevention established a research committee to meet another of its legislative mandates. The research committee brought together representatives from academic and state institutions for the purpose of stimulating research into the causes of developmental disabilities. To help reach this objective, the Advanced Research Fellowship Program was initiated. This program provided stipends to young researchers as an incentive to develop careers in fields pertaining to prevention and to remain residents of New Jersey. The committee also has sponsored public seminars to bring attention to emerging issues in the research world. In 1997, members of the Research Committee decided to disband the Advanced Research Fellowship Program as additional federal resources were available to provide this support.

In May 1998, following a statewide conference, *The Truth and Consequences of Fetal Alcohol Syndrome*, the Office for Prevention became responsible for sponsoring the New Jersey Fetal Alcohol Syndrome (FAS) Task Force. In September, the Task Force became a standing committee of the Governor's Council on Prevention. In 2001, the FAS Task submitted a report to Acting Governor Donald DiFrancesco on the status of FAS prevention and

treatment in New Jersey. Documenting the need for services resulted in the Acting Governor appropriating \$450,000 to the Department of Health and Senior Services to support FAS Diagnostic Centers located throughout the state. In 2003, in partnership with the New Jersey FAS Task Force and the CDC, the Office for Prevention sponsored the 30th Anniversary FAS Conference which brought together 350 individuals from across the United States and six countries to New Jersey.

The Governor's Council on Prevention and the Office for Prevention have been instrumental in focusing both state and national attention on issues relating to child health and disability prevention. Notable highlights include:

- 1 Providing leadership in the enactment of prevention legislation, including the Bicycle Helmet Law, the Seatbelts in School Buses Law, the Fetal Alcohol Syndrome Warning at Points of Sale Law and the Lead Safe Housing Act.
- 2 Serving as a primary support for statewide child health and safety initiatives, including the New Jersey Coalition for Prevention of Developmental Disabilities, Child Health Month, SAFE KIDS and Sex Etc., a newsletter written by and for adolescents.
- 3 Conducting studies on major prevention issues, such as the immunization status of children served by Early Intervention Programs.
- 4 Providing advocacy support for implementation of its recommendations, such as the establishment of the Fetal Alcohol Syndrome Prevention Program in the Department of Health and Senior Services.
- 5 Providing expertise and technical assistance in the design of health services for New Jersey children, including participation on the Perinatal Technical Advisory committee, the Pediatric Clinical Advisory Committee, State Interagency Coordinating Council, the Women, Infants, and Children (WIC) Advisory Board, the Covering Kids and Families Advisory Board and the Newborn Screening Advisory Panel.

The Office for Prevention has four staff persons: the director, Dr. Cohen, the program manager, Ms. Lynn

Spatzer, LCSW, the health educator/contracts administrator, Ms. Ellen Dunn, MSW and the administrative assistant, Ms. Hilda Mitchell. In addition, Ms. Rosemary Horner, MPH, and Ms. Myra Vaughn, LPN, serve as Community Educators. Other staff have been associated with the Office for Prevention during the past seventeen years and have also contributed to the establishment of programs and services for the prevention of developmental abilities. These individuals include Mary Ann Deery, R.N. program director, Mary Buchanan, M.S., injury consultant, Joan Cook Luckhardt, Ph.D., lead poisoning prevention specialist, and Christine Caruso, secretary. Ezinma Obi-Onuigbo, MPH, completed her internship in the Office for Prevention and assisted in writing this report. The Governor's Council on Prevention wants to acknowledge and extend its appreciation to Marianne Tracey, PhD, and Janet Puccio at the Department of Psychiatry, Developmental Disabilities Program at the University of Medicine and Dentistry of New Jersey - School of Osteopathic Medicine for their continuous support.

The information presented in this document is intended for use by persons in the fields of allied health, public policy, community service, education, and others. The format differs greatly from the two prior reports, published in 1985 and 1995, respectively. This 2005 edition concentrates on major issues that impact and affect our ability to prevent mental retardation and other developmental disabilities. As such, sections address changes in the way in which our health care is delivered as well as our ability to educate ourselves, the economics of prevention, and technological advances. Recommendations are presented in the life cycle periods of Preconception Health, Prenatal Health Issues, and Infant and Child Health, rather than by specific causes of developmental disabilities. Resources to learn more about individual causes are provided in lieu of a lengthy discussion.

As will be discussed in the preface, the Governor's Council recognizes that these recommendations are being presented in a socio-political environment that holds much uncertainty. Yet, the Governor's Council is committed to establishing for itself and for New Jersey an agenda for the next decade. If anything, the changes that are now being planned or are already underway for our

welfare and health care systems present new challenges and opportunities for the Governor’s Council as it works towards its mission of preventing developmental disabilities.

Furthermore, the Governor’s Council on Prevention clearly recognizes that the recommendations are presented in a period of great fiscal uncertainty. However, the old maxim that “an ounce of prevention is worth more than a pound of cure” seems to have greater relevance today. It is well documented that prevention efforts are generally less costly than services. It is, therefore, imperative that we continue to invest in prevention, not only as a social good, but as commitment to fiscal responsibility.

As most members of the Governor’s Council on Prevention have a disability themselves, are family members, or are individuals who work with persons with developmental disabilities, the Governor’s Council is sensitive to the perception that prevention of disabilities is sometimes equated with the devaluation of persons with disabilities. The Governor’s Council is wholly committed to insuring that, when a disability is present, individuals have access to services, health care, employment, housing, and recreation opportunities and are welcomed into independent community life.

Since its re-establishment in 1988, the Governor’s Council on Prevention has enjoyed a productive working

collaboration from the state agencies that participate on the council as well as from many community organizations. In particular, the Governor’s Council on Prevention is greatly appreciative of the support provided by our host agency, the Department of Human Services, and its Commissioners during the past twenty years, George Albanese, Geoffrey Perselay, Drew Altman, Alan Gibbs, William Waldman, Michelle Guhl, James Smith, and Gwendolyn Harris. We especially want to express our gratitude to James M. Davy, the current Commissioner, for his responsiveness and sensitivity to the issues associated with the prevention of developmental disabilities. During his tenure, Commissioner Davy has participated in numerous events to educate the public about the importance of insuring the safety of our youngest and most vulnerable citizens.

Fred Patterson, Chair
**The Governor’s Council on the Prevention of
Mental Retardation and Developmental Disabilities
June 10, 2005**



Affirmation

“Poverty is the worst form of violence.” Mahatma Gandhi

As the wealthiest state in the country, New Jersey is a “land of milk and honey” to the great majority of its citizens who earn enough to share in her splendors. According to the U.S. Census Bureau, the median annual income for a family of four residing in New Jersey in 1995 was \$59,263 while the national median income was \$46,165. By 2003, the state median family income level had risen to \$70,263 as compared to \$52,273 for the country.¹ White families had the highest median incomes. Black families earned approximately one-third less per year and Hispanic/Latino families earned only half as much as White families per year. Almost 64% of New Jersey’s children under the age of 18 are White, approximately 16% are Black, and 15% are Hispanic/Latino.

Much has changed in the social services landscape in the past decade. Sweeping changes in the welfare and health care systems occurred in the mid to late-1990’s during a period of unprecedented economic growth and prosperity. Welfare reform resulted in an enormous decrease in the public assistance rolls. The number of New Jersey families receiving welfare decreased by 67% in the period from 1996, the year before the reforms were enacted, to 2002. In 2003, however, the State experienced a 2.8% increase the number of families receiving assistance. Since 1996, the number of Black families living in poverty has steadily declined from 19 to 13%. However, the number of Hispanic families living below the poverty line has increased to about 13%.²

Despite New Jersey’s wealth and its efforts to assist families to become educated and join the work force, over 11% of the State’s children under age 18 live in families whose incomes are below the poverty line. An additional 5.4% and

25.5% of children reside in families that earn below 50% and 200% of poverty, respectfully.² Numerically, these proportions translate to more than 220,000 New Jersey children living in poverty. As stated in New Jersey Kids Count 2003, “Child poverty is perhaps the most important indicator of child-well-being.³ When families are unable to provide the basics - food, clothing, housing - children are much more likely to suffer from health problems and fail in school” (P. 14). One of the New Jersey’s greatest problems --- one which is difficult to fix -- is the cost of living here. Seventy-three percent of low income families with children spend more than the recommended 30% on housing costs (3). This circumstance makes it difficult to provide the other basics needed by children.

Welfare reform provided educational and economic opportunities as a means of getting out of poverty. Recognizing that getting off of the welfare roles required more than just training and a job, attention was given to important complementary social systems to help foster independence:

- 1. early child care programs were established so that women could leave their children in safe places while they went to school or work.**
- 2. alcohol and drugs were recognized as impediments to employment, resulting in the expansion of treatment services to help families “kick the habits”.**
- 3. after-school programs were developed to prevent the creation of a new generation of “latch key kids”.**
- 4. publicly-financed managed health care service packages were developed to provide all Medicaid-eligible persons with a medical home and health care benefits were extended for those whose employment benefits did not include health care.**

A greater proportion of children are receiving health care than a decade ago. Enrollment in Medicaid and Family Care grew almost 30% in the period from 1996 to 2003. However, almost 10% of New Jersey's children remain uninsured and, in 2003, only 79% of the State's children were immunized. Infant mortality, child deaths and infants born with low birth weight have declined over the past decade. In addition, due to continuous outreach and education, removing barriers to health care, and the advent of the effective medication, AZT, the number of children born HIV positive has decreased dramatically.

The State has recognized the importance of insuring that young children are "school ready" and has made much progress in providing the opportunity for young children to participate in preschool programs. As documented in the Kids Count New Jersey 2003, nearly 45,000 children were enrolled in public preschools in the 2002-2003 school year. From 1996 to 2003, the number of licensed child care centers grew by 39% and the child capacity at the licensed centers grew by almost 55%. These are the highest levels achieved since 1998 when the New Jersey Supreme Court mandated quality preschool for all children in 30 of the state's neediest districts. As a result, more children are likely to be prepared to enter and succeed in school.

Over 85% of New Jersey adolescents received a high school diploma in 2003. In addition, the proportion of adolescents dropping out of school dropped by almost 12% in the period between 1998 and 2002. New Jersey can also be proud of having one of the lowest rates of births to adolescents. This trend continued over the past decade with a decrease of almost 26%. Adolescent deaths have also decreased by almost 9% and juvenile arrests decreased by almost 30% in the past decade.³

While there is much good news for many families in New Jersey, it is important to bear in mind that not all of the Garden State's citizens have benefited equally. This point is particularly salient when considering how to secure our children's futures. In its 1995 report, the Governor's Council put forth several affirmations that have remained as constants in its mission to prevent primary disabilities and associated secondary conditions. These important affirmations are worth repeating:

1. Poverty and discrimination are antithetical to the convictions, interests, and expectations of this country.
2. The extent to which disparities are minimized and all citizens have access to the basic necessities of life, including food, housing, health care, education and the means to gain financial independence, enhances or diminishes the collective well-being of society.
3. Investment in prevention cannot generally be measured immediately, but the long-term benefits effect generations to come.

“The test of our progress is not whether we add more to the abundance of those who have much, it is whether we provide enough for those who have too little.”

As stated by Franklin D. Roosevelt in 1937

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The Information Technology Revolution: Collaboration and the Consumer Driven Health Paradigm

“It took 38 years for radio to reach 50 million users in the United States. In the case of computers it took sixteen years. The Internet reached 50 million users in four years. Computer power doubles every eighteen months and shows no sign of slackening. The number of DNA sequences we can analyze doubles every two years. A huge gap has opened up between the transformations happening around us and our ability to respond.”

Jonathan Sachs, *The Dignity of Difference*, Page 69

It is said that “hindsight is 20/20.” Looking back, it seems much easier to predict what life would be like in the first decade following the publication of Governor’s Council on the Prevention of Mental Retardation and Developmental Disabilities original report, *Programs for Preventing the Causes of Mental Retardation*, than in the second decade. The publication of the second report, *Changes and Challenges: Building Our Children’s Future*, in 1995 occurred just as a new revolution, information technology, was gathering speed. This revolution has occurred more quickly than any other in our past and this speed continues at an exponential pace. For example, in a post-presidential address, Bill Clinton noted that when he took office in 1993 there were a mere 50 registered websites. By the time he left office in 2000, there were upwards of 350 million.¹

The advent of smaller, affordable personal computers in the past ten years has resulted in information being available instantaneously. This information has had an enormous impact on how we live, give birth, are educated, and how we work and play. Information technology has enabled us to learn more about our own and our current and future children’s health, how we interact with physicians, and what we know about illness, medical procedures, and pharmaceuticals. Indeed, perhaps, the most profound impact has been on how we view life and death. What we have experienced during the past ten years is a radical shift in health paradigms.

“A paradigm is a set of criteria that we use to define what’s important and to determine how to do things. A paradigm is a viewpoint and a set of rules.”² “Paradigms change through radical and sudden shifts. These occur when new discoveries, knowledge or concepts occur which cannot be rejected or assimilated by the old paradigm.”³

In 1998, 54 million people searched the Web online for health information. In 2001, 97 million people searched for health information online. This past year, over 110 million adults went to the Web looking for information about health related matters. Just as the printing press was the catalyst for important and massive social and political change, the Internet is having an even greater effect on the way we view medicine and health care.⁴ Health care consumers are becoming increasingly better educated as a result of information that is presented on the Web and in the media. The Internet is now a mainstream information tool for health related resources. Websites include both laypeople and professionals who dispense advice and support. In fact, the National Library of Medicine’s MEDLINE is accessed by consumers as frequently as by health care professionals and researchers.⁵ “Professional medicine can no longer monopolize its special knowledge because the information highway is, in many respects, leveling the playing field.”⁶

Everyday, advertisements for new drugs and medications exhorting people to “talk to their doctor” appear on our T.V. screens. The way in which the public views the culture of medicine, and the attitudes and behaviors of the medical community are evolving and emerging into a new

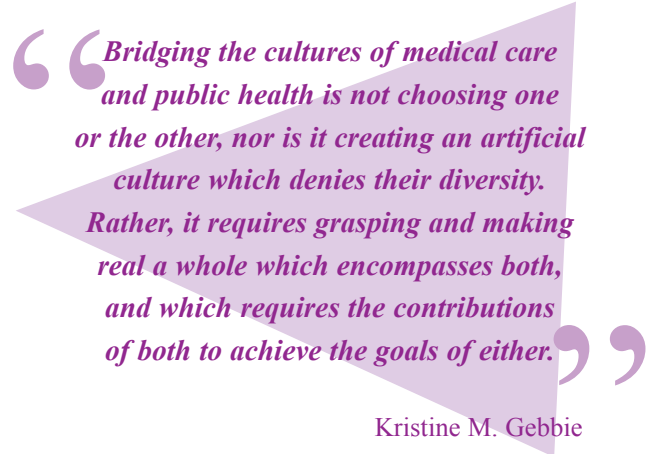
medical paradigm. “The control of knowledge reinforces power, and power is something patients are beginning to demand for themselves.”⁷ This new paradigm is influenced and speeded up, as well, by such factors as the rise in Health Maintenance Organizations (HMOs), the emphasis on preventive care by allied health practitioners, such as social workers, nurses and public health professionals, and “alternative” and “complementary” medicine that is entering into general use. In a sense, public health, alternative health care and traditional medicine are beginning to merge into an integrated health delivery system.

In the paradigm of traditional medicine, the individual’s responsibility was to be dependent and to comply with the doctor’s orders. The physician was considered authoritarian and omnipotent, was not to be questioned and instructions to take medicine as prescribed were to be followed. Most health care was based on treatment of acute disease (disease state) and “fixing” specific problems of the body. Often, symptoms of the disease, rather than cause were treated, and health was considered to be the absence of disease. Prevention consisted of general advice to exercise, lose weight, to get enough sleep and other similar entreaties. These were often ignored by the individual.

“In the new paradigm, the Internet, direct to consumer advertising and the growth of complementary medicines are helping consumers take control of their own health.”⁸ In response, insurance companies and managed health care now cover alternative care such as chiropractic, acupuncture, vitamin and nutrition therapy and other practices previously considered outside of mainstream treatment. Emphasis is being placed increasingly on prevention and wellness, rather than disease. The focus of treatment is on causes, rather than symptoms, and the body, rather than being seen as a series of individual parts, is viewed as an integrated whole.

A national Sunday supplement news magazine that reaches tens of millions of people recently devoted its entire issue to such information under the title, “Take Charge of Your Health”. Articles about personalized medicine entitled, “How to develop a personalized health plan with your doctor”, “When your insurance won’t pay” and “How to find the best medical help online” are typical of

advice and information directed towards the general population.⁹ This paradigm shift to the “consumerization” of healthcare is being driven by the advent of forces such as managed care, rapid technological advances and a barrage of information that empowers the medical consumer. In addition, government regulations, such as the Patient Bill of Rights, Health Insurance Portability and Accountability Act of 1996 (HIPPA) and the Patient Safety Act, serve to give consumers more control over their own healthcare.



Bridging the cultures of medical care and public health is not choosing one or the other, nor is it creating an artificial culture which denies their diversity. Rather, it requires grasping and making real a whole which encompasses both, and which requires the contributions of both to achieve the goals of either.

Kristine M. Gebbie

Public health is changing its focus as well. More resources are being invested in prevention than ever before. Instead of spending billions of dollars on costly treatments, stakeholders are taking a more active role in advocating for policies that support prevention efforts at the federal, state and local levels. These stakeholders; community based organizations and advocacy groups, professional and health worker organizations, consumer groups, funding agents and educators no longer consider themselves as isolated entities, but, by combining their resources and skills, have become partners in working towards a more comprehensive health system. An example is the current practice of “wraparound” services that co-locate a variety of professionals from various social, health and economic agencies and organizations at one location. These professionals provide case management, treatment, service coordination, health promotion, support services, information and other resources more efficiently, effectively and economically than could be done individually.

Another type of collaboration might consist of city planners who develop and build new neighborhoods that include exercise stations, walking trails and bike path and safe play areas. They work in conjunction with politi-

cians, hospital systems, businesses, schools, communities and the media. Together they explain and demonstrate the benefits of healthy behaviors.

Collaborations such as these lead to a greater understanding of, and ability to communicate with people around issues such as language, ethnicity, educational level, culture and customs. Ideally, they lead to a sum of parts that is greater than the whole while still retaining the individuality of these parts.

However, there are populations that continue to experience major disparities in health status and to bear a disproportionate burden of mortality and morbidity across a wide range of chronic and preventable health conditions. These vulnerable populations include people living in poverty and in unhealthy domestic and community environments, uninsured families, those with limited educational attainment, limited literacy skills, those who adhere to traditional health practices and beliefs, and, in and of itself, institutional racism. The overarching and constant variable is poverty. As poverty grows it further impacts these vulnerable populations by imposing barriers to insurance, transportation, accessibility and availability of health services.

Again, community based organizations are emerging as a model for addressing these risk factors and for identifying potential gaps in resources. As it is unlikely that in our current socioeconomic climate one agency or system can address multiple and competing needs, it is more of a possibility that these multi-dimensional groups will encourage information sharing and cooperation within specific communities. They are able to develop focused prevention and healthcare programs that provide for multiethnic and multicultural needs and that communicate in language that is understood. They focus on the effects of the community and the environment on people's health behaviors. As a result, they can be successful in engaging the population, in promoting communication, in establishing trust and in reducing inequalities. Preventable health risk factors for chronic conditions, such as unhealthy nutrition, physical inactivity and excessive alcohol or drug use can be modified with this collaborative management approach.



These models are the ideal and are costly in the short term. Funding restraints and the emphasis on cost reductions by HMO's and managed care, gaps between knowledge and practice and lack of resources for this biopsychosocial approach rather than the medical model of healthcare limit their growth. As they are incorporated into our system of healthcare, they will be able to address critical needs and to empower these populations to assume more responsibility for healthy behaviors.

The description that follows illustrates how such a program, by utilizing resources and funding creatively and collaboratively, can build a model that addresses the needs of the community. In addition, because consumers in the community become part of the process, they are more likely to take ownership and control of their own health.

The Office for Prevention of Mental Retardation and Developmental Disabilities, under its Public Information Small Grants Initiative, has funded programs run by FamCare for many years. FamCare, Inc. is a private, non-profit agency that provides reproductive healthcare and educational services to families. Located in rural Cumberland County in southern New Jersey, Famcare serves a very diverse population whose median household income is the lowest among the state's twenty-one counties. During the past ten years, FamCare has addressed many of the prevailing health and social issues in a way that encompasses a multitude of resources throughout the

county. Although a majority of clients are poverty-level, single adolescent females who are pregnant and/or parenting, FamCare also reaches out to grandparents, fathers and other family members in an effort to treat the family as a complete unit. FamCare incorporates the public health system, local hospitals, schools, community groups, local businesses, nurses, case managers and other social service agencies in an effort to provide comprehensive services and to concentrate efforts on those who otherwise do not have access to traditional sources or means.

Since a large percentage of participants are Hispanic, many staff members are bilingual and educational materials are provided in Spanish and at a 5th grade reading level so they can be read and understood by program participants. In order to reduce some of the many barriers to obtaining services, much of the prevention education is provided in the participants' homes and is free of charge so that transportation and cost are not issues.

