



State of New Jersey

DEPARTMENT OF HUMAN SERVICES

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CHRIS CHRISTIE

Governor

KIM GUADAGNO

Lt. Governor

JENNIFER VELEZ

Commissioner

August 4, 2010

Honorable Stephen M. Sweeney
Senate President
P. O. Box 099
Trenton, NJ 08625-0099

Honorable Sheila Y. Oliver
Speaker of the General Assembly
P.O. Box 098
Trenton, NJ 08625-0098

Dear Senate President Sweeney and Assembly Speaker Oliver:

Prevention of developmental disabilities is an important component of the work that is undertaken by the Department of Human Services, Division of Developmental Disabilities. The Governor's Council on the Prevention of Developmental Disabilities and its administrative partner, the Office for Prevention of Developmental Disabilities (OPDD), strive to educate and inform the citizens of our State of ways in which some risks for these disorders may be decreased.

Pursuant to P.L. 1987, c.5, enclosed is the Fiscal Year 2010 report of the Governor's Council on the Prevention of Developmental Disabilities and OPDD. The report summarizes the progress that New Jersey has made over the past year to prevent developmental disabilities. Using traditional approaches as well as social marketing techniques, educational programs sponsored by the Governor's Council on Prevention and OPDD have reached a broad spectrum of our State's citizens.

If you have any questions, please feel free to contact me or Deborah Cohen, OPDD Executive Director, at 609-689-1939.

Sincerely,

A handwritten signature in black ink, appearing to read "Jennifer Velez", written over a circular stamp or seal.

Jennifer Velez
Commissioner

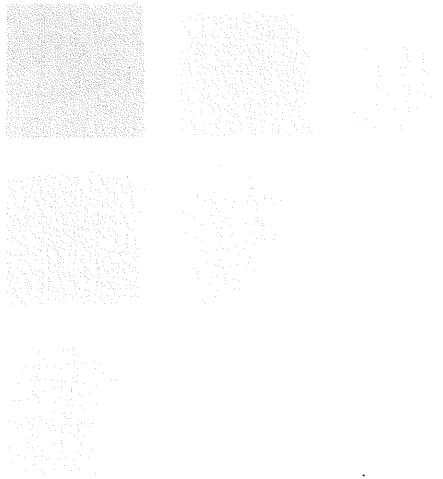
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Enclosure

c: Deborah Cohen, Ph.D.

Lori O'Mara-Van Driesen, OLS Office of Public Information

REPORT FOR FISCAL YEAR 2010



GOVERNOR'S COUNCIL
ON THE PREVENTION OF
DEVELOPMENTAL DISABILITIES

AND THE

OFFICE FOR PREVENTION OF
DEVELOPMENTAL DISABILITIES

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Report for Fiscal Year 2010

The Governor's Council on the Prevention of Developmental Disabilities (Council) and the Office for Prevention of Developmental Disabilities (OPDD) were created by Public Law 1987, Chapter 5, as amended by Public Law 2000, Chapter 82. The Council provides oversight and guidance to OPDD and makes recommendations to the Department of Human Services Commissioner, regarding policies and programs needed to prevent developmental disabilities. OPDD is based in the Department of Human Services' Division of Developmental Disabilities.

The Council is composed of 25 public members appointed by the Governor of New Jersey. Each member serves a three-year term. Five new members were selected and 11 members were re-appointed during the past year.

The Commissioners of the Departments of Human Services, Community Affairs, Education, Health and Senior Services, and Environmental Protection, and the Secretary of State, or their designees, serve as ex officio members. The Commissioners each sign an annual Interagency Agreement to participate on the Council and to work collaboratively with and support the OPDD.

2010 Activities of the Governor's Council on Prevention of Developmental Disabilities

The Council met quarterly during Fiscal Year 2010. To make sure members remain informed about the progress in preventing developmental disabilities, each meeting included a specific prevention issue presentation. The four presentations are described below.