Some of the critical issues that have been and continue to be addressed include prevention education encompassing adolescent parenting, nutrition, preventable injuries and safe environments, family planning, child abuse and neglect and family health. In addition, clients are followed from pre conception through a minimum of the first year of infant care. Collaborations with DYFS, the State Department of Health and Senior Services, Community Affairs, the Department of Human Services and many others help to insure funding and resources that provide an uninterrupted continuum of services. As a result, nearly all babies born to adolescents in the program are born at full birth weight and healthy, subsequent pregnancies are avoided, pregnant and parenting teens remain in school or are employed and babies are regularly monitored to maintain their health and continue their ability to thrive. Participants are involved in community services such as WIC, well baby clinics, job training and support programs, and father/child nurturing program. This is a perfect example of how a community agency can embrace the new paradigm and can maximize resources in order to provide the necessary healthcare and educational environment needed to address the critical issues confronting at risk populations in the 21st century.

“Education comes not from hunkering down in well-defended camps of agreement but from facing the challenge of other points of view, and being open to hearing, in them, that part of the truth that one’s own point of view has not yet managed to contain.”

Richard Brodhead, President of Duke University

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The Economics of Prevention: Investment of Dollars That Make Sense

Disabilities are a major public health problem in the United States because of the emotional and financial strains they place on families and society. It is estimated that 15% of our citizenry are born with or incur a disability during their lifetime.¹ Fortunately, in most instances, an illness or injury is a temporary condition that does not result in a permanent impairment. However, in the case of a developmental disability, the onset of the condition occurs early in life, before the age of 22. The impairment is usually life-long and causes functional limitations that require continuous care and services. These characteristics make developmental disabilities very costly to our nation and to families.

Today, nearly four million Americans have developmental disabilities and their associated costs are enormous.² The lifetime economic costs of a disability are estimated by calculating direct and indirect costs. Direct costs include medical treatment, supportive services and care, special education, assistive devices and home modifications. Indirect costs represent lost productivity. These costs are determined by approximating lost wages due to unemployment or underemployment. Although direct costs can be substantial, indirect costs represent a significantly larger portion of the equation. The Centers for Disease Control and Prevention (CDC) estimates the average lifetime costs for people with mental retardation who were born in 2000 will total \$51.2 billion in 2003 dollars. For persons born with cerebral palsy, the estimated costs will total \$11.5 billion.³ Thus, the cumulative lifetime costs for all developmental disabilities can easily soar to well above \$100 billion. In addition, economic costs relate only to dollars and cents. They do not address the greater human tolls of pain and suffering and other serious conditions such as depression, isolation and quality of life.

*“Not everything that is faced
can be changed,
but nothing can be changed
until it is faced.”*

James A. Baldwin

While the cause of many developmental disabilities is unknown, in some cases where the cause is known, prevention strategies can be implemented. Prevention efforts are not without costs, but such programs are justified when there is evidence that the benefits exceed the expenses. Thus, economic evaluation is necessary to enable better policy decisions and resource allocation. Evaluating health promotion and prevention initiatives poses many challenges. It requires considerable expertise and collaboration from many different organizations. Other inherent difficulties associated with evaluating prevention include the intricacies of showing cause and effect relationships, particularly when there is multiple causality and accountability, the differential timing of potential benefits, along with time-lags associated with behavioral change.

Despite these complexities, there is a growing body of research that supports the effectiveness and cost savings attributable to prevention interventions. Effective prevention efforts use multifaceted systems approaches that range in scope from educating individuals to influencing policy legislation. They involve interdisciplinary collaborations on an increasing continuum of awareness levels. The various intervention levels include increasing the awareness and knowledge of individuals and community groups, educating providers, establishing advisory boards and coalitions to coordinate efforts and make recommendations, and influencing policy and legislation.⁴ Another important piece of the prevention puzzle is developing surveillance and tracking systems that provide baseline data and capture information over time that allow for comparisons and identification of trends.

Many risk factors are known to cause birth defects which are a leading cause of developmental disabilities.

Of the 4 million children born each year in the United States, about 150,000, or 3-4% of all live births, have at least one serious birth defect.⁵ Of these, approximately 1-3% will result in a permanent developmental disability. As the New Jersey birth rate is estimated to be 114,000 live births per year, this translates to between 1000 and 3000 infants born each year with a developmental disability. While not all developmental disabilities are preventable, three case studies are presented here to illustrate the economic benefits of specific prevention interventions. In each instance, New Jersey has taken steps to implement prevention efforts and can expect, now and in the coming years, economic savings.

Preconception Health - Folic Acid Makes A Difference

Research demonstrating the efficacy of folic acid, a part of the Vitamin B complex, to prevent Neural Tube Defects (NTDs) emerged in the early 1990's. Similar to changes in other health behaviors, educating physicians and women of childbearing age about the importance of adequate folate levels to insure the proper closure of the neural tube took time, financial investment, mandatory and voluntary actions, and collaborative efforts to achieve. Over the last decade, however, great progress has been made in preventing NTDs.

NTDs are birth defects that involve the spinal cord and/or the brain, the most common of which are spina bifida and anencephaly. Spina bifida occurs when the lower end of the neural tube fails to close. Thus the spinal cord and backbone do not develop properly. Children born with spina bifida may experience learning disabilities, paralysis of legs, loss of bowel and bladder control, and hydrocephaly. The survival rate for infants born with spina bifida is 80-90% and, with good health care, many persons are now living into young adulthood.⁶ Anencephaly is a fatal condition in which the upper end of the neural tube fails to close. The brain either never completely develops or is totally absent.

The neural tube forms during the first weeks after conception, before a woman knows she is pregnant. Taking a folic acid supplement before conception and during early pregnancy has been shown to reduce the inci-

dence of neural tube defects by 50-70%.⁷ The incidence of NTD's in the United States is estimated to be 6 in every 10,000 live births or about 2,500 infants born each year.⁸ The average lifetime cost to society for each infant born with spina bifida is approximately \$530,000, although for many children the total cost can be well above 1 million dollars.⁹ The estimated annual medical and surgical costs to the nation for persons with spina bifida exceed \$200 million annually.¹⁰

In New Jersey, 129 infants were born with the most common neural tube defects, anencephalus and spina bifida, from 1997 through 2001. Twenty three infants were born with anencephalus, and 106 infants were born with spina bifida. This translates to an incidence of 2.25 per 10,000 live births for New Jersey during this time period. New Jersey's birth rate of approximately 114,000 live births a year would equate to about 26 infants born each year with the two most common types of NTDs.¹¹

Over the last decade a major public health success story has been the federally mandated program to fortify enriched grain products with folic acid. Enriched grains include foods such as cereal, pasta, flour and bread. The discovery that folic acid can prevent neural tube defects led to several prevention activities occurring throughout the country. In 1992, the US Public Health Service recommended that all women of child bearing age consume 400 micrograms of folic acid a day. In 1996, the US Food & Drug Administration made it optional to fortify enriched grain products with folic acid. In 1998, fortification of enriched grains was made mandatory. Although the amount of folic acid fortified in grain is relatively small, 140 micrograms per 100 grams of grain, compared to the recommended daily amount of 400 micrograms, since its inception, from 1995 through 2001, it is estimated that NTDs have declined by 26%. One study that analyzed economic benefit and cost savings concluded that, for every dollar spent on folic acid fortification in the United States, at least \$40 are saved in costs for providing care to children born with spina bifida.¹²

In order to insure that physicians and women of child-bearing age were educated about folic acid, the March of Dimes assumed a leadership role for the nation and implemented a five year medical and public health education

campaign. Further, the March of Dimes conducted a series of surveys to determine increases in knowledge about the important role folic acids plays as well as to determine changes in healthy behaviors, e.g., increases in the number of women of childbearing age who take a vitamin with folate on a regular basis. The most recent survey conducted by the March of Dimes found that 40% of American women of child bearing age are taking a multivitamin with folic acid. This is an all time high since the survey began in the 1990s. The previous survey revealed that 32% of American women were taking a daily supplement with folic acid.¹³ With increased public education regarding prevention of neural tube defects and promotion of multivitamins with folic acid for all women of child bearing age, we can expect to see the incidence of NTDs continue to decrease.

It is also important to note that the March of Dimes joined with the Centers for Disease Control and Prevention (CDC) and other federal, state and non-profit agencies to form the National Council on Folic Acid. In New Jersey, the March of Dimes and the Spina Bifida Association organized a state-level coalition. Initial funds to support this effort came from the National March of Dimes as well as from the Office for Prevention of Mental Retardation and Developmental Disabilities. The Department of Health and Senior Services now coordinates the coalition. Thus, the implementation of a combination of coordinated actions --- mandated food fortification - plus medical and public education have resulted in a decrease in the incidence of NTDs and the accompanying economic costs.

Prenatal Health - Fetal Alcohol Syndrome: The Numbers Will Go Up Before They Come Down

Despite the fact that Fetal Alcohol Syndrome (FAS) is among the birth defects that are mandated to be reported to the Birth Defects Registry, such reporting rarely occurs as most affected children are not diagnosed until after the mandated reporting age of one year. As a result, the incidence of alcohol-related developmental disabilities in the State is underreported. FAS is a leading known cause of mental retardation and is one of the few birth defects that is entirely preventable. FAS cannot occur if a woman

does not drink while she is pregnant. Nationally, about 40,000 babies are born each year with FAS. According to recent studies conducted by the CDC, prevalence rates for FAS range from 0.2 to 1.5 cases per 1,000 live births. The economic costs associated with FAS and fetal alcohol related disorders are staggering, with lifetime costs estimated to be as high as \$5 million for one child.¹⁴ In New Jersey, the annual birth rate is approximately 114,000 live births. This translates to a possible 20 to 170 infants born each year with FAS. For every child diagnosed with FAS, an additional 5 children are born with neurological and/or physical anomalies that comprise the Fetal Alcohol Spectrum Disorders (FASD).¹⁵

Over the last decade, New Jersey has made tremendous strides toward developing a comprehensive statewide systematic approach for preventing and ameliorating the effects of FASD through education, surveillance, diagnosis, and treatment. In 1998, the FASD Task Force was re-organized to become a committee of the Governor's Council on Prevention Mental Retardation and Developmental Disabilities. The Task Force is composed of representatives from several state agencies as well as from a broad range of health and community organizations. This collaboration works to coordinate statewide efforts and to make recommendations for influencing policy decisions and legislation. In 2002, as a result of a report on FAS submitted by the FASD Task Force to Acting Governor Donald DiFrancesco, \$450,000 was appropriated to the DHSS to establish six FASD Regional Diagnostic Centers. In addition to diagnostics, the centers are required to engage in outreach, information and referral services, case management, and community and professional education. The regional center at UMDNJ Medical School in Newark was awarded a CDC grant to serve as one of four national FAS Training Centers. The center is responsible for training medical students, residents and clinicians.

Acting upon one of the recommendations in the 1985 report of the Governor's Council, the DHSS initiated the FAS Risk Reduction System in 1988. In 2002, this system was transformed into the Perinatal Addictions Program and became part of the continuum of services provided by each of the six regional Maternal and Child Health Consortia (MCHC). Among other responsibilities,

the Perinatal Addiction Specialists work with local health care organizations and providers to educate them about the effects of prenatal alcohol and substance abuse upon fetal development. The Specialists also work with Addiction Treatment Centers so that staff and young women in recovery understand the effects of these exposures and are prepared to obtain the services that their children may need. In addition, the Southern New Jersey Perinatal Cooperative received a grant from the Robert Wood Foundation to augment the perinatal screening system by developing a common database to collect and analyze aggregate information about women screened and their treatment needs. All six MCHCs are participating in this effort.

In order to increase the number of professionals trained in this area, New Jersey became the first state to offer a certification specialty in Perinatal Addictions in 2004. This program focuses specifically on the effects of alcohol and drug exposure during pregnancy.

Along with educating those in the allied health professions, there have been many achievements in the area of public education and outreach. FAS education has been added to the core curriculum standards for Health and Physical Education for all New Jersey schools. Educational materials and curricula have been developed for distribution and use. With support from the Office for Prevention, The Arc of New Jersey's Coalition for

**Prenatal Screening Questions:
A Necessary Prevention Strategy**

Barbara May, BSN, RN

Southern New Jersey Perinatal Cooperative

Every year in New Jersey, nearly 15,000 babies are exposed to drugs and alcohol during pregnancy. Their mothers are represented equally across all socioeconomic, ethnic, and geographic groups. Prenatal exposure to drugs and alcohol can lead to a broad range of physical and neuro-developmental problems that affect the ability of children to perform in school and in society. Therefore, attention to substance abuse problems during pregnancy can improve infant health and reduce long-term medical, educational and social costs. Pregnancy presents a unique window of opportunity to prevent these problems because a woman is concerned about her infant's health. When pregnant, she cannot easily insist that her drug or alcohol use harms no one but herself.

The best practices of local and national programs have taught us important lessons about improving access to care for pregnant substance users. Across the country, researchers and clinicians have found that stresses and challenges in the personal lives of many women prevent them from negotiating barriers to treatment. Improved health outcomes for their children are best accomplished when pregnant women are:

- identified early in pregnancy through a uniform screening process;
- assessed, referred to treatment and supported by a case manager who is a certified drug and alcohol counselor and;
- followed to assure that the babies exposed to drugs and alcohol during pregnancy are assessed during infancy and provided with a treatment plan developed by a neuro-developmental specialist.

In 2003, New Jersey launched a significant prevention initiative to protect children from the effects of substance exposure and position them for school readiness and a safer, secure home environment. This statewide project establishes a uniform screening tool that is used to ask every pregnant woman about her drug and alcohol use. By asking these questions and responding with concern, prenatal care providers will help every woman in need of counseling, treatment and support to stop her use of drugs and alcohol and to protect her baby's future.

Prevention of Developmental Disabilities has worked with local agencies to increase the number of Pregnant Pause events from two counties in 1997 to 20 counties each year. In addition, the Coalition is working closely with the Juvenile and Criminal Justice Systems to educate them about FASD as many affected individuals become involved in illegal activities at an early age. Also with support from the Office for Prevention, The Arc of Atlantic County employs a FAS liaison who works with individuals and community groups interested in providing FAS prevention education. The number of community organizations conducting FAS prevention education has grown steadily over the past decade.

Over the last ten years New Jersey has laid the groundwork for future FASD endeavors where incidence and prevalence will be measurable and evaluating prevention interventions will be possible. To this end, the FASD Diagnostic Center at UMDNJ - New Jersey Medical School (NJMS) has established a FASD Surveillance System. The other centers will provide to UMDNJ-NJMS information on the children who have been diagnosed with FAS as well as important demographic information. The diagnostic information will be provided to the DHSS, Birth Defects Registry as well. As more children are referred to the Diagnostic Centers and as they, in turn, provide data to the FASD surveillance system, it is expected that the known incidence and prevalence of FAS in New Jersey will increase. This information can then be used to design appropriate and targeted educational campaigns to high risk areas. As more young persons are educated about the permanent damage that alcohol can cause to a developing fetus, it is expected that the incidence of FAS will ultimately decline.

Child Health - Injury Prevention Works

Unintentional injuries are the most common cause of disability and death in the United States and in New Jersey. Despite the fact that they occur at a rate much greater than infectious diseases, few Americans recognize injuries as being epidemic. Further, when questioned, many more persons believe that they will fall victim to a violent crime than to an unintentional injury, such as a car crash or a fall. Yet, the likelihood of sustaining a permanent disability is much greater for unintentional injuries

than for violent ones. For example, in 2002, 94% of all Traumatic Brain Injuries that were severe enough to result in hospitalization or death were due to unintentional incidences.

SAFE KIDS is a national organization, dedicated to preventing unintentional injuries among children. Initiated by the Children's National Medical Center in Washington, DC, Johnson & Johnson became the corporate partner and sponsor of SAFE KIDS in 1987. Fred Patterson, Chair of the Governor's Council on Prevention, was named Project Director. Not surprisingly, New Jersey became one of the first states to organize a SAFE KIDS coalition which was based at the New Jersey Safety Council and received support from both the Office for Prevention and Johnson & Johnson. In the past decade, 17 local chapters have been organized. The local chapters are responsible for conducting childhood injury prevention education and programs in every county in the state. New Jersey SAFE KIDS has reached over 500,000 individuals through car seat check up events. Since 2000 it has distributed over 5,200 child safety seats to underserved populations.¹⁶

It is estimated that 90% of all unintentional injuries can be prevented if families are made aware of the potential risks in their children's environment.¹⁷ In New Jersey, the five leading causes of hospitalization for unintentional childhood injury are falls, bicycle, pedestrian, motor vehicle occupancy and airway obstruction. Traumatic brain injury (TBI) is the most common cause of acquired developmental disability. The CDC estimates that each year 1.4 million Americans sustain a TBI.¹⁸ Falls and motor vehicle crashes are the leading cause of TBI. These disabilities result in enormous expenses. The estimated lifetime cost for one person who survives a severe TBI can be as high as \$4 million.¹⁹

In New Jersey for the year 2000 there were 8,006 traumatic brain injuries serious enough to require hospitalization or cause death.²⁰ Young adults, between the ages of 15 and 24, and the elderly, 75 years of age and older, are disproportionately affected by head injuries. However, in 2002, 1598 children from under age 1 to age 19 were hospitalized or died from severe traumatic brain injuries. This represents 20% of all hospitalizations and deaths.

Several major accomplishments have been achieved in the area of injury prevention and surveillance in the past several years. In 1994, as a result of funding that the Office for Prevention received from the CDC through the Disabilities Prevention Program, the New Jersey Traumatic Brain Injury Surveillance System was implemented. This system provides morbidity and mortality incidence rates, demographic information and classifies injuries according to severity and cause. It is an important instrument for data analysis, monitoring and evaluating the direction of public health objectives relating to brain injury. In 2004, building upon and expanding the work accomplished in TBI surveillance, the DHSS established an Office for Injury Control and Prevention in the Center for Health Statistics.

In 1998, through the advocacy of community agencies, such as the Brain Injury Association of New Jersey, the New Jersey Advisory Council on Traumatic Brain Injury was established. The council makes recommendations, establishes public hearings, guides community outreach and prevention education, encourages research and oversees programs. In 2002, Public Law 2001, c.332, the Brain Injury Fund was established. Funds from this source are used to implement injury prevention programs as well as to provide services to persons who have sustained a TBI.

Legislation can be a very effective tool for mandating injury prevention interventions. Two important areas where legislation has been instrumental are bike helmets for all wheeled sports including skateboards, roller skates and scooters and the 80 pounds or 8 years of age safety seats law. New Jersey was the first state in the nation to pass a mandatory bicycle helmet law requiring the use of bike helmets for all children under the age of 14 when it was enacted in 1992. Five years after the law went into effect, bike related fatalities had decreased by 60%.²¹ The mandated booster seat law was enacted in 2001. Data are still being collected to measure the effectiveness of this injury prevention measure.

Conclusion

Investing in prevention is a credible endeavor that has the potential to yield awesome returns. The economic costs

associated with a developmental disability are exorbitant and placing a value on the human toll is impossible. The advent of “magic bullets,” such as folic acid for NTDs, are rare. In most instances, prevention requires patience, perseverance, collaboration, time and funding in order to observe and measure changes in behaviors and outcomes. As a result, it is often frustrating and problematic to demonstrate achievements. However, when these ingredients are available, the old maxim that an “ounce of prevention is worth more than a pound of cure” can be demonstrated.

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Advances in Genetics and their impact On Prevention of Mental Retardation and Developmental Disabilities

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Seemingly miraculous advances in genetics have been achieved over the past 50 years since the discovery of DNA. These advances have resulted in a marked increase in knowledge about the biological and chemical basis of human birth defects and causes of mental retardation and developmental disabilities. More than 40 years ago, it was recognized that changes in the microscopic appearance of chromosomal structure or number could result in clinical disorders such as Down syndrome. Research that began 30 years ago in the 1970s focused on alterations in the DNA molecule. These investigations led to the establishment of an entirely new field of molecular genetics, resulting in the complete sequencing of the entire genome of humans and many other animal and plant and microbial species. Numerous investigations are now underway to determine the relationship between alterations in the DNA sequence and human disease.

Many of the advances in human genetics have been assimilated into the mainstream of medical practice in pediatrics, obstetrics and internal medicine. Laboratory medicine has embraced the field of clinical cytogenetics, biochemical genetics and molecular genetics as specialty areas of clinical pathology. Public health has incorporated a number of genetic testing protocols that are designed to prevent the occurrence of human genetic diseases in the human population. Screening programs designed to screen large populations of pregnant women for fetuses at risk for chromosomal disorders rely upon the use of maternal serum analysis in second trimester to determine the

risk for a fetus with a disorder like Down syndrome. The same specimen can be tested for alpha fetoprotein to detect a fetus at risk for neural tube defects or other malformations. Heterozygote screening programs for Tay Sachs Disease, beta Thalassemia and Sickle Cell Disease have provided information to individuals who carry a single copy of a mutant allele for a particular genetic disease found in certain ethnic or racially defined populations.

All of these emerging technologies have resulted in the development of a new branch of medical practice known as Medical Genetics, a board certified medical specialty with residency and fellowship training. The provision of medical genetic services is enhanced by laboratory scientists and genetic counselors who provide specialty care in their respective areas.

Yet, the new technologies have presented society with many ethical, legal and social/financial dilemmas:

- The ability to determine and possibly select the sex of a baby before it is born.
- The possibility to identify a gene for an adult onset disease like Huntington's Disease prior to the onset of symptoms.
- Genetically screened embryos produced in vitro (in the laboratory) before implantation in the uterus.
- The ability to detect a fetus with a potential disability before birth and terminate the fetus to opt for a healthier subsequent child.
- The risks of testing children for adult onset genetic disorders.

The completion of the Human Genome Project, which provides the potential to determine the role of genetic variation in human disease, presents society with many difficult questions to be answered. An entire section of the Human Genome Project is devoted to studying the Financial, Ethical, Legal and Social basis of the human genome project on society. It remains to be seen how society will integrate the new advances in biotechnology into the culture of modern day society. See www.nhgri.gov/ELSI/

THE ROLE OF MEDICAL GENETICS IN UNDERSTANDING MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

Mental retardation and developmental disabilities represent a broad range of human conditions defined by a deviation from normal expected behavioral or physiological performance. Human malformations take the form of variation in the normal structure of some human anatomical tissue or organ. The underlying role of genes in the formation of human structure and function is unquestionable. There are also many non-genetic causes of mental retardation and developmental disabilities, such as environmental toxins like lead and mercury, infectious disease agents like rubella, life style exposures to toxins like alcohol and smoking, and social conditions such as poverty. Likewise, interactions between these factors or conditions or in combination can enhance the risk for a disability.

The genetic basis of mental retardation and developmental disabilities heretofore consisted of many well described conditions such as:

Examples

- Chromosomal Disorders: Down syndrome, Klinefelter Syndrome
- Biochemical Disorders: Phenylketonuria, Galactosemia, Tay Sachs Disease
- Molecular Disorders: Fragile X Syndrome; Myotonic Dystrophy
- Multifactorial Disorders: Cleft Lip and Palate; Neural Tube Defects

The number of known conditions is now quite extensive with more than 10,000 listings posted in a web-based system, Online Mendelian Inheritance in Man (www3.ncbi.nlm.nih.gov/Omim/). This database provides information on human genes and genetic diseases and is jointly maintained by the National Library of Medicine, National Institutes of Health and the Johns Hopkins University School of Medicine. It provides resources to physicians, researchers, educators and the public on specific genes and genetic diseases.

Information on the diagnosis, counseling and management of persons affected with genetic disorders is now available on GeneClinics (www.geneclincs.org/), maintained by the University of Washington and supported by the federal government. This site provides physicians and other health providers with up-to-date clinical information on both common and rare genetic diseases. It can also assist in determining which laboratories provide testing for certain genetic diseases with links to genetic laboratory websites.

Genetic diagnosis, testing and counseling is often provided on an individual or family basis. It also assists families to gain understanding about the cause of the condition and interventions that might improve the life of the affected members and strategies for prevention of the condition in any subsequent family members.

IMPACT OF GENETICS IN PUBLIC HEALTH

The recognition of genetic causes of mental retardation and developmental disabilities has resulted in adoption of screening and testing of the public for certain conditions. The interest in genetics in public health has largely been facilitated by the development of Birth Defect Registries (BDR) which track the variation in incidence and prevalence of genetic disorders and birth defects by locality. Further, BDR can be useful in identifying regional changes in the incidence of certain disorder potentially associated with environmental causes or a change in population demographics for a certain type of birth defect or disability. Another development that has contributed to the integration of genetics in the public health arena has been the development of regional genetic networks which provide coordinated clinical services in large regions of the country.

Public health agencies are focused on several areas of genetic testing including:

- Heterozygote Screening;
- Newborn Screening for Metabolic Disorders;
- Maternal Serum Screening for Chromosomal Disorder and Open Neural Tube Defects; and
- Prenatal Testing for Genetic Disorders in High Risk Obstetrical Populations.

Heterozygote Screening:

Heterozygote testing has been directed towards identifying carriers of autosomal recessive genes for disorders such as Sickle Cell Disease, Tay Sachs Disease, beta thalassemia and cystic fibrosis. These programs focus on certain racial and ethnic groups with a higher incidence of these genes than found in the general population. The populations screened for each of these disorders is listed below:

Disorder	Population
Sickle Cell Disease	African Americans
Tay Sachs Disease	Ashkenazi Jewish
Beta Thalassemia	Mediterranean populations
Cystic Fibrosis	Northern European

A relatively new program has focused on heterozygous screening for Cystic Fibrosis (CF). While there are hundreds of mutations that can result in CF, most are rare. A protocol that screens for the most common mutation, DeltaF508, along with a few dozen additional mutant alleles, can identify almost 90% of all carriers. When applied to couples, this strategy will result in the detection of 80% of couples who may be at risk for having a child with CF. Another disorder considered as a possible candidate for heterozygote screening is Hereditary Hemochromatosis, an autosomal recessive condition which can result in liver disease, diabetes and cardiac disease caused by excessive iron storage in tissues.

Newborn Metabolic Screening:

All of the states in the nation have some form of legislation or regulation that provides for testing of all newborns for certain metabolic diseases. These inborn errors

of metabolism, if diagnosed early, can be treated and may result in children developing normally. New Jersey was among the first states to initiate a Newborn Screening Program (NBS), beginning in the 1960's when the technology became available to screen for Phenylketonuria (PKU). The program expanded to include galactosemia, congenital hypothyroidism and sickle cell anemia over the past several decades. Recently, the development of a new technology, Tandem Mass Spectroscopy (MS/MS) has provided for a remarkable transformation in the NBS program in New Jersey and other states as well. This and other technologies now make it possible to screen for more than 50 different metabolic disorders. These conditions include disorders of fatty acid, amino acid, and organic acid metabolism as well as other disorders like Cystic Fibrosis, hemoglobinopathies, congenital adrenal hyperplasia, biotinidase deficiency and galactosemia (www.pediatrix.com).

In accordance with Chapter 24 of the Public Laws of 1998 (N.J.S.A. 26:2-110 and N.J.S.A. 26:2-111), New Jersey has expanded its statewide system of newborn biochemical testing to include a total of 20 disorders, which, if not detected early, can cause severe health problems, mental retardation and even death. As described on the DHSS website (www.dhss.state.nj.us), the tests currently required for all newborns include:

- **Congenital Hypothyroidism** - Congenital hypothyroidism results when the body does not make enough thyroid hormone. If untreated, this disorder can cause mental retardation, abnormal growth, deafness, and neurological problems. Treatment includes medication to replace the missing thyroid hormone. Early treatment can prevent the damage caused by this disease.
- **Galactosemia** - Galactosemia occurs when the body cannot use the part of milk sugar called galactose. If untreated, babies with galactosemia can have mental retardation, developmental disabilities, or may even die. Babies with galactosemia require a special diet without any galactose (must avoid milk and milk products).
- **Hemoglobinopathies, including Sickle Cell Disease** - In this group of disorders, the red blood cells are malformed. Babies with these disorders are more likely to have anemia, episodes of severe pain, and life-

threatening infections. Babies with any of the hemoglobinopathies could require a variety of treatments, including antibiotics to prevent serious infections.

- **Phenylketonuria (PKU)** - Newborns with PKU cannot break down a substance called phenylalanine, which is found in the protein of many foods. If untreated, this disorder can cause mental retardation, seizures and developmental delays. Treatment consists of a diet with low levels of phenylalanine. Women with PKU, when they reach reproductive age, may require a modified diet to prevent fetal damage due to high levels of phenylalanine metabolites in the maternal circulation.
- **Biotinidase Deficiency** - Infants with this disorder cannot process the vitamin biotin in a normal manner. Regular medical care and treatment with a medicine containing biotin can prevent seizures, hearing loss and delays in development.
- **Congenital Adrenal Hyperplasia (CAH)** - This is a group of disorders in which the adrenal glands do not produce normal amounts of certain essential hormones. If untreated, serious loss of body salt and water, and even death, may occur. Lifetime treatment includes daily medication and close monitoring to prevent complications of the disease.
- **Cystic Fibrosis** - This disorder causes thick mucus to collect in the lungs and intestines, which can result in breathing problems, lung infections and poor digestion of food. These newborns need frequent medical monitoring, including specialist care, as well as a healthy diet. Early identification and treatment have been shown to improve growth and development in children with cystic fibrosis.
- **Maple Syrup Urine Disease** - This is a rare metabolic disorder in which a baby's body cannot break down certain proteins found in foods, including breast milk and formula. The name of this disorder comes from the distinctive maple syrup odor of the urine in an affected baby. Lifetime treatment includes a special diet of foods with low levels of certain proteins, and frequent monitoring by a doctor and a metabolic genetics specialist.
- **Fatty Acid Oxidation Disorders**
 - **Medium chain acyl-CoA dehydrogenase deficiency (MCAD)**
 - **Short chain acyl-CoA dehydrogenase deficiency (SCAD)**

- **Long chain acyl-CoA dehydrogenase deficiency (LCAD)**
- **Very long chain acyl-CoA dehydrogenase deficiency (VLCAD)**

Babies with any of these fatty acid oxidation disorders have trouble using fat for energy. A special enzyme, which converts fat to energy, is either missing or not working correctly. This can lead to a medical crisis if the baby fasts (goes without eating) for very long. This crisis can include vomiting, low blood sugar or more serious problems such as coma. Typically, a special diet and special precautions may need to be taken if the baby is sick.

- **Urea Cycle Disorders**
 - **Argininosuccinic acidemia**
 - **Citrullinemia**

These urea cycle disorders are metabolic problems where excessive amounts of ammonia accumulate in the blood. These excessive amounts of ammonia can lead to behavioral problems, mental retardation, coma and even death. Babies with these disorders need a special diet and/or medication with medical monitoring.

- **Organic Acidemias**
 - **Methylmalonic acidemia (MMA)**
 - **Propionic acidemia (PPA)**
 - **Isovaleric acidemia (IVA)**
 - **Glutaric acidemia Type I (GA -type 1)**
 - **3 - hydroxy - 3 methyl glutaryl - CoA Lyase deficiency (HMG)**
 - **3 - methyl - crotonyl - CoA carboxylase deficiency (3-MMC)**

Babies born with one of these disorders cannot remove certain waste products from their blood. This can lead to vomiting, low blood sugar, developmental delays and coma. Treatment depends on the disorder the baby has, but may include a low protein diet, vitamins, and avoiding fasting. A baby born with one of these disorders needs lifetime treatment and regular medical care.

Babies with abnormal screening results are aggressively followed by the New Jersey Department of Health

and Senior Services, Newborn Screening and Genetic Services Program in Special Child, Adult and Early Intervention Services, to ensure that affected children and their families are linked with a primary care provider and the regional network of specialty care centers to receive timely and appropriate services.

Early identification of all disorders screened in the newborn period is only the first step in a successful newborn screening program. Additional resources and funding to ensure immediate access to confirmatory testing, follow-up, and assurance of appropriate and comprehensive treatment services are also required. Consultants have been identified to provide comprehensive services for the various disorders and state funding has been committed to provide a statewide safety net of pediatric metabolic treatment centers, cystic fibrosis care centers, sickle cell programs, endocrine specialists and regional biochemical genetics laboratories.

Additionally, affected children must be reported to the Special Child Health Services Registry which will further link the family to community-based, culturally competent, comprehensive case management and early intervention services.

The use of this screening technology, accompanied by expansion of counseling and treatment programs will provide for the early diagnosis and treatment of young children affected with these conditions and possibly the prevention of subsequent children born with these metabolic disorders. The expansion of the newborn metabolic screening program has prompted a need for expanded treatment centers with physicians trained in treating newborns with complex metabolic disease, access to special foods and support services including genetic counseling.

Maternal Serum Screening for Chromosomal Disorders and Open Neural Tube Defects

Pregnant women are routinely offered testing, commonly called the Triple Screen, which consists of three laboratory tests: alpha feto protein, human chorionic gonadotropin and unconjugated estriol. These tests, taken in concert, can predict an increased risk for the pregnancy to result in certain type of chromosomal disorder like Down syndrome or other trisomy chromosomal disorders.

The alpha feto protein test alone is used to determine if there is an increased risk for an open neural tube defect, commonly known as spina bifida. It is important to emphasize that these are screening and not diagnostic tests. Positive screening tests require further diagnostic tests, such as cytogenetic studies for chromosomal disorders, or further alpha feto protein studies in amniotic fluid and ultrasound examination of the fetus to determine the presence of an open neural tube or other birth defect.

Primary Prevention of Neural Tube Defects

The incidence of neural tube defects (NTDs) has been reduced by up to 75% in women who may be deficient in folic acid, a vitamin that is part of the Vitamin B complex. With the discovery of the relationship between NTDs and foliate deficiency in the early 1990's, the Federal Drug and Food Administration (FDA) approved the addition of folic acid to grain based foods such as bread and pasta. However, the amount approved for dietary purposes is low and because the closure of the neural tube occurs during the first month of pregnancy, women must be educated about the importance of increasing their dietary supplement from 400 ug to 800 ug of folic acid per day at least one month prior to becoming pregnant.

Prenatal Genetic Testing for Genetic Disorders in High Risk Obstetrical Populations

Since the 1970's, prenatal testing for certain genetic disorders, such as Down syndrome, has been possible. The advances in cytogenetic technology over the past decade, using molecular genetic probes to identify chromosomal segments, has assisted in understanding the cytogenetic basis of certain conditions resulting in mental retardation and developmental disabilities. One technology in particular, referred to as fluorescent in situ hybridization or FISH, is used as an adjunct technology along with chemical banded cytogenetic analysis to determine if any chromosomal disorder is present in the developing fetus. Fetal samples are obtained either through chorionic villus sampling in first trimester or amniocentesis in second trimester. Results can take 2 weeks or more to complete and this is often a very anxious period for soon to be parents. Genetic counseling is an important part of any prenatal genetic services.

Although prenatal diagnosis does not provide for in utero treatment of a chromosomal disorder, it does allow parents to decide if they wish to continue the pregnancy or terminate and possibly try again. For couples who continue the pregnancy it offers them time to adjust to the diagnosis and to plan for the special needs of their soon to be born child.

While rapid prenatal testing is not yet possible, technology is moving in the direction of using a rapid screening technique for looking at chromosome number and structure of certain chromosomes which, if abnormal, might result in a viable fetus with significant disabilities, such as those associated with chromosomes, 13, 18, 21 and the X and Y. Future research will determine if this new, rapid technology can be used without extensive and time consuming laboratory testing.

Future Directions for Genetics

Several areas of active research will likely contribute to the field of prevention of mental retardation and developmental disabilities. The completion of the Human Genome Project has resulted in the initiation of the Human Proteomic Project (www.nhlbi-proteomics.org) that is designed to identify the structures of the proteins of the human and determine the role of these proteins in normal anatomy and physiology. Only by obtaining this information can we completely understand the genetic and biochemical basis of genetic disorders which result in disabilities.

Stem cells offer the potential of developing new cells that can be directed to replace defective or damaged cells and ultimately correct disabilities. While there has been much focus on the ethics of stem cell research, the controversy has largely been related to the source of such cells rather than their potential utility. In general, it is agreed that stem cells provide the potential to treat many physical and mental disabilities and further research should begin to answer many complex questions.

To date, scientists have not yet solved the complex interactive relationships between genetic and non-genetic factors (environmental) as causative agents in disabilities. Gene-environmental interactions have been suspected as

important factors in the occurrence of a host of human disorders, such as cleft lip and palate, neural tube defects and, possibly, many forms of mental retardation and developmental disabilities, including autism. The same complex interactions are likely to be the basis for disorders of adult onset, such as heart disease, cancer, diabetes and mental illness. Most recently, autism has been proposed as a disorder that may result from a genetic predisposition and environmental exposure in certain populations and a similar causation may be true for some forms of Alzheimer's disease as well.

Thus, science must begin to unravel the mysterious relationship between the genes and environmental agents since the cure for genetic disease may lie less in the ability to change genetic structure but rather in reducing exposure to the non genetic, triggering environmental agents. As we gain a better understanding of both the genetic and non genetic factors as causes of disabilities, new strategies for prevention of mental retardation and developmental disabilities are likely to become realities in the future.



Arsenic and Old Lead ***The Paradox of Our High Standard of Living****

We live in a world that is infused with chemicals and toxins, whose purpose is to make our lives easier and more comfortable. Our homes, both inside and out, are built and furnished with materials that are treated or have substances added to them to make them more durable and attractive. Necessities, including our food and clothing, are subjected to chemical exposures, both natural and synthetic. Common appliances, like washing machines and dishwashers, and conveniences, such as dry cleaners, all require the use of environmentally harmful substances.

These toxins accumulate in fat, blood, organs, hair and nails. They pass easily through the body in amniotic fluid, breast milk, urine, feces sweat and semen. As a result of these exposures, our health and that of generations to come is greatly threatened.

Two reports recently issued by federal agencies underscore the magnitude of our environmental problems. The Centers for Disease Control and Prevention (CDC) report, ***Second National Report on Human Exposures***, documents the extent to which our bodies are subjected to numerous chemicals and heavy metals on a daily basis.¹ While improvement was found in some areas, e.g., decreased levels of exposure to lead and cotinine (a metabolite of nicotine), increased levels of exposure were cited for other toxins, e.g., phthalates found in common household products such as soap, shampoo and flexible plastics. The second report, ***America's Children and the Environment***,² issued by the Environmental Protection Agency (EPA), found that:

- Almost 5 million women or 8% of those of child-bearing age have mercury concentrations greater than the maximum precaution-

ary level. Children born to these women are at increased risk of cognitive and developmental damage. Mercury in fish is the greatest source of exposure, with coal burning serving as the highest source of mercury.

- Children whose parents worked with pesticides and wood preservatives were at a higher risk for having birth defects and for dying young.
- Pesticides, other chemicals and radiation may contribute to an increased frequency of some childhood cancers. Children born to parents who work with or use certain chemicals are more likely to have cancer in childhood.
- The number of children having respiratory illnesses, particularly asthma, is increasing due to exposure to air pollution. This has resulted in difficulties in breathing resulting in increased use of medication, visits to doctors' offices and outpatient emergency rooms and hospitalization.
- Children of women who were exposed to chlorinated solvents have an increased risk for heart and oral cleft defects.

These reports underscore the paradox of contemporary life and illustrate the societal dilemma we face. On one hand, chemicals and metals have enabled us to attain relatively high standards of living. On the other hand, our high standards of living are now threatened by these same elements due to their toxicity to ourselves and particularly to the developing neurological systems of our children.

Toxic exposures result in poor developmental outcomes or illnesses in an equal opportunity fashion. However, differences in the expression of the outcomes may be attributed to age, e.g., child versus adult, and socioeconomic standing. Race and ethnicity are greatly influenced and affected by socioeconomic status, e.g., where one lives and works.³ Thus, children with lower

socioeconomic status are often at greater risk of being exposed to toxicants.

For the most part, our health care providers are not well educated about environmental exposures. A recent survey by Emory University researchers found that “the importance of environmental exposures to children’s health is well known to pediatricians, but they need more training in that area”.⁴ One-quarter of medical schools offer no instruction in environmental medicine. Those that do offer training average less than 10 hours of education over four years.

In reality, we know very little about the effects of most modern day pollutants. Under the Toxic Substances Control Act (TSCA), chemical companies are allowed to release new compounds on the market without conducting any studies of their effects on humans or the environment. Some manufacturers conduct rudimentary research prior to production, but fewer than half of all applications to the EPA for new chemical production include any toxicity data. Eighty percent of new chemicals receive approval in less than three weeks with an average rate of seven a day.^{5,6} Therefore, it is reasonable to assume that women of childbearing age, fetuses, and young children are exposed to toxic elements with no prior assessment of the harm they may cause. As discussed below, these exposures occur in all settings in which we spend time.

OUR HOMES

Historically, the most well-known toxin found in our homes has been lead. Despite decades of evidence that lead is harmful to the developing neurological systems of young children, manufacturers continued to add this heavy metal to house paint. New Jersey took a leadership role by banning lead additives in house paint in 1971, seven years prior to the federal ban enacted in 1978. (It is important to note that this legislation applied only to house paint. Lead continues to be added to other types of paint, e.g., paints used for boats and some art supplies.) The good news is that, as new housing has been built and lead has been removed from paint, gasoline, water pipes and solder, fewer children are experiencing high blood lead levels.

A significant decline in both the number of children with elevated blood lead levels and in the blood level considered to need medical intervention has occurred over the past three decades. In 1970, the US Public Health Service established a blood lead level of 60 ug/dl as the standard requiring medical intervention. This standard was revised in 1971, with the level dropped to 40 ug/dl; in 1975 with the level set at 30 ug/dl; and in 1985 at a level of 25 ug/dl.⁷ The CDC established our current limit of 20 ug/dl for medical intervention and greater than 10 ug/dl for environmental and nutritional intervention in 1991.