Act Early (September 2009) -Deborah Spitalnik, Ph.D., Director of the Boggs Center for Excellence in Developmental Disabilities and a member of the Governor's Council, and Kathy Roberson, MSW, Policy and Information Coordinator, Boggs Center, made a presentation on the Act Early program. This national initiative seeks to enhance state-wide identification of and/or interventions for children with an Autism Spectrum Disorder and other developmental disabilities. (The Boggs Center, located at the University of Medicine and Dentistry of New Jersey and the Robert Wood Johnson School of Medicine in New Brunswick, operates with leadership from the federal Centers for Disease Control and Prevention, and the Maternal and Child Bureau).

As a result of the presentation, the Council decided to support the Boggs Center with implementing the **Act Early** program in New Jersey. Several Council members volunteered to participate in this endeavor. Through the use of consultation with the Early Intervention Collaboratives, a decision was made to support translation of **Act Early** materials into Arabic, Portuguese and Korean languages. The materials will be available for use in Early Intervention Collaborative outreach activities.

Newborn Screening (December 2009) – Newborn screening has expanded greatly in New Jersey over the past several years. As a result, more children with genetic abnormalities are identified at birth and more receive the treatment and services to ameliorate their congenital anomalies. The Council learned more about this expansion development through a presentation on the Newborn Screening and Follow-Up programs made by Michael McCormack, Ph.D., Chief Geneticist at UMDNJ-SOM and member of the Council, and Suzanne Karabin, MSC, CGC, Department of Health and Senior Services (DHSS).

2010 Activities continued...

As a result of the presentation, the Council identified a concern regarding newborn screening: the lack of a system to insure that hospitals submit all newborn specimens to the State Laboratory for analysis. The Council recommended that this matter be referred to the DHSS' Newborn Screening Annual Review Committee (NSARC). As both Dr. McCormack and Deborah Cohen, Ph.D., OPDD Director, are members, each were charged with bringing this issue to NSARC's attention.

Identification of Pregnant Women at Risk (March 2010) – Barbara May, RN, MPH, Prevention Programs Director of the Family Health Initiatives and a Council member, made a presentation on the statewide initiative to identify women who are at-risk of using alcohol, drugs, or cigarettes and/or who may be at-risk of domestic violence during pregnancy. Prenatal exposure to alcohol is the most common preventable cause of developmental disabilities and a high priority for the Council. DHSS has established the Perinatal Addictions Prevention Projects (PAPP) in each of the six Maternal and Child Health Consortia (MCHC). The PAPP staff work with providers of prenatal services to incorporate screening of pregnant women into their practices. The Council did not identify any needed follow-up activities.

New Jersey's Environmental Public Health Tracking Network (June 2010) – It is generally recognized that the link between some developmental disabilities and environmental health threats can be better documented if their relationship can be identified and then tracked. In New Jersey, this occurs through the DHSS Environmental Public Health Tracking Portal. Jerald Fagliano, MPH, Ph.D., and Richard Opiekun, MA, MS, Ph.D., both currently developing the Portal, made a presentation on the efficacy of this system to isolate specific variables that may be implicated in causing some disabilities. These included utilization of data from the electronic birth certificate and birth defects registry. The Council did not identify any items that required follow-up.

Prevention Activities

The Council has prioritized the following three areas for preventing developmental disabilities:

- prevention of childhood lead poisoning,
- prevention of Fetal Alcohol Spectrum Disorders (FASD), and
- prevention of unintentional childhood injuries.

The Council addresses the first two of listed priorities through two separate standing committees: the Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) and the Fetal Alcohol Spectrum Disorders (FASD) and other Perinatal Addictions Task Force (FASD Task Force). The Council addresses the third issue, preventing unintentional childhood injuries, through partnership with a number of existing community agencies.

A primary purpose of the task forces and partnership is to achieve one of the mandates of the enabling legislation: to enhance cooperation, collaboration and communication in efforts to prevent developmental disabilities.

The activities of the task forces are more fully described in the next section. The activities of the partnership, in addressing the prevention of unintentional childhood injuries, are also included with the information about OPDD in this report.

Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force)

The Lead Task Force is composed of representatives from state agencies charged with addressing the health and environmental problems caused by exposure to lead. These include the Departments of Human Services, Community Affairs, Environmental Protection and Health and Senior Services, and formerly the Office of the Child Advocate. The U.S. Environmental Protection Agency, University of Medicine and Dentistry of New Jersey (UMDNJ), and many local public health, housing, and social service agencies also participate on the task force. The task force oversees DHSS' New Jersey Child Lead Poisoning Elimination Plan. The plan was required in order to receive lead prevention funds from the federal Centers for Disease Control and Prevention.

Lead remains the leading environmental threat to the health of New Jersey's children. As a state with one of the oldest and most extensive industrial heritages of any in the country, New Jersey's environment contains a substantial amount of lead. This reality, coupled with the fact that New Jersey is the most densely populated state in the nation, creates heightened risks of lead poisoning for our residents.

While this threat remains, New Jersey and other states have made great strides in identifying and reducing the level of lead exposures in young children. As a result, federal agencies have begun to focus on other environmental health risks.

The Lead Task Force sponsored a statewide conference on April 16, 2010 to educate constituents about New Jersey's progress in reducing childhood lead poisoning, and help orient people to other environmental issues that need to be addressed. The conference, **Lead and Beyond: Progress in Eliminating Lead Poisoning and New Opportunities for Collaboration in New Jersey**, was well attended by 300 professionals from the health, housing, education and environmental fields.

The participants highly rated the quality of the conference, and documented the educational opportunity provided an excellent orientation to other environmental hazards that can affect the health and well-being of New Jersey's children. The Lead Task Force is using information garnered from the evaluations to develop plans to continue this needed education on a regional basis.

Fetal Alcohol Spectrum Disorders (FASD) and Other Perinatal Addictions Task Force

Alcohol is the most **preventable** cause of intellectual and other developmental disabilities. The common myth is that only alcoholic women give birth to a child with FASD, when, in fact, it can be dangerous for any pregnant women to consume even small amounts of alcohol. Unfortunately, this fact is not well known or understood. Too often, a pregnancy is not planned, and because the woman is not aware that she is pregnant, she continues to consume alcohol during early months of her pregnancy, putting the fetus at risk of sustaining permanent organic brain damage.

The FASD Task Force is composed of representatives from the Departments of Human Services and Health and Senior Services, as well as UMDNJ, the Perinatal Addiction Prevention Programs, the FASD Diagnostic Centers, and local community health, addictions treatment, and social service agencies. The task force maintains both a Speakers Bureau and a system for tracking the number of presentations given and who attends them. During 2010, more than 200 hundred presentations on prenatal addictions were delivered to more than 10,000 New Jersey residents. Audience members included high school students, medical and other allied health students and practitioners, addictions treatment center personnel, child welfare case workers, developmental disabilities intake workers and psychologists, and families.

The FASD Task Force administers two committees:

The **Public Education Committee**, which works to expand professional and community knowledge about the dangers to unborn children from exposure to alcohol, drugs and tobacco. To this end, the committee has designed a public education campaign about the risks of perinatal exposures that includes both televised ads and printed materials. All materials include the number of the DHSS' Family Health Line and a website address, www.beintheknownj.org, where concerned constituents can learn more and receive information about addiction services.

The **Website Committee**, which oversees the www.beintheknownj.org website. Supported by UMDNJ and The Arc of Atlantic County, the website provides information on New Jersey services for individuals coping with addiction problems, as well as resources for individuals affected by prenatal exposures, particularly to alcohol. In addition, the website informs visitors about other important maternal and child health issues.

The FASD Task Force was instrumental in getting FASD included in the Department of Education's Core Curriculum Standards for Physical and Health Education. Task force members have been implementing creative strategies to help educate adolescents about the dangers of prenatal exposures to fetal development. Currently, the task force is compiling these approaches into a manual that will be distributed to school districts and agencies that provide services to adolescents.

2010 Activities of the Office for Prevention of Developmental Disabilities (OPDD)

OPDD serves as staff to the Governor's Council on Prevention and its Task Forces. In addition, OPDD is charged with implementing, monitoring and evaluating community prevention education programs that receive support through OPDD's annual state appropriation.