PRECAUTIONARY PRINCIPLE

The precautionary principle indicates that when there is plausible scientific evidence of significant harm from a proposed or ongoing activity, precautionary action should be taken to reduce or eliminate harm. These actions can include using the safest alternatives and ensuring that the proponent of an activity, such as a manufacturer of a chemical, bears the burden of assessing its safety and of showing that it is both necessary and the least harmful alternative.

New Jersey has made progress towards eliminating childhood lead poisoning. The State enacted Public Law 1995, Chapter 328, an Act Requiring Screening of Children for Lead Exposure that requires all physicians and other appropriate health care providers to conduct a risk assessment of all New Jersey children under six years of age and to screen for lead poisoning. In the decade extending from 1994 to 2003, the number children reported to the DHSS with blood lead levels >20 ug/dL has declined from 4,757 in SFY 1994 to 832 in SFY 2003, a 82.5% decrease.⁸ Since the reporting of all blood levels began in July 1999, the number of children reported with blood lead levels > 10 ug/dL declined from 6,847 in SFY 2000 to 5,230 in SFY 2003, a 23.6% decrease.

An estimated 1 million housing units in New Jersey contain lead-based paint.^{9,10} While the bans on lead paint have effectively reduced the risk of lead exposure for children who live in houses built after 1978, any house built before this year may still contain leaded paint. The highest risk for children is found in houses built before 1950, when paints contained a very high percentage of this heavy metal. Approximately 30% of the housing in the State was constructed prior to 1950. A high percentage of these houses are located in the metropolitan areas, and are thus the residential dwellings of greater proportions of poor and minority children. However, every county in New Jersey has more than 9,000 units that were built prior to 1950.

In 2004, New Jersey enacted the Public Law 2003, Chapter 311, the Lead Hazard Control Assistance Act. The purpose of the Act is to provide a comprehensive program to identify lead hazards in residential housing and to identify housing that is safe from exposure in order to eradicate the major source of lead to our State's children. The comprehensive program will emphasize methods to safeguard children residing in rental housing and require the State to track the progress of making all of New Jersey's rental housing stock more lead safe. In addition, the Lead Hazard Control Assistance Fund was also established by this legislation. This dedicated funding mechanism will assist property owners with the cost of removal of lead paint and/or making their properties lead safe. This far-reaching and innovative law promotes primary prevention of childhood lead poisoning and provides the resources needed to make it possible,

While New Jersey has taken powerful steps to rectify the problems inherent in residual lead in older housing, other lead-related problems regularly crop up in an insidious fashion. Lead has been found in the paint used on plastics covering our foods, e.g., bread bags, in children's toys, in decaying venetian blinds, in calcium supplements and in many other common products. Lead has been banned from products that are often used by young children, such as crayons and chalk. However, many American companies have plants in foreign countries, notably Southeast Asia. Despite packages having the appropriate federal regulations citations to insure these products are lead-free, some have been shown to have lead in them upon testing. This is of particular concern for toddlers who exhibit pica behaviors.

In addition to lead, our children are exposed to a multitude of chemicals and pollutants through other toys. For example, many play items are made from synthetic vinyl in which cadmium and other toxins are present.¹¹ Beginning in infancy with coolers that hold breast milk and continuing throughout their formative years, children play with and use hundreds of vinyl-based products on a daily basis. Some common products are teething rings, backpacks, dolls, coaxial cables for computers and computer games, placemats, raincoats and hats and costume jewelry, to name a few.

Our homes include other agents that have toxic effects on child development and our health. Tobacco smoke is an irritant to the eyes, nose, throat, and lungs. Children exposed to tobacco smoke have increased bouts of ear infections, upper respiratory infections, and colds. The levels of cotinine, a metabolite of nicotine, dropped significantly for all age groups from 1991-1994 to 1999-2000. However, in 1999-2000, cotinine levels in children were more than twice that found in adults.¹ Non-Hispanic blacks had levels more than twice those of Mexican-American and non-Hispanic whites. Tobacco smoke, as well as dust and dust mites, molds, furry pets and roaches, are all triggers for asthma and allergies.¹²

Combustion products are gases and fine particles produced when any fuel is burned. All of these products are unhealthy, causing irritation and illness. In normal operation of a furnace, these pollutants go up the chimney, but these pollutants are also produced by fuel-fired space

heaters and gas ranges. When appliances are not properly vented, combustion products collect in the building and may include formaldehyde, oxides of nitrogen, carbon monoxide, carbon dioxide and other chemicals as well as fine particles of soot.¹²

OUR FOOD

Our daily food is not immune from toxins. While studies have shown that lead stored in bones is released during pregnancy, recent investigations are beginning to document that breast feeding may also stimulate and promote the release of lead from bone. Children who were exclusively breast fed by their mothers had higher blood lead levels than children whose mothers both breast fed and used formula and those who were not breast fed at all.¹³

High levels of mercury, commonly found in fish like tuna, have also been found in breast milk. Because this metal remains in the body, and travels easily through the placenta and breast milk, women of childbearing age need to limit some fish intake before and during pregnancy and while breast feeding.¹⁴⁻¹⁵

TOXIC BREAST MILK

Despite research on the benefits of eating fish, this food source has emerged as a host for a broad assortment of pollutants. Mercury, polychlorinated biphenyls (PCBs), dioxins, flame retardants and other toxic chemicals build up in fish and seafood. Big predatory fish tend to have higher pollutant levels. Fatty fish species tend to carry higher levels of PCBs and dioxins. Mercury and PCBs are particularly toxic to the brain, so exposure early in life when the brain is still developing can lead to IQ loss and changes in learning and behavior.¹⁴

New Jersey is called the Garden State due to our fertile soil that produces wonderful fruits and vegetables. Lead arsenate was used as a common pesticide for decades and leached into our foods (carrots, onions, potatoes and other root crops as well as fruits and grains). Currently, there are no federal regulations requiring fertilizer manufacturers to test their products to determine the amounts of heavy metals, dioxin, or other pollutants they may contain, nor are fertilizer companies required to list

the sources from which they obtain minerals.¹⁶ Humans are subjected to numerous chemicals and pollutants through meats and poultry. Both types of livestock are subjected to high levels of toxins through their feed, both that occur naturally or through additives as well as through the air.

Cadmium, chromium, dioxins, and mercury are also found in many vegetables. These metals have been found to have known or probable carcinogenic effects. Some (dioxins, lead, and mercury) have been linked to infertility, birth defects, and neurological system abnormalities.¹⁶ Some heavy metals do occur naturally in the environment, e.g., rock phosphate fertilizers contain high levels of cadmium. However, many micronutrient fertilizers contain heavy metals and dioxins that come from the “recycling” of hazardous industrial waste. These include aluminum or copper smelting; the manufacture of cement, and steel production.¹⁶

Arsenic is a naturally occurring element found throughout the state. Water systems can be affected by arsenic leaching into the ground due to the erosion of rock deposits. As result, New Jersey established the strictest arsenic standards in the country. The new standards will cut in half the acceptable limit of arsenic in drinking water by 2006, setting a limit of 5 parts per billion (ppb). These standards apply to both public community water systems and private wells.

While not food per se, it is important to be aware that some medications have teratogenic effects. In the late 1980s, the New Jersey Department of Health and Senior Services, Birth Defect Registry was the first in the nation to document severe birth defects in infants whose mother had taken the anti-acne prescription medication, Accutane (isotretinoin), prior to or during pregnancy. The Federal Drug and Food Administration enacted regulations that mandate warnings be given to all women of child-bearing age prior to having a prescription filled and a symbol is included on the packaging to warn women that the product is known to cause severe birth defects. Despite these efforts and the fact that other, less toxic anti-acne medications are available, physicians are still giving women of childbearing age prescriptions for the medication.

Toxic Breast Milk?

**Florence Williams
New York Times Magazine
January 9, 2005**

If, as Cicero said, your face tells the story of your mind, your breast milk tells the decades-old story of your diet, your neighborhood and, increasingly, your household décor. Your old shag-carpet padding? It's there. That cool blue paint in your pantry? There. The chemical cloud your landlord used to kill cockroaches? There. Ditto, the mercury in last week's sushi, the benzene from your gas station, the preservative parabens from your face cream, the chromium from your neighborhood smokestack. One property of breast milk is that its high-fat and -protein content attracts heavy metals and other contaminants. Most of these chemicals are found in microscopic amounts, but if human milk were sold at the local Piggly Wiggly, some stock would exceed federal food-safety levels for DDT residues and PCB's...

Ultimately, the question for me as a mother is not at what threshold of exposure will my baby be harmed, but why we are manufacturing common products made with toxins at all? "There is almost no example of a toxic chemical in breast milk that doesn't have a nontoxic substitute," said Sandra Steingraber, a visiting scholar at Ithaca College and author of "Having Faith: An Ecologist's Journey to Motherhood." "We haven't yet compromised breast milk to such an extent that it's a worse food than infant formula, but why get to that point?"



In response, CDC strengthened its recommendations for Accutane use in August 2005 to encourage physicians to have women have two negative pregnancy tests, including one on the second day of their next normal menstrual period, before taking the medication. Additionally, CDC recommended that women taking Accutane should use two forms of birth control, have repeat pregnancy tests every month and register with a survey that monitors the experience of women taking the drug.

EIGHT HOURS A DAY: OUR DAY CARE CENTERS, SCHOOLS, WORK, AND LEISURE

It is impossible to name an environment where we spend our time in which we are not subjected to pollutants. Paints, varnishes, solvents, pesticides, new carpets, and poor indoor air quality and inadequate ventilation in schools can be harmful to children's physical and mental health. From aggravating asthma and allergies to causing cancer and brain damage, these powerful toxins may be at the root of illness and behavior problems for millions of children. Most states, for example, do not have regulations regarding where child day care centers are situated. Thus, many are based in church basements, old buildings and other places that are covered with lead-based paint.

All child care facilities in New Jersey that serve five or more children are required to be licensed by the Department of Human Services. In 2000, the Bureau of Licensing adopted amendments to the child care licensing regulations to strengthen the provisions related to lead paint. The rules provide that all licensed centers located in buildings constructed before 1978 must have an inspection to determine if lead paint is present. If so, the facility must have a hazard assessment completed and develop a plan for removing the paint or maintaining it in a lead safe condition.

Recess and outdoor athletic events do not necessarily provide our children with a breath of fresh air. A recent report by the National Environmental Trust, Physicians for Social Responsibility and the Learning Disabilities Association of America estimate that industry releases 24 billion pounds of neurological toxins annually.⁵ However, only 5 percent of the estimated total emissions, 1.2 billion pounds, are reported to the EPA.

In April 2003, New Jersey enacted the strictest standards for mercury in the nation. These rules will reduce mercury emissions from certain facilities by up to 90 percent by the end of 2007. The facilities, which include coal-fired boilers in power plants, iron and steel smelters, and municipal solid waste incinerators, are also directed to make major reductions in their emissions of sulfur dioxide, nitrogen oxides, and fine particulates.

With over 80,000 chemicals included in the federal inventory, it is impossible to calculate the number of neurological toxins to which Americans are exposed in their workplaces - and which may be carried home in their bodies and in their hair and nails or on their clothes. As a result, we will continue to expose ourselves to toxic elements and chemicals that endanger our health and that of our children for generations to come.

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***Windows of Vulnerability:
How Toxicants and Timing Effect Brain Development****

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Brain development begins very early in human gestation and continues well after birth through adolescence. Healthy brain development depends on a tightly orchestrated cascade of sequential and concurrent events. During development, brain cells proliferate, migrate to the appropriate location in the brain architecture, differentiate into the correct cell type, and establish connections (synapses) with nearby and distant cells in complex neuronal circuits. Programmed cell death (apoptosis) is important to normal brain development and occurs in two waves in prenatal and postnatal development.

Disruption of this sequence at any point during brain development can have a lasting impact on brain function later in life. The nature of the impact will depend in large part on the timing of the disruption. Experimental data show that extremely short term exposures to developmental neurotoxicants can have permanent impacts on later brain function, and that the abnormalities observed after exposure to a single toxic agent may vary with the timing of the exposure. The nature of the neurotoxicant, the extent of exposure, and the timing of exposure are, therefore, each important determinants of outcome.

Brain development is controlled by genetic and environmental factors that interact in complex ways. Environmental factors can significantly impact developing tissues, by altering signaling chemicals that mediate brain development (neurotrophins), or by modifying gene expression. Environmental factors include nutrition, pharmaceuticals, other chemicals, infection agents, maternal illnesses, and the psychosocial context.

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Preconception Health Care: A Concept that Has Come of Age

*“We need to teach
the next generation children
from Day One
that they are responsible
for their lives.”*

Elisabeth Kubler-Ross

In 1995, when the 10th anniversary report of the Governor’s Council on the Prevention of Mental Retardation and Developmental Disabilities was published, the concept of preconception health care was just emerging. Since that time, the major organizations responsible for providing health care have recognized that, while past achievements in public health and medical care have greatly improved pregnancy outcomes, more can be done to assure optimal health for mothers and infants. A great opportunity for further improvement lies in prevention strategies that, if implemented prior to conception (i.e., preconception care), would result in further improvement of pregnancy outcomes. The American College of Obstetrics and Gynecology (ACOG), the American Academy of Pediatrics (AAP), the American Academy of Family Practitioners (AAFP), the American College of Nurse-Midwives (ACNM) as well as the March of Dimes and the Centers for Disease Control and Prevention (CDC) have developed guidelines, materials and websites for practitioners and the public addressing this issue.

In fact, the importance of optimizing the health care status of women prior to pregnancy has emerged to such an extent that the CDC, National Center on Birth Defects and Developmental Disabilities will sponsor the first national Preconception Summit in June 2005.¹ In its brochure, the CDC notes that:

- The great majority of perinatal risk factors could be identified in the preconception period.
- Each year, hundreds of thousands of women give birth without benefit of existing preconception interventions.
- At least twelve sentinel indicators for preconception care - evidence-based and in existing guidelines - are available for public health surveillance.
- Preconception care is based on, but is more focused and specific than routine well-woman health care.

Existing “Guidelines for Perinatal Care” developed by ACOG and the AAP recommend that “All health encounters during a woman’s reproductive years, particularly those that are a part of preconception care should include counseling on appropriate medical care and behavior to optimize pregnancy outcomes”. ACOG and AAP have grouped the main components of preconception care under four categories of interventions:

- Maternal assessment (e.g., family history, behaviors, obstetric history, general physical exam, etc); vaccinations (e.g., Rubella, Varicella and Hepatitis B).
- Screening (e.g., HIV, STD, genetic disorders, etc); and counseling (e.g., folic acid consumption, smoking and alcohol cessation, weight management, etc).
- Effective, evidence-based interventions of preconception care include: promotion of folic acid use; management of diabetes, hyperthyroidism, HIV/AIDS, maternal phenylketonuria; use of anti-epileptic drugs, oral anti-coagulants, and Accutane.
- Evaluation for rubella immunization; and addressing smoking, alcohol use, and obesity.

While these interventions are currently available, no national guidelines or policies support the provision of a

preconception care “package”. Bundling the various components into a preconception care visit (or visits) has the potential to improve perinatal outcomes and reduce costs associated with adverse perinatal outcomes. A substantial prevention opportunity lies in increasing the delivery and financing of evidence-based preconception care. As such, the desired outcomes for the National Summit, and which will assist New Jersey to strengthen its preconception health initiatives, are:

1. Develop and publish recommendations for preconception care in collaboration with professional organizations and public and private partners.
2. Develop, and evaluate strategies for bundling health messages and interventions.
3. Train health care providers to implement preconception care.
4. Initiate research to support marketing, outreach, and education to physicians, other health care professionals, and the public about the importance of preconception care.
5. Use the principles for diffusion of innovation to change public health and medical care practice.
6. Conduct studies regarding the economic impact of widespread implementation of evidence-based preconception care bundles, and the effectiveness of evidence-based preconception care bundles in managed care organizations.

The initial components of preconception planning should occur long before prospective parents decide to start a family. In fact, when considering optimal health promotion practices, preconception health actually begins at the time of birth. This preparation begins at home with a focus on the development of positive living skills and healthy life styles, including good nutritional habits and exercise routines. Reinforcement can be accomplished in partnership with the educational system through the implementation of comprehensive family life and health education curricula.



New Jersey has been in the forefront of recognizing the importance of preconception health. In 1980, New Jersey became the second state in the nation to mandate Family Life Education (FLE) in public schools and the first to include elementary grades within the mandate. The mandate specifies that FLE address interpersonal relationships; human growth, development and sexuality; responsible personal behavior; and building strong families.

In 1996, the New Jersey State Board of Education adopted the New Jersey Core Curriculum Content Standards that provided an ambitious framework for educational reform in the State’s public schools. The State Board also required that the standards be reviewed and revised every five years. As the review was undertaken in 2001, the Office for Prevention, the Department of Health and Senior Services, and community organizations worked with the Department of Education to insure that specific health promotion and disability prevention issues were included in the Core Curriculum Content Standards. As noted in the standards, “many of the health challenges that young people face today are different than those of past generations. Advances in medicines and vaccines have largely addressed the illness, disability and death that resulted from infectious disease. Today, the health of young people and the adults that they will become is critically linked to the health-related behaviors they choose to adopt.”²⁻³

The State Board of Education, based on the recommendations of the Comprehensive Health and Physical Education Standards Revision Panel, established six comprehensive health and physical education standards to promote and insure that New Jersey's children and youth are educated regarding health promotion and wellness. The knowledge and skills outlined in the revised standards are cumulative; that is, the progress indicators begin at a foundational or basic level and increase in complexity as the student matures, requiring more complex interaction with the content. The six comprehensive health and physical education standards are:

1. Wellness (personal health; growth and development; nutrition; diseases and health conditions; safety; and social and emotional health),
2. Integrated Skills (communication; decision-making; planning and goal setting; character development; leadership, advocacy and service; and health services and careers),
3. Drugs and Medicines (medicines; alcohol, tobacco and drugs; dependency/addiction and treatment),
4. Human Relationships and Sexuality (relationships; sexuality; pregnancy and parenting),
5. Motor Skill Development (movement skills; movement concepts; strategy; rules, safety and sportsmanship; sports psychology), and
6. Fitness (fitness and physical activity; training, achieving and assessing fitness).

As a result of adopting these new Core Curriculum Content Standards, New Jersey students will be educated about healthy behaviors beginning at an early age and continuing through graduation. For the first time, injury and safety will be incorporated into the curriculum as well other important prevention education issues such as the effects of prenatal exposure to alcohol and Fetal Alcohol Syndrome.

However, local school districts have discretion in the selection of curricula and the amount of time devoted to

and importance given to specific topics within each of the areas. As such, consistency and level of achievement may vary among students depending upon the school district.

Preconception Recommendations

1. Medical education needs to increase training regarding preconception health, and recognize that health promotion begins at a very early age.
2. Medical practice should incorporate preconception health as an integrated standard of care. Patients should be assessed and advised about conditions and behaviors that may impact upon healthy pregnancies and optimal fetal outcome.
3. The New Jersey Board of Education should insure that curricula used to implement the Core Curriculum Content Standards for Comprehensive Health and Physical Education are consistent and culturally sensitive and appropriate among all school districts.

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A Good Beginning: Nutrition during Pregnancy

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Nutrition exerts an important influence on pregnancy outcome. Adequate dietary intake during pregnancy has been linked to better perinatal outcomes. Recent research has indicated that fetal undernutrition and low birth weight in utero are associated with certain chronic diseases (type 2 diabetes, chronic hypertension and coronary heart disease) later in life. In the 1990 Institute of Medicine publication, "Nutrition During Pregnancy," nutrition services was identified as an essential component of prenatal care and is to be incorporated into the health care delivery system. "Nutrition Services in Perinatal Care" describes two basic types of services: (1) basic nutrition services should be available to all women, infants and children, and (2) special nutrition services should be provided to women with health problems that complicate their nutritional care, to preterm infants, and to full-term infants with serious health problems. Premature infants are at increased risk for developmental and learning disabilities. Nutrition plays a key role in the prevention of prematurity and in neonatal care during hospitalization and in the follow-up period.

The importance of providing nutrition services to infants, children and adults with developmental disabilities and special health care needs was addressed in a position statement from the American Dietetic Association. It stated that nutrition services are essential components of comprehensive care for those with developmental disabilities and special health care needs. Nutrition services should be provided throughout the life cycle in health care, educational, and vocational programs in a manner that is interdisciplinary, family centered, community based, and culturally competent. Persons with developmental disabilities and special health care needs frequently have nutrition problems, which include poor feeding skills, dependence (partial or total) on enteral or parenteral nutrition, or medication-nutrient interaction. Poor health habits, limited access to services, and long-term use of multiple medications are considered risk factors for additional health problems.

Nationally credentialed dietetics professionals are best prepared to provide appropriate nutrition information as it pertains to wellness and the maintenance of good health and quality of lifestyle. The responsibility of the dietetic professional is to assess the clinical, biochemical, and anthropometric measurements, as well as dietary concerns and feeding skills. It is recommended that medical nutrition therapy be a reimbursable service as part of the comprehensive health care for people with developmental disabilities and special health care needs.

Prenatal Health Recommendations: Building Health Literacy in New Jersey

The core of prenatal care is the degree to which women who are pregnant have access to and utilize health information, resources and support. Health literacy plays an enormous role in achieving these goals. Lack of appropriate educational level information is particularly relevant in the area of pregnancy and birth. According to Richard H. Carmona, United States Surgeon General, health literacy consists of an individual's ability to access, understand and use health related information and services to make appropriate and informed decisions about healthy behaviors. More than 90 million Americans cannot adequately understand basic health information. A recent study of English-speaking patients in public hospitals found that one-third was unable to read basic health materials: of these, 26% of the patients could not read their appointment slips and 42% did not understand the labels on their prescription bottles.¹

The steps that women can take to reduce their babies' risk of birth defects and developmental disabilities require a high level of understanding. Some of the information that is now available, such as that emanating from the Human Genome Project, is highly technical and requires a great deal of education. However, a health literate woman is more likely to consult with her obstetrician about keeping herself well and about getting early prenatal care for a healthy pregnancy.

Women who are pregnant should not drink alcohol, smoke, take illegal drugs and should consult their obstetrician prior to taking any over the counter medications or herbal supplements. It is important that all health professionals, including policymakers and researchers, ensure that these health messages reach all pregnant women, especially those who need them most. Above all, these include racial and

ethnic groups who may be at higher risk than others. Today, in New Jersey, low socioeconomic, urban women represent nearly half of the total number of women receiving no prenatal care, or who wait until after their first trimester before seeing a doctor.²

Over the past ten years, strides have been made in New Jersey in improving prenatal health care and in improving poor birth outcomes. However, there is still progress that needs to be made if we are to reduce and to prevent mental retardation and developmental disabilities. Some of the programs and highlights during the past ten years include:

- WIC (Special Supplemental Nutrition Program for Women, Infants and Children) reported a 4.4% increase in participants.³ The groups who use WIC services are at highest risk and are those who benefit most from good nutrition. Since studies confirm that participation in WIC helps to increase birth weight and to reduce the incidence of preterm birth, continued increase in WIC participation is critical. However, recent proposed cuts in the Federal level of funding for WIC administration at the state level over the next ten years projects a loss of 12,200 WIC recipients by the year 2010 in New Jersey.⁴ Therefore, it is essential that funding to WIC for vital services be continued and increased in the coming years.
- Teen mothers have the lowest percent of first trimester prenatal care. In 1995, births to NJ teenagers, ages 15-19 was 8.2% of total births or one in 12 births. In 2003, that number was reduced to 6.5 percent.⁵ This is positive news in that 30% of mothers who received no prenatal care gave birth to low birth weight babies (under 5.5 pounds at birth).
- Level of education is correlated with the likelihood of receiving prenatal care. Of those who had not completed high school, 4.1% had no prenatal care in 1995. That number was reduced to 3.3% in 2002. However, 8.7% of those without a high school education did not receive prenatal care until the third trimester.

Therefore, it is especially necessary to target education about early prenatal care to those women who are pregnant and who have not completed high school.

- Premature birth is the leading cause of neonatal mortality and morbidity in African-Americans. The number of women receiving late or no prenatal care (having the first visit with a health professional within the first trimester) has increased, in NJ from 4.2% of all mothers giving birth in 1995 to 4.9% of all women in 2002.⁶ Of even more concern is that less than 63.8% of pregnant black women and 68.7% of Hispanic women received adequate care, while 89% of white women received care in 2002.⁷ Therefore, targeted educational campaigns about the importance and necessity of early prenatal care should be focused towards Black and Latino populations.

- In 2002, the March of Dimes launched a national and statewide campaign to increase public awareness of the problems of premature birth. In New Jersey, the rate of preterm births has increased more than 10%. Among the campaign's goals are to educate women about the signs of premature labor, to invest in research to identify causes and promising interventions, and to engage medical professionals to advocate for state and federal support for this research and for programs to improve prematurity risk detection.
- "Wipe Out Lead in N.J." is a new program, implemented in 2005, whose goal it is to help pregnant women identify home-based lead hazards before the birth of their babies. Thirty thousand low and moderate income women who are pregnant will receive free kits to test their homes for lead dust.

Moving Toward the Vision: Close the Gap

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Race continues to play a significant role as a determinate of health in America. Specifically, Black infants are 3 times more likely to die in the 1st year of life compared to their White counterparts. The largest portion of this disparity is due to the fact that approximately 12% of pregnant Black women deliver prematurely regardless of their age, education, income or marital status (Kleinman, & Kessel, 1987; Schoendorf, Hogue, Kleinman, & Rowley, 1992; Creighton-Zollar, 1993; Reichman & Pagnini, 1997). New Jersey's Department of Health and Senior Services has been proactive about closing this gap and the good news is that the 10-year trend (1990-2000) shows that fewer infants die every year in New Jersey. In fact, the State's Blue Ribbon Panel on Black Infant Mortality in 1997 revealed the effects of racism on birth outcomes. As a result, the State launched a 1 million dollar awareness campaign, which led to increased funding in cultural competency training and the establishment of a Black Infant Mortality Reduction Resource Center.

Today, the Black Infant Mortality Reduction Resource Center continues to educate the community as well as health care professionals in the latest techniques designed to close the gap. These techniques highlight the influence that psycho-socio factors have on mortality rates and current interventions focus on exposure to stress and protective factors not only during pregnancy but over the course of a woman's life.

It is clear that health communication alone cannot change systemic problems related to healthcare, such as poverty, hazardous environmental exposures or lack of access. However, as patients are being asked to assume more responsibility for their own care in an increasingly complex system and to make healthy choices, improving health literacy is a critical challenge for the medical and educational community.

Dr. Carmona has recommended the following activities to improve health literacy, and thus, to strengthen the ability of women to take charge of their prenatal care:

1. Build a robust health information system that provides equitable access,
2. Develop appropriate information and support services for all segments of society, especially under-served populations and
3. Train health professionals in the science of communication and the use of communication technologies.

The Governor’s Council on Prevention endorses these recommendations.

Although the causes of many birth defects are still unknown, genetics, risk behaviors and environmental factors can play a significant role. Therefore, the Governor’s Council on the Prevention of Mental Retardation and Developmental Disabilities recommends the following strategies be implemented over the next decade:

1. Institutions that are serving multi-cultural and low socio-economic populations should employ appropriate staff who are proficient in local languages and who reflect their communities.
2. Universal screening should be implemented for pregnant women to identify use of alcohol and other drugs, domestic violence and depression and women should be assured of access to services and treatment for these problems.
3. Statewide education should be presented repetitively for all populations, including public awareness campaigns for folic acid, newborn screening, fetal alcohol

spectrum disorders and other harmful substances, environmental toxins such as lead and other contaminants. In addition, targeted educational campaigns should be delivered to at risk populations, including those with low income, low literacy, non English speaking and those with ethnic and racial disparities.

4. Medical education should encompass prevention as an overreaching arch that includes, but is not limited to, genetics, environmental toxins, nutrition, fetal alcohol spectrum disorders and health promotion.
5. With the information now readily available due to the Human Genome Project as well as New Jersey’s expanded Newborn Screening, the State can expect that the demand for genetic services will increase. It is therefore imperative that New Jersey ensure that an adequate supply of geneticists is available. In addition, genetic counselors should be licensed so that they can receive third party reimbursement.
6. The State of NJ should insure the availability of resources and support for WIC in order that at-risk pregnant women, children and mothers continue to receive services and that participation be increased during the next decade.

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Infants and Child Health Recommendations to Secure Our Children's Future

Herbert Hoover said, "Children are our most valuable natural resource." As such, every child should be loved and protected, live in a safe home, have adequate nutritious food to eat, proper clothing to wear, safe schools to attend and good medical care. Poverty continues to be the largest obstacle to reaching these goals. New Jersey children have, overall, fared better than those residing in other parts of the country. Nationally from 2002 to 2003 there has been a 40.7% increase in the percent of poor families who are raising children under age 5. In 2002, an estimated 220,320 New Jersey children were living in poverty compared to 270,538 in 1998. The good news is this is nearly a 19% decrease in the number of children living in poverty.¹ However, our challenge for the next decade is to address the needs of the many children who remain at risk due to economic disadvantage.

New Jersey has a lot to be proud of since the publication of the last Governor's Council Report, *Changes and Challenges: Building Our Children's Future*, in 1995. A great deal of progress has been made in the realm of prevention of developmental disabilities in infants and children:

- The Electronic Birth Certificate or the EBC was designed in 1995 and became fully implemented in all New Jersey hospitals in 1997, thus replacing the traditional paper Birth Certificate. The EBC contains information on data related to maternal and child health in New Jersey. Data are entered directly into the computer at the time the information is provided and is transmitted to the Department of Health and Senior Services on a 24 hour basis. The database includes information related to the prenatal

period, labor and delivery, parent information, newborn discharge, maternal discharge and postpartum.

- In the area of newborn care, New Jersey has expanded its mandated newborn screening for 4 disorders and now screens for a mandated 20 metabolic disorders. Due to the availability of technology, infants are screened for an additional ten disorders. Further, all newborns are screened for hearing loss in the first month of life. As a result, infants who have hearing loss at birth or who may be at risk of this disability, are identified very early.
- Infant mortality rates in NJ have consistently decreased over the past fifteen years. According to CDC, in the period of 1989 to 1991, the infant mortality rate was 8.4 per 1,000 live births. By 2002, this rate had decreased to 6.1. Both rates are lower than the average rates for the country. White babies die much less frequently than African American or Hispanic infants. In 1989, 6.9 per 1,000 white infants died as compared with 17.8 black and 7.5 Hispanic babies. By 2002, these proportions had decreased to 4.0 white children, 13.6 African American and 6.3 Hispanic infants. While significant gains have been achieved in reducing infant mortality in all races, it is clear that efforts to eliminate racial disparities must be continued and strengthened to reduce Black infant mortality.

For all races and ethnicities, congenital anomalies continue to account for the greatest proportion of infant mortality. However, premature birth and low birth weight as well as multiple births contribute to these rates

- Pediatric AIDS is another success story. In 1995 there were 50 infants born HIV positive. As of June 30, 2004, only 1 infant was born with HIV.²

- New Jersey has become a recognized national leader in FASD prevention education, diagnosis and treatment. Six Regional FASD Diagnostic Centers have been established throughout the state. Further, Perinatal Addictions Specialists are working with health care personnel, addiction treatment centers and others to educate about FASD and to have pregnant women screened for substance abuse. The New Jersey Perinatal Addictions Certification Program is the first in the country, and UMDNJ - New Jersey Medical School, School of Public Health serves as one of six CDC-funded FAS medical education and continuing education regional centers.
- The establishment of Medicaid Managed Health Care and Kids Care has resulted in greater opportunities for children to receive health insurance and to have a medical home.
- In 2003, the DHSS introduced its web-based, statewide universal childhood Immunization Registry. Building on the electronic birth certificate system, the Immunization Registry allows for direct interface with hospitals, private insurance carriers, and pediatric providers as well as with WIC and Medicaid.
- Great strides have been made in reducing the number of children with elevated blood lead levels. Of the children tested for lead poisoning in state fiscal year (SFY) 1994 there were 4,757 children were identified with blood lead levels elevated to 20 ug/dl or higher. In SFY 2003, that number decreased to 832 children.³ The state has established a goal to have no child with a blood lead level above 10 ug/dl by the year 2010. In 1995, New Jersey passed a Universal Lead Screening law mandating that all NJ children be screened for lead at ages 1 and 2 up to age 6. In addition, in 2004 New Jersey established the Lead Hazard Control Assistance Fund that provides financial loans and grants to eligible families and landlords for lead abatement. This legislation serves as a model for the rest of the nation.

In addition, the implementation of demonstration projects by the Department of Human Services,

Division of Medical Assistance and Health Services (DMAHS) has increased the number of Medicaid children who are screened for lead poisoning. These efforts have resulted in the forging of new partnerships between the State and local community agencies, such as with day care centers. Further, DMAHS encouraged the utilization of filter papers as an improved means to collect samples, which allows for screening of children while in physicians' offices and thus eliminated a significant barrier to screening.

- The State has undertaken a massive overhaul of the child welfare system. This initiative should result in fewer children being abused and neglected.
- New Jersey enacted several pieces of legislation that have contributed to decreases in childhood injuries. In 1998 the bicycle helmet law was expanded to include helmet use for skateboarding, in-line skates, and roller skates. In 2000 legislation was enacted to elevate the enforcement of the seatbelt law to a primary offense. In 2001 the 8-80 Booster Seat Law was enacted. As a result, New Jersey went from one of the worst states to one of the best states in the nation for child occupant protection.

These examples highlight prevention efforts that have been undertaken during the last 10 years and which should contribute to decreases in infant and child mortality and morbidity over the next decade. While much has been accomplished, much remains to be done.

“*Children have never been very good at listening to their elders, but they have never failed to imitate them.*”

James Baldwin

During the past ten years, the technology needed to save the lives of infants born prematurely and of very low birth weight has become more advanced and sophisticated. The use of surfactant and corticosteroids to assist in

the development of lungs and breathing capacity has resulted in many more premature infants surviving. However, the long-term developmental outcomes for many of these children are not yet known. According to a British study published in the *New England Journal of Medicine*, extremely premature infants, 25 weeks gestational age or less, have a high prevalence of neurologic impairment and developmental disabilities at age 6.⁴ New Jersey, in 2002, had 11,026 preterm births. Preterm is defined as less than 37 completed weeks of gestation. Of those 1,866 infants were very preterm, or born at less than 32 completed weeks of gestation. Black infants had the highest preterm rate at 14.9%, compared with Hispanic infants whose preterm was 9.3% and white infants whose preterm rate was 8.5%.⁵ The US Department of Health and Human Services has as a 2010 objective to reduce preterm births to a rate no greater than 7.6% of live births, and for very preterm births a rate no greater than 1.1% of live births.

According to the New Jersey Kids Count for 2005 there was a 51% increase in the number of uninsured children from 1999 to 2003. The number of children living in families receiving welfare increased 4% from 2003 to 2004. Incidents of school violence rose 2.3% from school year 1999-2000 to 2002-2003. It is difficult to determine if these increases are “one-year blips” or if they are symptoms of the beginnings of worsening trends.

Rates of children between 19 and 35 months of age who received the full schedule of appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B have varied greatly during the past decade. The lowest proportion of appropriately immunized children was 70% in 1995 and the highest rate of 82% was achieved in 1998. The percentage of children who were completely vaccinated at the appropriate age in 2003 was 76%.

In order to follow our progress, identify trends and ensure that our most vulnerable population, infants and children, are getting the best possible start in life, the Governor’s Council on the Prevention of Mental Retardation and Developmental Disabilities makes the following recommendations for the next ten years.

1. Ensure that all New Jersey children have health insurance and a medical home.
2. Establish a registry and a surveillance system for premature and low birth weight infants to determine their long term developmental achievements or disabilities.
3. Expand the ages of reporting to the NJ Birth Defects Registry to include children up to the age 6. Reporting to the NJ Special Child Health Registry should be a mandatory requirement.
4. Continue the NJ Department of Health and Senior Services Black Infant Mortality Campaign and the research into the disparities in outcomes.
5. Continue the March of Dimes Prematurity Campaign and the research into understanding and preventing preterm labor.
6. Establish a registry for infants and children with developmental disabilities to enable the State to determine incidence and prevalence, to design and implement appropriate targeted prevention campaigns and to inform and prepare the service and educational systems to meet of these children and their families.
7. Presumptive eligibility to receive early intervention services should be available to all at risk babies, including those born prematurely, with low birth weight, alcohol and drug exposure and those whose mothers had no prenatal care.
8. Establish a seamless early intervention/pre-school handicap system serving children from birth to age five.
9. Promote breastfeeding education through physicians, WIC and hospitals. Education should emphasize the benefits of breast milk and the potential hazards due to environmental contaminants. Women must have up-to-date information on the effects of medication use during lactation.

10. Establish a web-based database between the Department of Health and Senior Services and the Department of Human Services, Division of Medical Assistance and Health Services, to enable the sharing of data in real time.
11. Establish a universal child health record for use in all public and private schools including child care centers and preschools.
12. The DHSS should strengthen its efforts to insure that all New Jersey children are immunized at the appropriate age. In addition, as recommended by the March of Dimes, the State should expand its immunization program to include vaccinations for Varicella (chickenpox), Pneumococcus, and Influenza (the Flu).

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APPENDIX A - Legislation

PL 2000, Chapter 82

Sponsored by:

Senator C. LOUIS BASSANO

District 21 (Essex and Union)

Senator RICHARD J. CODEY

District 27 (Essex)

Co-Sponsored by:

Senator Allen

SYNOPSIS

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

CURRENT VERSION OF TEXT

As introduced.

An Act concerning the Governor's Council on the Prevention of Mental Retardation and amending P.L.1987, c.5.

Be It Enacted by the Senate and General Assembly of the State of New Jersey:

1. Section 3 of P.L.1987, c.5 (C.30:1AA-12) is amended to read as follows:
3. The administrator and chief executive officer of the office shall be the director, who shall be a person qualified by training and experience to perform the duties of the office. Subsequent to consultation with the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities, the Commissioner of Human Services shall appoint the director, who shall serve at the pleasure of the commissioner during the commissioner's term of office and until the appointment and qualification of the director's successor. The director shall devote his entire time to the duties of his position and shall receive a salary commensurate with the responsibilities of the office. The director shall serve in the State unclassified service of the Civil Service.

The director may appoint, retain or employ officers, experts or consultants on a contract basis or otherwise, which he deems necessary, and employ investigators or other professionally qualified personnel who shall be in the noncompetitive division of the career service of the Civil Service.

(cf: P.L.1987, c.5, s.3)

2. Section 5 of P.L.1987, c.5 (C.30:1AA-14) is amended to read as follows:
 5. The responsibilities of the office shall include, but are not limited to:
 - a. Developing a long-range comprehensive plan for the prevention of mental retardation and developmental disabilities in accordance with the priorities established by the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities;
 - b. Encouraging cooperative programs of research among State governmental departments and agencies, universities and private agencies;
 - c. Developing public information campaigns about the causes of developmental disabilities and the means for preventing developmental disabilities;
 - d. Coordinating public education programs about the causes and prevention of developmental disabilities and determining professional in-service training needs in these areas;
 - e. Stimulating expanded and new services for the prevention of developmental disabilities; and
 - f. Making recommendations to the Commissioner of Human Services regarding any needed executive or legislative action.

(cf: P.L. 1987, c. 5, s. 5)

3. Section 6 of P.L. 1987, c. 5 (C.30:1AA-15) is amended to read as follows:
 - 6.a. The Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities, originally created by Executive Order No. 72 (signed May 24, 1984), shall serve as an advisory council to the Commissioner of [the Department of] Human Services and to the Office for Prevention of Mental Retardation and Developmental Disabilities.

The State Departments of Human Services, Education, Health and Senior Services, Environmental Protection and Community Affairs are authorized and directed, to the extent consistent with the law, to cooperate with the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities and to furnish it with resources necessary to carry out its purposes under this act.

The Governor shall appoint 25 public members to the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities to serve three-year terms, except that, of the members first appointed, nine shall be appointed to serve for three years, eight shall be appointed to serve for two years, and eight shall be appointed to serve for one year.

- b. The Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities shall establish from its members the Executive Committee of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities. This committee shall have full power to act in lieu of the full council. The executive committee shall consist of [11] 12 members, all of whom are members of the Governor's council. The Commissioners of the Departments of Health and Senior Services, Human Services, Education, Community Affairs and Environmental Protection shall serve as ex officio members. [An advocate for the mentally retarded and developmentally disabled] The Secretary of State and the Chairperson of the Governor's council shall serve as nonvoting, ex officio members of the executive committee. The Governor's council shall elect from its membership the remaining five members of the executive committee. These persons, as members of the Governor's council, shall be selected for their knowledge, competence, experience or interest in connection with the prevention of mental retardation and developmental disabilities. Members of the executive committee may, from time to time, designate other individuals as their representatives. The executive committee shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties. The

Governor's council shall elect an executive committee chairperson from among the [four] five voting cabinet members of the executive committee. The executive committee may select from among its members a vice-chairperson and other officers or subcommittees which are deemed necessary or appropriate.

(cf: P.L. 1994, c.58, s.26)

4. Section 7 of P.L.1987, c. 5 (C.30:1AA-16) is amended to read as follows:

7. The Commissioner of Human Services and the executive committee of the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities established pursuant to section 6 of this act shall report annually to the Governor and the Legislature concerning the status of prevention programs in the State.

(cf: P. L. 1987, c. 5, s. 7)

5. Section 9 of P.L.1987, c.5 (C.30:1AA-18) is amended to read as follows:

9. [Within 120 days of the effective date of this act, the] The Commissioner of Human Services shall execute written agreements with the Departments of Health and Senior Services, Education, Community Affairs and Environmental Protection which are designed to coordinate the effective use of funds appropriated to the office.