OPDD is small and composed of only three staff persons:

Executive Director - Deborah Cohen, Ph.D.
Contracts Manager - Ellen Dunn, MSW
Community Educator - Rosemary Horner, MPH

OPDD strives to maximize the effectiveness of its staff and funding by investing most of its resources into community education endeavors. It also works in partnership with UMDNJ – School of Osteopathic Medicine to implement two programs

- **Train the Trainer**, which educates community groups throughout the state about a broad array of prevention issues including lead poisoning, Pediatric HIV/AIDs, FASD and unintentional childhood injuries. It emphasizes both the acquisition of knowledge about the specific issue as well as utilization of effective communication skills. The intent of this program is to develop a network of trainers who can provide effective prevention education in their community. The program provides materials and technical support to these community educators. Over the past year, more than 500 individuals, including approximately 100 adolescents, participated in the trainings. The trainings are led by Ms. Horner.
- **The Child Health and Injury Prevention Program (CHIPP)**, which aims to educate staff of preschool programs, young children and their families about health and prevention issues. Teachers participate in an on-site educational program on specific issues, such as lead poisoning prevention, healthy nutrition and childhood injuries. After the teacher education, an OPDD-supported Community Educator Consultant meets with the pre-school children to teach them about protecting themselves from injuries and lead poisoning. During the past year, the CHIPP Education Consultant trained approximately 300 preschool teachers and parents. An estimated 1,300 children participated in the school-based program.

OPDD also provides support for and works collaboratively with the **New Jersey FASD Training Center** at UMDNJ-New Jersey Medical School. OPDD's Director and the New Jersey FASD Training Center's staff work together to educate many including: medical students, physicians, nurses and other allied health professionals, juvenile and criminal justice system personnel, child welfare system workers, adolescents, prospective parents and others about the dangers of consuming alcohol during pregnancy.

Statewide Prevention Education Programs

OPDD helps fund six community agencies that engage in prevention education activities. The programs, which are statewide and part of national initiatives, are described below:

1. The **New Jersey Coalition for Prevention of Developmental Disabilities** is administered by The Arc of New Jersey. The coalition 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. The Coalition accomplishes this goal through various means, including publication of a quarterly, on-line prevention newsletter that is distributed to approximately 3,000 subscribers.

In addition, the coalition organizes and helps to sponsor Pregnant Pause events in each county. Pregnant Pause is a national program to educate prospective parents about the importance of not drinking alcohol during pregnancy. The county events strive to meet residents' needs through a variety of approaches. These include sponsoring Mother and Daughter luncheons, holding special events in malls and at Toys-R-Us, supporting baby showers for pregnant adolescents, and partnering with colleges to educate students about FASD.

The coalition also provides trainings in prevention issues to public health and social service professionals. These have included trainings on FASD to Family Care Workers based in school systems and educational programs about the prevention of unintentional injuries and childhood lead poisoning.

2. **Child Health Month** is a year-round campaign that promotes community health, and safety education and awareness for children throughout New Jersey. The program, sponsored by the Association for Children of New Jersey, encourages projects and activities that give children an opportunity to become positively involved in their own health and well-being.

Obesity is one important issue addressed by **New Jersey Child Health Month** during the past year. While obesity has become a national public health priority, pregnant women who are overweight carry additional health risks for themselves and their children, including higher risk of giving birth prematurely and having low birth weight babies. In turn, these infants are at much higher risk of having permanent developmental disabilities. As part of a national program, **New Jersey Child Health Month** concentrated on issues associated with childhood obesity by implementing school-based programs focused on the importance of eating good, wholesome foods.

Statewide Prevention Education Programs continued...

3. **The New Jersey Safe Kids Campaign** promotes and implements strategies to prevent unintentional childhood injuries. Unintentional injuries are the leading cause of mortality and morbidity among children under age 15 and are a major cause of acquired developmental disabilities. **The New Jersey Safe Kids Campaign**, funded in partnership with Johnson & Johnson, builds on community awareness, education and public/private sector partnerships. The campaign addresses the five major risk areas: traffic injuries, drowning, fires and burns, falls, and poisoning. In addition, the campaign sponsors special events during the first week in May, which is designated nationally as "Safe Kids Week."