These agreements shall fulfill the intent of the comprehensive prevention plan prepared pursuant to this act and shall provide coordination of all the departments' budget requests. They shall also minimally provide the protocol for: dispersing appropriate prevention funds, programmatic and fiscal monitoring of prevention programs, ensuring against the duplication of services, and identification of gaps in prevention efforts.

(cf: P. L.1987, c.5, s. 9)

This act shall take effect immediately.

STATEMENT

This bill amends N.J.S.A.30:1AA-10 et seq. to rename the Governor's Council on the Prevention of Mental Retardation as the Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities. In so doing, the bill codifies the provisions of Executive Order No. 178 which took effect on July 30, 1987.

The bill also amends N.J.S.A. 30:1AA-10 et seq. to:

1. Include the Department of Community Affairs as a member of the Governor's council and to require the department to furnish the council with the resources necessary to carry out its purposes, as is required by the other departments who are members of the council. The Department of Community Affairs was originally added to the council pursuant to Executive Order No. 30 which took effect on April 15, 1991;
2. Require the Governor to appoint 25 public members to serve on the council;
3. Expand the membership of the executive committee of the Governor's council to include the Commissioner of Community Affairs and the Secretary of State; and
4. Remove the individual serving as an advocate for the mentally retarded and developmentally disabled from the membership of the council's executive committee.

APPENDIX B - Public Education Projects

Funded by the Office for Prevention of Mental Retardation and Developmental Disabilities

FY 96 and 97 FUNDED PROJECTS

“AN ETHNO-CULTURAL APPROACH TO PREVENTION OF FETAL ALCOHOL SYNDROME IN NATIVE AMERICANS IN NEW JERSEY”

University Of Medicine And Dentistry Of NJ
School of Osteopathic Medicine

This project will develop a comprehensive public education program directed toward prevention of Fetal Alcohol Syndrome in Native Americans in New Jersey. Programs will be developed by a planning committee that includes representatives of the NJ Native American tribes, physicians and others. Formal presentations at Tribal Pow-wows, displays at Tribal events, newsletter articles in DRUM-BEAT and a program to train Native American Trainers are among some of the activities that will be conducted.

“PRENATAL PARTNERSHIP PROGRAM”

Famcare, Inc.

The Prenatal Partnership Program pairs volunteers with pregnant women in order to enhance the outcome of pregnancy and to reduce the number of low birth weight infants, premature labor and infant mortality. The volunteers provide support, transportation, companionship and encouragement to women whose pregnancy outcomes might otherwise be at risk due to lack of prenatal and postnatal care

“BRING YOUR BABY BACK”

Health Research And Educational Trust

The major goal of this project is to decrease the likelihood of mental retardation and developmental disabilities in newborns by educating prospective parents and health care workers about newborn screening. Using a variety of

media, including a videotape, education will promote a comprehensive understanding of the purpose of newborn screening. It will emphasize the need for parents to accept a greater responsibility in returning with their infant for a second screen, when necessary.

“ROCK-A-BABY GENTLY”

New Jersey Chapter-National Committee For Prevention Of Child Abuse

Research on developmental disabilities cites that partial or total blindness, hearing loss/deafness, speech difficulties, learning disabilities, developmental delays, cerebral palsy, paralysis and mental retardation can be caused by shaking a baby. Rock-A-Baby Gently is a program designed to alert new parents, child care providers, health care professionals and the public-at-large about the dangers of Shaken Baby Syndrome. Through volunteer presentations, nursery doorhangers, video tapes, public service announcements and posters, alternatives to soothing a crying child will be publicized.

“THE COMMUNITY HEAD SMART PROJECT”

New Jersey Head Injury Association, Inc.

A whole community approach to brain injury prevention will raise awareness of the causes and consequences of unintentional and intentional injuries. Five public elementary schools in central New Jersey will participate in the program using lessons integrated into the regular school curriculum. In addition, parents, teachers and community members will participate in seminars and a Community Awareness Day event that will promote the use of bicycle helmets, safe behaviors and reduction of violence.

“HEALTH STARTS”

Plainfield Neighborhood Health Services Corporation

The goal of this program is to reduce developmental disabilities associated with HIV infected infants and chil-

dren. Outreach and education programs about the importance of HIV testing will encourage and motivate medically indigent, urban pregnant women in Plainfield to be tested. Also, they will be taught to identify and modify high risk behaviors with the use of low literacy, bilingual literature and counseling. Special attention will be given to educate and encourage the infected patient to consent to AZT treatment protocols designed to reduce perinatal disease transmission of the HIV virus to the unborn child.

“SEX ETC.-FAMILY LIFE NEWSLETTER BY AND FOR ADOLESCENTS”

Rutgers University-Office of Research & Sponsored Programs

Three issues of “Sex, etc.” will be written by New Jersey high school students, published and distributed to over 100,000 teens throughout the state. This newsletter contains accurate, up to date information about healthy behaviors, sexuality, the effects of drugs and alcohol, violence and prenatal health, written in a format and language that appeals and speaks to teens. Teachers are encouraged to use the newsletter for class discussion, essay and poster contests and as a supplement to the Family Life curriculum.

“DESTINATION NUTRITION”

Tri-County Community Action Agency, Inc.

In order to provide poor, rural clients with nutrition education and the opportunity to purchase low cost, healthy foods, this project transports them to supermarkets and fresh produce stands. A van will be staffed by a bilingual registered nutritionist who will provide weekly transportation and a five week nutrition education program to WIC and WIC-eligible families in Cumberland and Salem counties. On site nutrition information and the development of critical thinking and planning skills help families to select foods that will promote better health and prevent growth retardation, developmental delay, obesity, dental disease and poor academic performance in children.

“OCEAN COUNTY COALITION FOR THE PREVENTION OF DEVELOPMENTAL DISABILITIES”

The Arc-Ocean County Chapter, Inc.

The Ocean County Coalition will publish a quarterly newsletter to increase public awareness of health and safe-

ty issues and to promote ongoing information, education and activities regarding the prevention of mental retardation and developmental disabilities. In addition a “DID YOU KNOW” campaign will focus on educating the public about the importance of Folic Acid in the prevention of neural tube defects, including spina bifida. WaWa stores’ milk cartons, posters and bookmarks promote this message in English and in Spanish. These will be distributed in pharmacies, supermarkets, clinics, hospitals, libraries and community agencies. Other activities include injury prevention events, “A Pregnant Pause”, Fetal Alcohol Syndrome prevention day, and Halloween safety information and trick or treat bag distribution.

“OPERATION CAR SEATS”

Institute for the Prevention and Study of Injury
Cooper Hospital

This project is a car seat lease program for children in the Cooper Hospital community. The program offers three size seats infants, toddler and booster. If the seat is returned, it can be exchanged for the next size.

“TAPP” THE ARC PREVENTION PROGRAM

Arc of Union County

The goal of this project is to support Union County Prevention Coalition activities.

FY 98 FUNDED PROJECTS

“BABIES BORN DRUNK” FAS RAP VIDEO

NJ Network Public Television

This video resulted from a contest originally sponsored by the National Organization on FAS (NOFAS). In New Jersey the FAS contest was run by The Arc of New Jersey through the School Based Youth Services Program. The winning project was a rap song that became the rap video “Babies Born Drunk”.

“FAS PREVENTION PROJECT”

The Arc of Atlantic County

The goal of this project is to encourage women to abstain from alcohol while pregnant by increasing awareness of

FAS among Atlantic County residents. The Arc will train community members and high school peer leaders to present an FAS Prevention Program to ninth grade students and to community groups. They will make presentations at local health fairs, on cable t.v. programs and in ninth grade health classes.

**“LET’S ALL LEARN:
SCHOOLS & COMMUNITY EDUCATING TO
PREVENT DEVELOPMENTAL DISABILITY”**

Plainfield Board of Education School Based Youth Services Program

“Let’s All Learn” is a comprehensive, educational program designed to prevent FAS/ARBD and other preventable developmental disabilities in Plainfield. It will reach several varied populations through a K-12 alcohol and drug prevention curriculum; EPIC workshops, referrals, case management and incentives to high risk pregnant women who get early and regular prenatal care; and a community-wide public information campaign about FAS/ARBD.

“THE FAS PREVENTION SCHOOL PROJECT”

Southern New Jersey Perinatal Cooperative

The “Fabulous FAS Quiz Show” will be introduced, piloted and evaluated in Atlantic County schools in conjunction with the Center for Social and Community Development, Rutgers University. Seventh grade students in two schools will participate in the “Fabulous FAS Quiz Show” through the family life curriculum. Follow up studies will be done when students reach the eighth grade to determine information retention about Fetal Alcohol Syndrome and changes in at-risk attitudes and behaviors regarding the use of alcohol and other substances.

FY 99 FUNDED PROJECTS

**“CHILD HEALTH JOURNAL- FIELD TESTING
PROJECT”**

Central NJ Maternal & Child Health Consortium

The goal of this project is to field test a Child Health Journal with providers and parents of newborns. Central NJ Maternal and Child Health Consortium will establish distribution sites and train provider staff on the purpose

and utilization of the Child Health Journal. Focus groups with parents who have enrolled in the field test will be conducted for evaluation purposes.

“PARENTS AS TEACHERS-MOTHERS EDUCATING MOTHERS”

City of Trenton - Division of Health

Mothers Educating Mothers (MEM), is a mentoring program that has been designed to improve pregnancy outcomes for 25 pregnant women and successful post natal outcomes for their children. Community volunteers will work with at risk pregnant women to provide prenatal care education, support and preventive child health services for their children through age five. The mentors will visit each pregnant women at least twice monthly in her home. Prenatal care visits, immunizations, lead screening and other preventive health care services will be monitored on an ongoing basis.

“ADOLESCENT PARENTING PARTNERSHIP”

FamCare, Inc.

The Adolescent Parenting Partnership is a comprehensive education program for pregnant and/or parenting adolescents between the ages of 12-19 years. The objectives of the program are to reduce the incidence of repeat pregnancies, to enroll each adolescent with a primary health care provider, to increase the number of infants receiving age-appropriate immunizations and to assist program participants in the utilization of community resources. To accomplish these objectives, each adolescent will be assigned a case manager and a nurse who will make twice monthly home visits during the pregnancy and for a year following birth. The case manager and the nurse will teach the adolescent the developmental milestones of growth, how to have fun with her baby and how to be a nurturing parent. The importance of completing her education will also be stressed.

**“PARENTING AND CHILD NURTURING AND
DEVELOPMENT PROGRAM**

Department of Law & Public Safety - Juvenile Justice Commission

Many of the youth under the supervision of the Juvenile Justice Commission are parents or have assumed the

parental role in caring for siblings. Yet, most of these youth have not themselves experienced what it is like to be part of a nurturing parent/child relationship that would provide the knowledge needed to undertake this responsibility. This program will provide a culturally sensitive, age and gender specific parenting skills curriculum to incarcerated adolescents. The curriculum includes a focus on physical and emotional child development and innovative methods of providing parental nurturing despite incarceration.

“PREVENTING NEURAL TUBE DEFECTS”

Spina Bifida Association of New Jersey

The goal of this project is to inform and educate women of child bearing age about how they can significantly reduce the chance of bearing children with neural tube defects. The project will accomplish this through a multi-pronged public information campaign that will educate women about the importance of consuming folic acid daily during childbearing years. Together with Rotary and Interact Clubs, SBANJ will disseminate information about folic acid to area high schools for students in the 9th through 12th grades. The Rotary Club will also launch an informational campaign in the general community with posters and information displayed at fairs, community functions and local businesses as, well as on shopping carts in local grocery stores. Managed care organizations will be contacted and urged to include information about folic acid in their prevention and wellness programs. In conjunction with a vitamin company, an informative and entertaining interactive web site will be created that will educate about the use of folic acid and multivitamins.

“UCPA/NJ TEEN PREVENTION EDUCATION PROGRAM”

United Cerebral Palsy Association of NJ, Inc.

Hunterdon, Warren and Sussex counties are the target of a prevention education program that will reach 2,400 students, ages 12-17, over a three year period. A series of four seminars will be offered to students in at least six schools in the tri-county area. The seminars will focus on preventing substance abuse, teen pregnancy, AIDS, and accidents resulting in severe injury. Leaders of the seminars will include community volunteers who have experienced disability because of risk taking behaviors. Due to

the rural nature of the Northwest counties, many of the students never come in contact with social service providers. Therefore, at the conclusion of the seminars, each school will present the Game of Life, which will introduce the students to community resource agencies and organizations that can help them to solve real life problems by using role play.

FY 01 FUNDED PROJECTS

“FAS PREVENTION FOR FAITH-BASED ORGANIZATIONS”

The Arc of Atlantic County, Inc.

The primary goal of this program is to prevent FAS by increasing awareness among the congregations of faith-based organizations throughout Atlantic County. Recruiting and training adult and youth representatives from the various faith communities for the purpose of establishing FAS prevention programs that will inform and educate their respective congregations will accomplish this. Faith-based organizations ideally cut across almost every level of economic, social, health and educational status.

“REMeDy: THE FAS RESOURCE CENTER OF NJ”

Central NJ Maternal & Child Health Consortium, Inc.

REMeDY stands for Referral, Education, Materials, Directory. The FAS Resource Center of New Jersey will provide community, professional and paraprofessional education utilizing a variety of strategies. These include a) the distribution of FAS/ARND information to couples seeking marriage licenses; b) the development of an FAS/ARND professional educational program and instructor’s guide; c) a regional FAS/ARND conference for health care professionals and d) the publication of an edition dedicated to FAS, of Clinical Updates, a regional publication for health professionals.

“FAS-PREVENTION-EDUCATION IN MONMOUTH/OCEAN COUNTIES”

Preferred Children’s Services

This project is a collaborative effort among Preferred Children’s Services (PCS), a community based behavioral

health agency servicing Ocean County and surrounding areas; Substance Abuse Resources (SAR), a Monmouth County prevention services provider and the Alcoholism and Drug Abuse Council of Ocean County (ADACO). Together, they will provide a wide range of education about FAS for staff, treatment providers, adolescents and high-risk children and their families in Monmouth and Ocean counties.

“PRESCRIPTION FOR A HEALTHY PREGNANCY”
UMDNJ-New Jersey Medical School

This project includes both an educational program for health care providers who treat pregnant women, and a tool resembling a physicians prescription pad, called a “Prescription for a Healthy Pregnancy”. The prescription pad will facilitate the discussion of alcohol consumption, along with other issues affecting pregnancy outcomes, with patients. A study is planned that will ascertain current health provider practices regarding advice given to women about alcohol use. This advice will be contrasted with other advice given regarding diet and smoking. It also address practitioners’ perceptions of barriers that impede their discussing alcohol use with their patients.

“FETAL ALCOHOL SYNDROME TRAINING TRACK (FASST)”
UMDNJ-University Behavioral Healthcare

The FASST program is designed to reach Mercer County pregnant and post-partum women, adolescents involved in the criminal justice system and Work First New Jersey recipients at sites where Mercer Trenton Addiction Science Center (MTASC) is currently providing addiction prevention/intervention services. An education component will consist of FAS presentations with clients who present as high risk for alcohol abuse at the clinics. In-service training for professional staff at MTASC sites and a series of brown-bag lunches will serve to increase staff awareness of FAS.

FY 02 FUNDED PROJECTS

“GREAT BEGINNINGS”

Fam Care, Inc.

Pregnant and/or parenting adolescents are at risk for poor birth outcomes, such as low birth weight infants, developmental disabilities and growth problems due to poor nutrition and eating habits during pregnancy and infancy.

The goal of this program is to provide nutrition education and guidance for developing healthy eating habits for a minimum of 75 pregnant and parenting teens. The participants will receive an intensive, research based nutrition education program in their homes in order to: (1) decrease the low birth weight rate from a state level of 8% to 4% or lower; (2) increase their awareness about the importance of Folic Acid in reducing the occurrence of neural tube defects; and (3) ensure that at least 90% of the infants enrolled in the program remain in the 5th to 95th percentile of the growth chart.

“HEADS UP FOR SAFETY”

Epilepsy Foundation of New Jersey

Each year more than 200 children age 14 and under are killed and nearly 350,000 are injured in bicycle related incidents. Yet, only 15% of all children 14 and under use helmets. Bicycle helmets have great potential for reducing injuries and deaths due to head injuries. Properly worn helmets reduce the risk of head injury by 85% and the risk of brain damage by almost 90%.

Heads Up for Safety is a broad based public education campaign that will target children ages 6-12 and their families and will focus on head injury prevention. Safety events will be held at public schools and other community-based locations. Free bike helmet distributions, demonstrations on proper fit for helmets and safety related presentations and displays, including safe play, skateboard, scooter and in-line skate safety are some of the activities that are planned. An anticipated 600 bicycle helmets will be distributed free of charge to low-income families.

“FAIR CHANCE”

The Arc of Hunterdon County

Currently, area schools do not include Fetal Alcohol Syndrome (FAS) in their health class curriculums. FAIR Chance, (Fetal Alcohol Information and Referral) is an educational enhancement to the school health programs in Hunterdon County. The goal of this program is to provide education for students between the ages of 12 - 18 about the cause and effects of FAS. In addition, the program also will be offered to community organizations. During the first year, over 1000 students and at least 200 community group members will receive information and will view the video, “Alcohol & Pregnancy: FAS and FAE.

“TARGETING TEENS TO REDUCE UNINTENDED PREGNANCY”

HiTOPS, Inc. (Health Interested Teens’ Own Program on Sexuality)

Eighty per cent of pregnancies among teenagers are unintended. Unplanned pregnancies are more likely to result in children born with mental retardation and/or developmental disabilities due to lack of preconceptional education, risky behaviors, including drug and alcohol use, and poor nutrition and health care.

The primary goal of this program is to reduce the risk of unintended pregnancy in Mercer County’s adolescent population by training a target team of high school students who will become peer educators. They will work with 200 at-risk youth in Trenton’s Martin Luther King Middle School, Trenton School Based Youth Services Program, Ewing High School and Mercer County Community College. The targeted students will receive five intensive educational modules designed to address issues including pregnancy prevention, contraception, postponing sexual involvement and date rape prevention.

“TRENTON PROMOTING EXCELLENCE IN PARENTING (PEP)”

City of Trenton - Division of Health

It has been estimated that children of parents who have been imprisoned are almost six times more likely than their counterparts to become criminally involved and

incarcerated at some point in their future. Research conducted on children of incarcerated parents showed that the loss of a parental figure has profound effects, including poor academic achievement, involvement in delinquency and gang-related activities and eventually, adult criminal behavior.

In collaboration with the NJ Association of Corrections - Clinton House Transitional Living Facility, this program will implement a parent education program for incarcerated fathers in transition to being paroled back into the community. PEP is designed to assist inmate fathers in developing skills to become more involved with and supportive to their children. The fathers will develop increased awareness regarding the psychological, developmental, economic and social impacts that their long-term absences from the home have on their children. They will increase their ability to improve their children’s health outcomes through a better understanding of their role as parents.

FY 03 FUNDED PROJECTS

“PREVENTING BRAIN INJURY AMONG PRE-SCHOOLERS IN CAMDEN”

Brain Injury Association of New Jersey

The primary goal of this project is to provide prevention education to the families, caregivers, teachers and pre-school children who attend Head Start programs in Camden County, and particularly in Camden city. Education will focus on the causes and consequences of brain injuries and on prevention strategies and behavioral habits that can help protect children from brain injury throughout their childhood. In collaboration with the Camden County Council on Economic Opportunity’s (OEO) Head Start Program, the Brain Injury Association will provide teachers with ideas and materials for incorporating brain injury prevention into their pre-school curriculums. The project will include the following causes of brain injury in children: automobile/pedestrian/bicycle crashes, falls and playground safety, fighting and violence, including shaken baby syndrome.

“PROJECT BUCKLE UP”

Central NJ Maternal & Child Health Consortium, Inc.

CNJMCHC will publish a newsletter, “Especially for Parents”, which will be distributed twice a year to over 3000 people in central New Jersey. The newsletter, in both English and Spanish, will educate about the need for properly installed child car safety seats and booster seats for children weighing 40 to 80 pounds. Emphasis will be placed on consistent use of the car safety seats in order to prevent and minimize disability and death. In addition, consumer information packets on car seat and booster seat safety will be distributed to families serviced by the prenatal and immunization outreach workers in central New Jersey.

“BRING YOUR BABY BACK”

Health Research & Educational Trust of NJ - NJ Hospital Association

This three-year project plans to develop updated educational resources on New Jersey’s enhanced newborn screening program in an effort to prevent mental retardation and other serious medical conditions caused by certain newborn diseases. HRET will conduct a statewide public awareness campaign about newborn screening through a variety of media. Educational resources will be developed in the first year of the project. They will be duplicated in the second year and widely distributed during and after a conference and a statewide awareness campaign. Resources will include a generic newborn screening video in English and Spanish, geared for parents, and a poster created in several languages. It is expected that over 4000 copies of the video will be distributed throughout New Jersey. Media effectiveness will be evaluated in the third year of the project.

“PREVENTION OF DEVELOPMENTAL DISABILITIES EDUCATION PROGRAM”

Hudson Perinatal Consortium

The primary goal of this project is to educate school personnel, who will in turn, educate over 3,000 11th and 12th grade Jersey City public school students. Five staff members in each of six Jersey City high schools will be trained

about Fetal Alcohol Syndrome (FAS) and about preventing babies being born with mental retardation and developmental disabilities due to maternal alcohol use. These thirty staff will include health teachers, school nurses, substance awareness coordinators and administrators. They will receive six hours of education on the characteristics of FAS and its’ prevention. They will be trained, as well, about how to teach the curriculum to students. This training will ensure the continuation of FAS prevention education in the following years.

“ALCOHOL/SUBSTANCE USE TRAINING MODEL PROJECT”

Prevention First

Sixty middle school professionals throughout Monmouth County will be trained to teach middle school students about the risks and effects of prenatal alcohol and drug use related to Fetal Alcohol Syndrome, mental retardation and developmental disabilities. They will attend a two-day professional development workshop that will educate them about how to present effectively a curriculum that will reach over 1,500 students. Prevention First will provide ongoing technical assistance to each professional. The students, in turn, will receive education about the importance of resisting drug and alcohol use, both during pre-conception and during pregnancy.

“NUTRITION AND LEAD”

Programs for Parents, Inc.

Essex County had the highest number and percentage of children with elevated blood lead levels in New Jersey in 2001. This educational campaign targets children from six months to five years of age who attend registered family day care in Newark, East Orange, Irvington and Orange, New Jersey. The goal is to reach 600 children in 150 Family Day Care Homes and to follow them over two years. Children in the day care homes will have their nutritional intake and lead levels monitored. This will allow for early identification of elevated lead levels and establish a correlation between lead levels and good nutrition. Parents and child-care providers will receive education regarding the importance of nutrition in preventing lead poisoning. The project will demonstrate that children

under the age of five who are receiving nutritionally sound diets have lower lead levels than the general population of children who are in family day care homes.

FY 05 FUNDED PROJECTS

“LEAD POISONING PREVENTION MANUAL”

Legal Services of New Jersey

This one year project will inform New Jersey citizens, particularly those who are low income and most at risk, about their legal rights concerning lead poisoning. A secondary goal is to heighten awareness of the dangers posed by lead poisoning and of the legal obligations of landlords, physicians and those in a position to further the public education. This information will be disseminated through an updated, fully revised version of the manual, Lead Poisoning: What It Is and What You Can Do About It. Ten thousand copies of the booklet will be published in English and 3,000 in Spanish.

“FOCUS ON FASD PREVENTION FOR WOMEN’S ADDICTIONS PROGRAMS”

Cerebral Palsy of New Jersey, Inc.

Prenatal exposure to alcohol is the leading preventable cause of mental retardation and developmental disabilities. 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. Substance abuse treatment programs are doing little to educate their clients about FASD prevention. The primary goal of this project is to provide 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 will receive education about the risks associated with alcohol consumption during pregnancy.

“INJURY PREVENTION, HOUSEHOLD SAFETY”

FamCare, Inc.

Fifty pregnant and/or parenting adolescents will develop a home safety action plan before the birth of their infants

and will use safety devices in their home by their infant’s first birthday. The goal of the program is to reduce the number of preventable injuries to infants and to increase the number of parents using baby proofing/safety procedures. The participants will receive safety devices and education that will include smoke detectors, poison prevention, injury prevention, water safety and child proofing a home. In addition, three home safety assessments will be made by a case manager visit, before birth, at six months and at twelve months.

“LEAD POISONING PREVENTION: TRAIN-the-TRAINER”

Citizen Policy and Education Fund of NJ

Train-the Trainer workshops educate the staff of health, social service and child care agencies, as well as family members, school nurses and teachers. Education focuses on how to recognize, prevent and respond to lead poisoning, as well as techniques for talking to individuals and groups about lead poisoning prevention in easy to understand language. Day-long workshops to train and to strengthen the skills of front line leaders will be held in Newark, Irvington, East Orange and Perth Amboy. These are communities with significant numbers of lead poisoned children. Those who receive training will then deliver lead poisoning prevention information that is culturally appropriate to parents of children at high risk of lead poisoning. In addition, regular monthly communication about lead poisoning prevention issues will be provided through fax, phone and e-mail to participants in order to keep them involved and up-to-date.

“THE NEWARK ENVIRONMENTAL EDUCATION TASKFORCE”

University of Medicine and Dentistry of New Jersey

The primary goal of this project is to test the effectiveness of health education in preventive medicine. Families who participate in Women, Infants and Children (WIC) at UMDNJ will be selected to take part in this project which will focus on the topics of lead poisoning prevention and fire safety. A health educator will visit the homes of the participants and provide an assessment of potential envi-

ronmental hazards involving lead and fire safety. Educational materials will be distributed at this time, as well. At the end of the project, data will be compared for various family groups. Participant compliance will be analyzed in order to assess variations after each training and visit from the health educator. Information obtained from this study may help in defining what education is effective and could aid in the design of additional health education.

“TEAM UP WITH TEENS”

The Arc/Warren County Chapter, Inc.

A “Teen Summit” for over 60 students from Warren County Middle and High Schools will be held to educate, heighten awareness and train peer mentors about the prevention of Fetal Alcohol Spectrum Disorder (FASD) and Traumatic Brain Injury (TBI). In addition, over 40 agencies involved with developmental disabilities, alcohol and drug issues and TBI serving teens and their families, will be invited to the teen summit to present their information during the teen summit. Materials and training will be provided to the student+ participants to help them develop various community/school outreach activities aimed at educating the adolescent population of Warren County.

STATEWIDE PROJECTS

NEW JERSEY COALITION FOR PREVENTION OF DEVELOPMENTAL DISABILITIES

The Arc of New Jersey

The New Jersey Coalition for Prevention of Developmental Disabilities works to mobilize individuals and agencies/organizations in a cooperative effort to educate and promote prevention of developmental disabilities among the public and private sectors.

CHILD HEALTH MONTH

Association for Children of New Jersey

Child Health Month promotes community health and safety education, awareness and action for children throughout the state of New Jersey. Major conferences

are held that train adults to involve children and parents in community developed child health and safety activities.

NJ SAFE KIDS CAMPAIGN

NJ State Safety Council

The New Jersey SAFE KIDS Campaign promotes and implements strategies to prevent unintentional childhood injuries, the leading killer andcrippler of children under age 15, through community awareness, education and public/private sector partnerships. The Campaign addresses the five major risk areas: traffic injuries, fire and burns, falls, drownings and poisonings.

HEADS UP FOR SAFETY

Epilepsy Foundation

This is a broad based public education effort to increase public and professional awareness of preventable head injuries. Heads Up for Safety has expanded to sites across the nation.

FAS PREVENTION EDUCATION

The Arc of Atlantic County

This program provides an FAS consultant to serve as a 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.

“SEX ETC”

Rutgers Family Life Education

This is a health/sexuality newsletter written by and for teens. The newsletter communicates vital health information to over 130,000 New Jersey teens each year. Other funding has enabled the newsletter to be distributed to an additional 370,000 teens in other states. The newsletter is produced three times a year.

Lead Poisoning Prevention Small Grants Program

1996

Legal Services of New Jersey

“Lead Poisoning: What It Is and What You Can Do About It” Manual was updated and revised. Legal Services printed and distributed statewide 10,000 manuals (7,500 English and 2,500 Spanish).

City of Trenton-Division of Health

Trenton Loves Children - Lead Poisoning Prevention Project focused on increasing public and professional awareness of lead poisoning prevention by providing educational and outreach activities to over 1400 participants throughout Trenton.

Citizen Policy and Education Fund of New Jersey

Newark Lead Education

Train-the-Trainer workshops were developed and presented to staff from Newark area agencies. The program emphasized how local agencies could teach parents of young children about childhood lead poisoning prevention. Nineteen Newark area agencies completed the Train-the-Trainer lead education program.

Jersey City Lead Education Advisory Board

Lead in Water and Reaching Minority Communities

This project focused on educating residents of Jersey City about the risks of lead in drinking water. It also developed materials to educate the specific residents from the Middle East, North African and South Asian about the risks and sources of lead in traditionally applied eye cosmetics on infants and toddlers. Materials developed and distributed included:

- 85,000 addressed lead in drinking water
- 10,000 brochures described lead in eye cosmetics
- 5,000 copies of a fact sheet about lead in eye cosmetics were distributed.

Visiting Nurse and Health Services

Childhood Lead Poisoning Prevention Program

Lead poisoning prevention education was presented to parents and day care providers in collaboration with the

Elizabeth Public Health Nurses, the Women, Infant and Children Program (WIC), and the Community Coordinated Child Care Agency. This resulted in the following audiences being educated:

- 579 parents
- 37 childcare providers
- 19 home inspectors

Rutgers Cooperative Extension

Lead Point of Purchase Project

This project focused upon raising awareness of lead poisoning hazards among residents in Hunterdon County who were engaged in house renovation and painting projects. Brochures were distributed through retail paint outlets, hardware stores, and a home center. Approximately 760 homeowner brochures and 559 contractor brochures were distributed.

1998

Burlington County Health Department

Childhood Lead Poisoning Prevention Program

Educational campaigns targeting households, physicians and landlords in the neighborhoods of Burlington City and Beverly were implemented. This project resulted in :

- A total 718 of homes were contacted by door to door outreach workers
- 306 homes and the remainder received literature
- 80 children younger than 6 years resided in these homes and were referred for screening.
- Over 300 households located in Historic Yorkshire received information by mail on safe home renovation.
- 464 landlords were contacted and received literature
- 11 physicians were contacted and received a packet of information
- 25 people attended community meetings and received information.

Monmouth County Health Department

Childhood Lead Poisoning Prevention Program

The Monmouth County Health Department, in collaboration with the Monmouth County Urban League, imple-

mented a multifaceted public education campaign targeting the communities of Red Bank, Neptune, Asbury Park, Keansburg, Freehold and Long Branch. The results of this project were:

- A total of 12,000 resource items were distributed. These included flyers, brochures, fact sheets, imprinted buckets and sponges.
- A total of 7,000 risk assessment forms distributed to the general public.
- Over 30 community presentations were given to approximately 5,000 attendees
- 4,700 risk assessment forms were distributed to the target area school districts
- 600 posters were distributed

Cumberland County Health Department Childhood Lead Poisoning Prevention Education

This campaign emphasized both increasing public awareness and educating health care providers about the dangers of lead and the need for continued screening. The public was reached through health fairs, kindergarten and preschool registration sites, immunization sites, WIC sites, formal presentations to community groups and by mailings generated by referrals from physicians. Health care providers were reached through mailings and through presentations. These outreach efforts resulted in:

- 887 families and 88 Head Start children were reached through health fairs;
- 84 parents were reached through WIC sites
- 33 physicians received information packets
- 159 families and 15 staff reached through community groups/churches
- 219 parents reached through school registration sites
- 423 parents reached through immunization sites.
- 38 families outreached from physician referrals.

City of Trenton-Division of Health Trenton Loves Children

Primary prevention education was provided to youth, pregnant women, and parents/guardians of infants and young children in Trenton. One hundred school age chil-

dren were reached through participation in the Red Cross Babysitting Course. Lead poisoning prevention education was provided to 595 parents and 880 children through presentations at WIC sites.

Camden County Council on Economic Opportunity Head Start

Lead Awareness and Prevention Project

This project focused on providing lead poisoning prevention education at all 29 Head Start locations in Camden County. Head Start children with lead levels between 10-19 ug/dl were identified and their families contacted for lead poisoning prevention education. Home visits by Head Start lead poisoning prevention workers were part of the educational package. Workers also provided staff-in-services and conducted educational programs for the children in the classrooms. This resulted in:

- 44 children were identified with blood lead levels over 10ug/dl.
- All 44 families received educational materials through the mail.
- 12 families received home visits.
- 28 workshops were conducted for parents, staff and children.

Citizen Policy and Education Fund Train-the-Trainer Initiative

This project focused on training leaders and staff of community groups and social service agencies to create a lead poisoning prevention education infrastructure in key urban areas of New Jersey. A total of 142 individuals from 30 organizations received training.

Rutgers Cooperative Extension Point of Purchase

This initiative expanded the original Point of Purchase project in Hunterdon County to Home Depot stores throughout the state and resulted in:

- 2279 customers were given information
- 318 training programs were conducted in 21 stores
- 840 Home Depot employees participated in training
- 9000 brochures were distributed

2001

Citizen Policy and Education Fund

Train-the-Trainer Initiative

This project focused on training leaders and staff of community groups and social service agencies to create a lead poisoning prevention education infrastructure in key urban areas of New Jersey. The results were:

- 157 individuals from 42 organizations received training.
- 88 of the individuals trained were Newark public school nurses.

Burlington County Health Department

Lead Poisoning Prevention Education Program

This educational and awareness program was designed to reach young children in childcare centers and their parents, and to educate child care providers and their staff. The project resulted in:

- 23 child care centers in Burlington County received lead poisoning education.
- Over 146 staff members received education.
- Over 628 parents received information.
- Over 520 children received education through puppet show and/or handwashing activity.
- Literature was sent to 243 family daycare centers in Burlington County.

City of Trenton-Division of Health

Wash Away Lead Today

This project was a collaboration between the Trenton Health Department and the Child Care Connection. It provided lead poisoning prevention education to several target groups, childcare center workers, family daycare providers, preschool children, and parents/guardians in Trenton.

- 2082 preschool children received lead poisoning prevention education at 30 licensed childcare centers in Trenton.
- 98 childcare center workers from 12 licensed centers received a formal training on lead poisoning prevention.

- 271 childcare workers attended the children's education session and received education packets.
- 100 licensed family daycare centers in Trenton were mailed education packets.
- 2042 parents/guardians received education packets.

Legal Services of New Jersey

“Lead Poisoning: What It Is and What You Can Do About It” Manual was redesigned and revised. Legal Services printed and distributed statewide 13,000 manuals (10,000 English and 3,000 Spanish).

Ongoing Programs and Projects

University of Medicine and Dentistry School of Osteopathic Medicine

Lead Poisoning Prevention Education Training

This initiative had several components over the years 1996 - 2005

- **Train-the-Trainer**

This ongoing statewide initiative is designed to create a group of well-trained agency and community leaders to inform and motivate their clients and neighbors about lead hazards and prevention strategies. A turnkey training and communication skill building training manual was created.

Print and Distribute Task Force Publications

- 3000 Sources Manual distributed
- Educational Resources Manual was developed

Roundtable Lunch Programs

Topics presented included: liability issues, bioremediation of lead contaminated soil, reclaiming city land for residential and commercial use, update on local, state, federal legislation and regulations on lead, and export and import of lead: consumer product safety commission recalls and export of toxic waste containing lead.

Get the Lead Out

This prevention education program targets childcare center staff, parents and community groups, primarily in the

southern half of the state. The program began in 2000 as an expansion of the “Get a Head Start on Lead” initiative, funded by the US Department of Housing and Urban Development in 1999 - 2000.

Lead Exploratorium

A mobile exhibit on lead poisoning prevention with interactive play stations designed for preschool children to learn about lead issues, such as the importance of hand-washing, eating nutritious foods, and playing in safe areas. It was inaugurated in October 2000 during Childhood Lead Poisoning Prevention Week.

Other Projects

Lead Free New Jersey (1995/96)

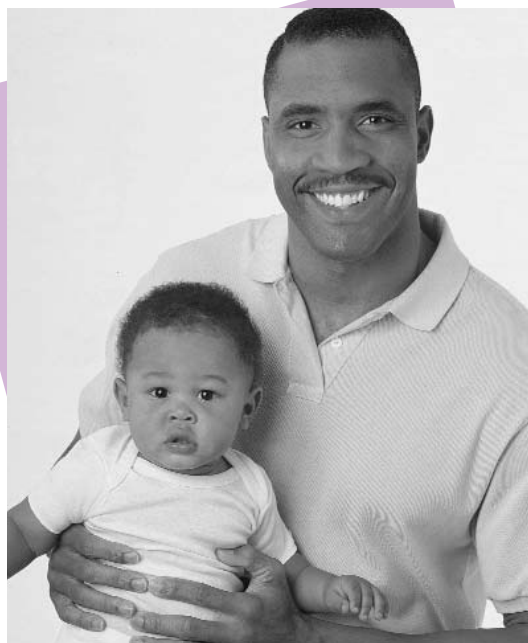
Lead Free New Jersey was a demonstration project, funded by Johnson & Johnson, and implemented in five Head Start sites during 1995/96. Prevention education was provided to the Head Start community, staff, parents, and children. A video was produced using a Head Start parent to tell her story about her children who were lead poisoned. Entitled, ***“Getting the Lead Out, Monica’s Story,”*** 1500 copies of this video now have been distributed throughout the state.

Get a Head Start on Lead (1999/00)

This project was a collaborative effort by the New Jersey Department of Human Services, Office for Prevention of Mental Retardation and Developmental Disabilities, the New Jersey Head Start Association and the University of Medicine and Dentistry of New Jersey, Lead Poisoning Prevention Education Program. Funded by the US Department of Housing and Urban Development, it was an expansion of the Johnson & Johnson Lead Free New Jersey demonstration project. The program provided prevention education to over 20 Head Start sites throughout the state. A curriculum for preschool teachers and an educational packet for parents were developed. Both of these materials are used in the “Get the Lead Out” program and the “Train-the-Trainer” program and have been distributed throughout the state.

Conference (June 2001) *“The Best of Intentions: Keeping Our Children and School Personnel Safe and Healthy During School Renovations”*

The conference addressed the multiple health and safety issues likely to arise during construction and renovation projects that take place while schools are occupied and in session. Approximately 125 school representatives attended.



APPENDIX C - Prevention-related websites

ONLINE RESOURCES

The following websites are a representative list with up-to-date, relevant information about health and safety for women, children and families. This list is not exhaustive, but these sites contain links to many other resources that can provide the user with accurate and comprehensive information concerning pregnancy, childbirth, health-care, childcare, injury, disability and disease prevention and many other areas of interest.

Alliance for Healthy Homes	www.afhh.org
American Academy of Family Physicians	www.aafp.org
American Academy of Pediatrics	www.aap.org
American College of Obstetricians & Gynecologists	www.acog.org
American Medical Association	www.ama-assn.org
Annie E. Casey Foundation	www.aecf.org
Association for Children of New Jersey	www.acnj.org www.kidlaw.org
Centers for Disease Control and Prevention	www.cdc.gov
Children's Defense Fund	www.childrensdefensefund.org
Consumer Product Safety Commission	www.cpsc.gov
Environmental Protection Agency	www.epa.gov
Healthtouch Online	www.healthtouch.com
Johnson & Johnson	www.babycenter.com
March of Dimes	www.modimes.org
Maternity Wise	www.maternitywise.org
Mayo Clinic	www.mayohealth.org

MedicineNet	www.medicinenet.com
MEDLINEplus	www.nlm.nih.gov/medlineplus
Medscape	www.medscape.com
National Center for Education in Maternal&Child Health	www.ncemch.org
National Center of Excellence on FASD	http://fascenter.samhsa.gov
National Organization on Fetal Alcohol Syndrome	www.nofas.org
National Research Center for Women & Families	www.center4research.org
National SAFE KIDS Campaign	www.safekids.org
National Safety Council	www.nsc.org
New Jersey Department of Health & Senior Services	www.dhss.state.nj.us
New Jersey Department of Human Services	www.dhs.state.nj.us
Network for Family Life Education	www.sxetc.org
The Arc of New Jersey	www.arcnj.org
The Arc of the United States	www.thearc.org
The National Women’s Health Information Center	www.4women.gov

This excellent website contains links to many other relevant resources, as well as a toll free phone number to call for questions and for more information. Information is available in Spanish and other languages, as well.

APPENDIX D* - How Many Children In New Jersey Have Developmental Disabilities?

Conditions Reported to the Special Child Health Registry Likely to Result in Developmental Disabilities

BIRTH DEFECTS REGISTRY CONDITIONS ASSOCIATED WITH DEVELOPMENTAL DISABILITIES

The Office for Prevention of Mental Retardation and Developmental Disabilities is often asked, “How many New Jersey children have a developmental disability?” While this question seems straightforward, it is actually quite complex and difficult to answer. The reasons for the difficulties in determining incidence and prevalence encompass issues of medical or diagnostic classification, functional abilities, and eligibility criteria for different services. These complex issues include:

First, while there are federal and state definitions of developmental disability, there is no national consensus regarding which medical or diagnostic classifications should be included in the definition of developmental disabilities. Almost identical to the federal definition, New Jersey legislatively defines “developmental disability” as a condition that:

- 1. Is attributable to a mental or physical impairment or combination of mental or physical impairments;**
- 2. Is manifest before age 22;**
- 3. Is likely to continue indefinitely;**
- 4. Results in substantial functional limitations in three or more of the following areas of major life activity:**
 - **Self-care**
 - **Receptive and expressive language**
 - **Learning**
 - **Mobility**
 - **Self-direction**
 - **Capacity for independent living**
 - **Economic self-sufficiency**
- 5. Reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services that are of lifelong or extended duration, and are individually planned and coordinated.**

In New Jersey, mental retardation, autism, cerebral palsy and spina bifida are among the conditions considered to be developmental disabilities. Other states exclude some medical conditions, such as spina bifida.

*Much appreciation is extended to Leslie Beres-Sochka, Joseph Sweatlock, Mary Knapp, Kathryn Aveni, and the staff of the Department of Health and Senior Services’ Birth Defect Registry for compiling the data reported in this Appendix.

Second, New Jersey, like most other states, does not maintain a centralized registry of children with developmental disabilities. In fact, no single entity in the state is required to maintain a listing of all persons with developmental disabilities. (See Recommendations for Infant and Child Health.)

Third, the only developmental disabilities that have mandated reported requirements in New Jersey are those associated with birth defects. Developmental disabilities that may be acquired, such as those that result from an illness or an injury, do not have to be reported.

Fourth, the information contained in New Jersey's mandated Birth Defects Registry, one component of the Department of Health and Senior Services' Special Child Health Services Registry (SCHS), cannot be used as a proxy to estimate the incidence of developmental disabilities, because a large proportion of birth defects do not result in impairments that meet the legislatively established criteria for developmental disabilities. As described herein, however, the SCHS Registry is a valuable resource to use as a first step in estimating the incidence.

Finally, New Jersey's legislative definition for developmental disabilities is clear. However, eligibility criteria for services, based upon the legislated definition, are applied in different fashion among agencies that are responsible for providing services to persons with developmental disabilities. For example, the criteria for eligibility for Early Intervention Services in New Jersey are based upon both diagnostic categories, when available, as well as percentages of developmental delay(s). Eligibility for services from the Department of Human Services, Division of Developmental Disabilities relies upon both diagnostic classification, when available, and function assessments.

As a result, determining the incidence of developmental disabilities is not an easy task. In 1988, the Office for Prevention entered into a cooperative agreement with the Centers for Disease Control and Prevention (CDC) to participate in the Disabilities Prevention Program. One part of the program concentrated on developing a method to identify persons who were potentially affected by developmental disabilities through the use of the Birth Defects Registry. This applied methodology was effective in so far as it resulted in the ability to estimate the number of infants who were born with congenital anomalies that were likely to result in permanent developmental disabilities.

The Birth Defects Registry, created by legislation in 1983, is a population-based system to which all infants who are diagnosed with a congenital anomaly before the age of one year must be reported to the DHSS. Hospitals, physicians, dentists, nurse midwives, genetic services, cytogenetic laboratories and medical examiners are required by law to register children who are diagnosed with a congenital anomaly in the Birth Defects Registry. While it is considered to contain the census of children born with congenital defects, some developmental disabilities, such as Fetal Alcohol Syndrome, are not diagnosed until after age one and are thus not reported to the Birth Defects Registry.

The Birth Defects Registry is one of the two components that together comprise the SCHS Registry. Children with special health care needs and developmental disabilities who are older than age one may be reported to the second component, the Special Needs Registry. Children are reported into this component primarily from hospital social services, child evaluation centers, county case management units, early intervention programs and other service providers. Wide variation is found in the conditions that are included in the Special Needs Registry, including asthma, cancer, premature birth, and developmental delay. There is no mandate to report children without congenital defects and, for each child registered, up to eight diagnoses may be recorded. Because registration is voluntary, the Special Needs Registry does not contain a full census of all children with special health problems, diagnostic categories of developmental disabilities that emerge after age one, or acquired developmental disabilities.

Under the CDC-supported program, staff from the Birth Defects Registry extrapolated data from specific diagnostic categories to use as the baseline for estimating the number of children with developmental disabilities in New Jersey. In addition, because not all the diagnostic conditions of the children included in the SCHS Registry result in a developmental disability, a classification scheme was designed to predict which children were "highly likely" and "likely" to have a

developmental disability. In 1995, the Governor's Council on Prevention reported in *Changes and Challenges: Building Our Children's Future*, that a total of 67,470 children were registered with SCHS between the years of 1985 and 1992. Of these, 24,408 children (36%) were registered in the Birth Defects Registry and 43,062 (64%) in the Special Needs Registry.

The staff of the SCHS Registry applied these methodologies to data available in the Birth Defects Registry and Special Needs Registry. As shown in Table A, in the period from 1995 through 2003, a total of 73,870 children were registered in the SCHS Registry. During the period from 1995 through 1999, 53.75% of the children were registered in the Birth Defects Registry and 46.25% in the Special Needs Registry. In the period from 2000 through 2003, the proportion of children reported to the Birth Defects Registry had increased to 62.96% with 37.04% registered with the Special Needs Registry.

While 64% of New Jersey's children who are younger than 18 years of age are White, the proportion of these children reported to both Registries in the period from 1995 to 2003 was approximately 45%. African American children comprise an estimated 16% of all children younger than 18. Fifteen percent of the total number of registered children was Black. Likewise, an estimated 15% of all children younger than 18 are Hispanic/Latino and a similar proportion were registered. Data on Hispanic/Latino children were not collected when the 1995 report was published. Having such data available increases the value of the SCHS Registry and reflects the concerted effort put forth to identify children in these communities.

As has been well-documented by epidemiological studies, males (58%) are more likely to be born with a birth defect than are females (42%). In the period between 1995 through 1999, 5.38% of the registered children did not have any health insurance and this proportion increased to over 6% from 2000 to 2003. The great majority of children were privately insured with an estimated 25% receiving their health insurance through Medicaid. Most children (60%) were registered with only one or two birth defects or special health needs during the eight year period.

Out of the total of 73,870 children registered in the SCHS Registry from 1995 through 2003, 13,821 or 19% are predicted to have a congenital anomaly or other condition that is highly likely to result in developmental disabilities while 11,783 or 16% meet the criteria. As a result, 25,604 or 35% of all children who were reported to the SCHS are likely to have permanent developmental disabilities and a great proportion of them will require lifelong special services.

Table 1 presents the conditions that are perceived to be highly likely to result in developmental disabilities. However, at least one of the conditions, Fetal Alcohol Syndrome, is known to be underreported. Table 2 summarizes the conditions that are associated with being likely to result in developmental disabilities. Here, too, underreporting may be occurring as in the case of injuries and poisonings.

Finally, beginning in May 2000, children with certain risk factors were required to have hearing screening done and many hospitals began working toward implementation of universal screening. New legislation mandating Universal Newborn Hearing Screening in New Jersey was enacted in January 2002. The hearing screening rate in New Jersey exceeds the national average of 87% in 2003. As illustrated in Table 3, by 2004, 99% of all newborns were screened for hearing problems prior to hospital discharge. Over 1600 infants were identified as having hearing loss.

In conclusion, the SCHS Registry can provide the data needed to estimate the number of children who may be born with congenital anomalies that result in developmental disabilities. If the mandated reported age was increased to 6, as recommended in this report, a more accurate census of all children with developmental disabilities would be available. These data are needed to develop and evaluate prevention strategies. Of equal importance, they can assist service planners and providers in identifying and, when needed, establishing appropriate services for these children and to project the life-long needs of these individuals and their families.

Table A: Trends in Characteristics of Registered Children, 1995-2003

Characteristic	Total	1995-1999 Total and %	2000-2003 Total and %
Total Registered	73,870		
in Birth Defects	42,596	22,843 53.75%	19,753 62.96%
in Special Needs	31,274	19,652 46.25%	11,622 37.04%
Race			
White, non-Hispanic	32,954	18,318 43.11%	14,636 46.65%
Black, non-Hispanic	11,454	6,714 15.80%	4,740 15.11%
Other, non-Hispanic	3,304	1,728 4.07%	1,576 5.02%
Hispanic	12,056	6,706 15.78%	5,350 17.05%
Don't Know	14,102	9,029 21.25%	5,073 16.17%
Sex			
Male	43,011	24,677 58.07%	18,334 58.44%
Female	30,841	17,812 41.92%	13,029 41.53%
Indeterminate/Unknown	17	5 0.01%	12 0.04%
Insurance			
None	4,198	2,287 5.38%	1,911 6.09%
Private	41,075	22,822 53.71%	18,253 58.18%
Medicaid	18,631	11,841 27.86%	6,790 21.64%
Unknown	9,966	5,545 13.05%	4,421 14.09%

* Based upon Birth Defects Registry information as of February 15, 2005

Table A continued

Number of Diagnoses per Child			
1	30,155	16,959 39.91%	13,196 42.06%
2	16,464	9,408 22.14%	7,056 22.49%
3	9,636	5,556 13.10%	4,070 12.97%
4	6,059	3,493 8.22%	2,566 8.18%
5	4,004	2,379 5.60%	1,625 5.18%
6	2,753	1,585 3.73%	1,168 3.72%
7	2,180	1,303 3.07%	877 2.80%
8 (maximum in Registry)	2,619	1,802 4.24%	817 2.60%
Children Highly Likely or Likely to have Developmental Disabilities			
Registration Type	Highly Likely	Likely	Total
in Birth Defects	4,766	5,436	10,202
in Special Needs	9,055	6,347	15,402
Total	13,821	11,783	25,604

Table 1: Frequency of Conditions Thought to be Highly Likely to be Associated with Developmental Disabilities

Groups	Total				Current Age				Age at Registration				Total	
	LT 3	3-5	6-12	13+	LT 1	1-2	3-5	6-12	13+	LT 1	1-2	3-5		6-12
Metabolic Disorders	8	0	3	4	1	1	3	4	0	0	0	0	0	8
Mental Conditions														
Psychosis	802	14	150	522	116	27	227	348	170	30	30	30	30	802
Neurotic & Other Disorders	812	2	14	377	419	9	51	179	482	91	91	91	91	812
Mental Retardation	212	5	7	75	125	16	10	43	102	41	41	41	41	212
Developmental Delay	5446	268	1410	3214	554	794	3220	794	567	71	71	71	71	5446
Conditions of the Nervous System														
Cerebral Palsy	570	23	116	322	109	148	145	136	108	33	33	33	33	570
Other Conditions	1523	407	422	610	84	1222	126	71	80	24	24	24	24	1523
Conditions of the Eye and Adnexa														
Vision Impairment	64	7	9	30	18	30	7	6	15	6	6	6	6	64
Other	18	1	10	7	0	10	3	5	0	0	0	0	0	18
Conditions of the Eye and Mastoid Process														
Hearing Loss, non-congenital	1480	181	244	679	376	374	228	277	499	102	102	102	102	1480
Congenital Hearing Disorders	124	41	39	38	6	108	2	4	6	4	4	4	4	124
Circulatory System Conditions	30	2	3	20	5	15	4	4	4	3	3	3	3	30
Chromosomal Anomalies														
Down Syndrome	1232	382	379	442	29	1133	39	21	31	8	8	8	8	1232
Other	704	213	243	234	14	630	46	10	15	3	3	3	3	704
Failure to Thrive	2767	221	607	1810	129	1072	1190	330	153	22	22	22	22	2767
Fetal Alcohol Syndrome	64	8	15	37	4	46	4	5	8	1	1	1	1	64
Conditions of the Musculoskeletal System	113	31	32	47	3	99	6	6	2	0	0	0	0	113
TOTAL CHILDREN	13821	1677	3333	7264	1547	5194	4719	1811	1753	344	344	344	344	13821

* Based upon Birth Defects Registry information as of February 15, 2005 ** 2003

* Based upon children registered 1995 through 2003 and current age < 22 years

Table 2: Frequency of Conditions Thought to be Likely to be Associated with Developmental Disabilities

Groups	Total		Current Age				Age at Registration				Total		
	LT 3	8	3-5	28	6-12	100	13+	LT 1	1-2	3-5		6-12	13+
Infections and Parasitic Diseases	159	8	28	100	23	117	13	117	13	6	17	6	159
Neoplasms	69	6	15	25	23	28	9	28	9	8	19	5	69
Mental Disorders	12	0	0	1	11	0	0	0	0	1	7	4	12
Conditions of the Nervous System	147	36	60	49	2	129	14	129	14	1	3	0	147
Congenital CNS Disorders	2676	561	852	1181	82	2381	148	2381	148	59	75	13	2676
Non-congenital CNS Disorders	58	11	15	29	3	42	12	42	12	1	2	1	58
Peripheral Nervous System Conditions	257	56	78	118	5	215	29	215	29	6	6	1	257
Degenerative CNS Conditions	8	0	0	2	6	0	1	0	1	1	1	5	8
Spinal Cord Conditions													
Conditions of the Eye and Adnexa	24	2	2	17	3	10	5	10	5	4	5	0	24
Vision Impairment	1704	364	528	805	7	1643	49	1643	49	7	4	1	1704
Other Eye Conditions													
Conditions of the Ear and Mastoid Process	1	0	0	0	1	0	0	0	0	0	1	0	1
Conditions of the Musculoskeletal System	1277	373	408	470	26	1145	82	1145	82	16	25	9	1277
Conditions of the Respiratory System	21	13	4	4	0	19	1	19	1	1	0	0	21
Maternal Causes of Perinatal Morbidity/Mortality	446	170	107	169	0	437	8	437	8	0	1	0	446
Maternal Drug Use	2463	474	751	1234	4	2393	53	2393	53	12	4	1	2463
Other Conditions	4071	936	1341	1754	40	3834	155	3834	155	39	38	5	4071
Prematurity													
Injury, Poisoning, and Ill-Defined Conditions	347	31	86	203	27	140	114	140	114	58	28	7	347
TOTAL CHILDREN	11783	2662	3644	5226	251	10695	607	10695	607	201	225	55	11783

* Based upon Birth Defects Registry information as of February 15, 2005

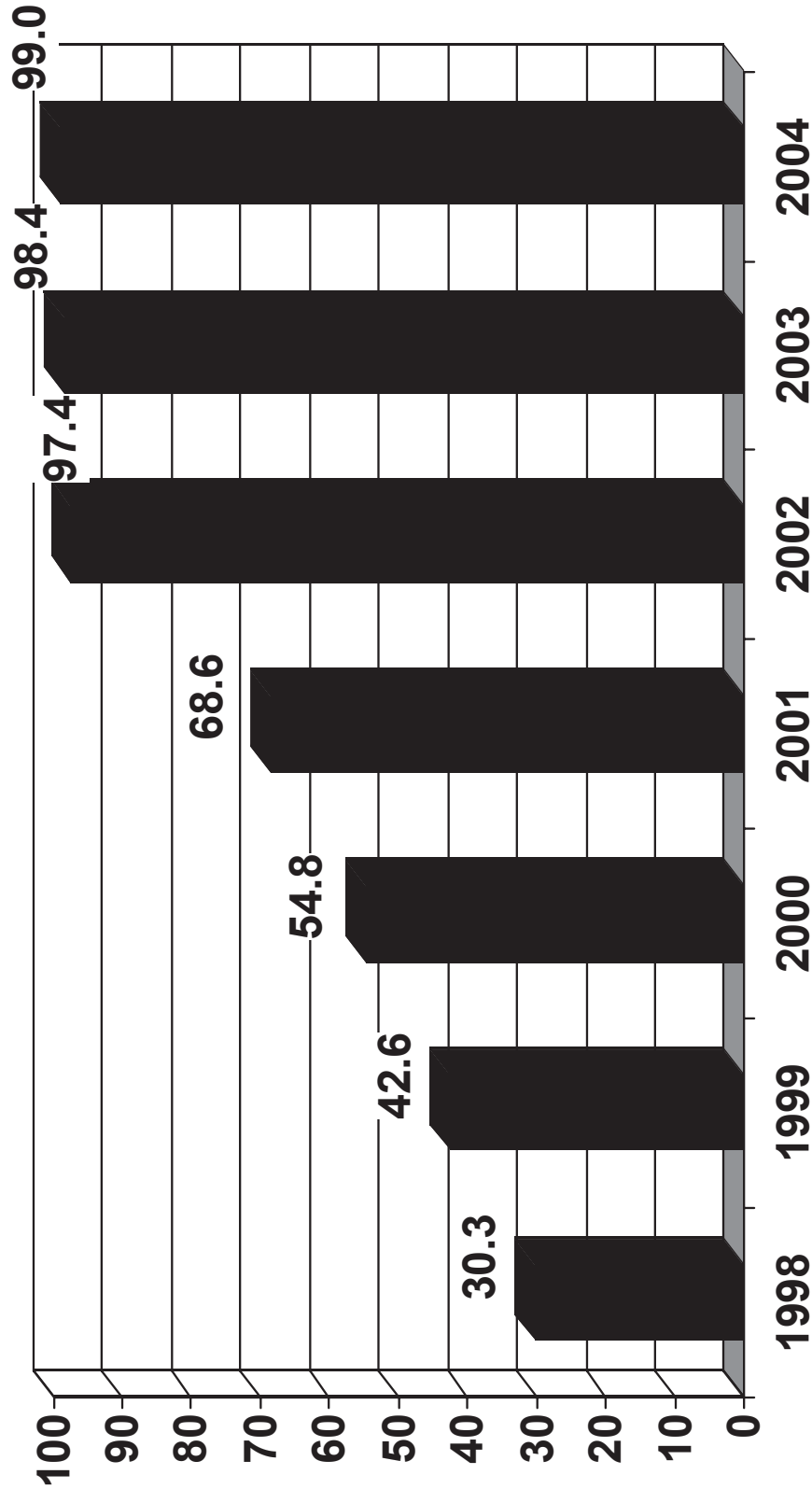
** Does NOT include children with diagnoses to be Highly Likely to be associated with developmental disabilities

*** Current Age on December 31, 2003

**** Based upon children registered 1995 through 2003 and current age < 22 years

Table 3: Newborn Hearing Screening

Percent of New Jersey Newborns Screened Prior to Discharge or by 30 Days of Age



Source: Electronic Birth Certificate data reported as of 2/4/05

Preconception Health Committee

Dorothy Angelini, Robyn Carroll, Deborah Cohen,
Rosie Horner, Hilda Mitchell, William Moore,
Rosalyn Seawright,

Infant and Child Health Committee

Morris Cohen, Ellen Dunn, Candice Feiring,
Andrea Mahon, Fred Patterson, Paul Potito,
Deborah Spitalnik, Yvonne Wesley

Prenatal Health Committee

Thomas Baffuto, Deborah Davies, Lula Linder,
Artea Lombardi, Barbara Mays, Mike McCormack,
Judy Morales, Ezinma Obi-Onuigbo, Lynn Spatzer,
Alyce Thomas, Ann Wilson

20th Anniversary Planning Committee

Dorothy Angelini,, Robyn Carroll, Mir Lund,
Andrea Mahon, Judy Morales, Ezinma Obi-Onuigbo,
Deborah Spitalnik, Alyce Thomas, Ann Wilson,
Yvonne Wesley

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Susan Adubato, Sharon Ahern, Denise Aloisio, Celeste Andriot-Wood, Dorothy Angelini, Lisa Ashbaugh, Maria Basora, Kathy Bedard, Barbara Caspi, Carol Chamberlain, Wanda Cintron, Deborah Cohen, Elizabeth Collins, Susannah Combs, Ray Cortese, Mary DeJoseph, Roberta Dihoff, Kristine DiRocco, Jane Downey, Mary Jane Drury, Ellen Dunn, Karen Dunn, Jeanette Flanagan, Margaret Gray, Rosemary Horner, Brian Illencik, Ronnie Jacobs, Marilyn Kent, Marilyn Kinelski, Judy King, Suzanne Kinkle, Mary Knapp, Felissa Lashley, Lori Lloriatte, Deborah Maslansky, Barbara May, Michael McCormack, Kyle McLaughlin, Uday Mehta, Judy Morales, Wendy Nehring, Natalie Roche, Cindy Sickora, Stephen Smith, Lynn Spatzer, Myra Vaughns, Cathleen Vieira, Patricia Wells, Ann Wilson, Barbara Zimmerman-Bier

Interagency Lead Poisoning Prevention Task Force

Margaret Bennett, Donald Bryan, Sarah Campbell-Hicks, Deborah Cohen, William Connolly, Sylvia Dellas, Dawn D'Orlando, Ellen Dunn, Joseph Eldridge, Randy England, Amy Fenwick-Frank, Claudia Funaro, Sandra Galayda, Barbara Gerwell, Jan Goodman, Barker Hamill, Robert Haug, Rosemary Horner, Nisha Jani, Felicia Johnson, Diane Jordan, Maryann Kokidis, Laura Livingston, Dianne Kinnane, Joan Luckhardt, Kevin McNally, Cynthia Mitchell, Crystal Motlasz, Eileen Murphy, Beatriz Oesterheld, Colleen O'Hara, Kristy Paolillo, Elyse Pivnick, Joe Ponessa, Meredith Povich, Maribeth Robenolt, Bob Roe, Cynthia Rogers, Phyllis Sabino, Michele Schwartz, Cindy Sickora, Devendra Singh, Ed Stevenson, Stanley Stopa, Joseph Surowiec, Marcie Tyson, David Valiante, Myra Vaughns, John Weber, Judy Weisel, Donald Wiggins, Ann Wilson, Chrystene Wyluda,



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