The New Jersey Safe Kids Campaign has partners on the county level. Based primarily in hospitals, the local Safe Kids Coalitions sponsor injury prevention events for children and their families. These include bicycle rodeos where children are taught the importance and correct wearing of helmets; car seat installation seminars, and water and boat safety programs. Approximately, 10,000 children and their families participated in these programs statewide during the past year.

4. The "**Sex, etc.**," a family life newsletter/magazine, by Teens, for Teens, is sponsored by the Network for Family Life Education at Rutgers University. Each year, New Jersey high school students write three issues of "Sex, etc." that are published and distributed to teens throughout the state and the country. This newsletter contains accurate, up-to-date information about healthy behaviors, sexuality, the effects of drugs and alcohol, violence and prenatal health. It is 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. The program also sponsors a website for adolescents at <http://www.sexetc.org>. Approximately 500,000 copies of each edition are distributed to teachers for their use as part of the school-based Family Life Education curriculum.

Statewide Prevention Education Programs continued...

- 5. Fetal Alcohol Spectrum Disorders (FASD) Community Education Outreach** is a program that serves as a resource to New Jersey agencies and organizations involved in the prevention, education and diagnosis of FASD to assure their access to up-to-date and comprehensive information. Sponsored by The Arc of Atlantic County, the program is responsible for developing, implementing and evaluating new approaches to prevention education. When the efficacy of these strategies have been ascertained, the FASD Community Education Outreach staff train other FASD professionals in their use. During the past year, staff designed an FASD program that was delivered to persons mandated to participate in the Intoxicated Drivers Resource Center (IDRC) due to being charged with drunk driving. This unique setting was proved to be an effective place to educate about the dangers of consuming alcohol during pregnancy.

In addition, the outreach program coordinated the FASD Task Force's public education campaign. Staff also conducted school-based FASD education, with an estimated 1,500 high school student's participation. The Community Education Outreach Program also sponsors the Pregnant Pause event in Atlantic County that is conducted in partnership with Toys-R-Us, a national kids store for children, toddler and baby toys and more.

- 6. "Heads Up for Safety"** is a broad-based public education effort sponsored by the Epilepsy Foundation of New Jersey. The purpose of the program is to increase public and professional awareness of preventable head injuries by promoting the use/wearing of helmets when riding a bicycle, scooter, skateboard, and in-line skates. A statewide poster contest is held in schools across New Jersey. The posters are then displayed at the New Jersey Education Association's annual convention and teachers vote for the best poster. A ceremony is held at the New Jersey State House to honor the poster-winning students, their families and their teachers. An estimated 1,000 children participate in the contest. **"Heads Up for Safety"** is part of a national initiative and also sponsors a website.

Small Grant Public Education Demonstration Programs

The OPDD provides small grants to four community agencies that are developing, implementing and evaluating new models of prevention education. OPDD grants focus on unintentional injury prevention programs. Three of the demonstration projects funded by these grants are primarily urban based, while the fourth project focuses on a rural area of the state.

Operation Safe Actions For Everyone (S.A.F.E.), sponsored by The Arc of Warren County, is educating children in Warren County, ages 4 – 14, about ways to prevent unintentional injuries. The program components include:

- An age appropriate puppet show for children, some preschool through second grade children
- A Game of Life for students in grades three (3) through eight (8)
- Providing material and support to schools, and other entities, which participate in **Operation S.A.F.E.**
- Distributing bike helmets and booster safety seats to low-income families
- Participating in community safety events

Safe Sitter, targets youth between ages of 11 - 13 to teach them about safe and nurturing child care techniques, with the goal of reducing the risks of unintentional childhood injuries. Sponsored by the Central New Jersey Maternal and Child Health Consortium, this nationally recognized program has recruited adolescent's participation from the Trenton Public School District, the New Brunswick Public School District and the Boys and Girls Club of Perth Amboy. Many of these adolescents are responsible for caring for their younger siblings after school. The **Safe Sitter** program has been adapted to address issues associated with inner city latch key children.

The Safety Ambassador Program is a cross-age tutoring intervention in which 11th and 12th grade students teach first and second grade students about injury prevention and risk awareness. The program, which is sponsored by the Robert Wood Johnson University Hospital Level One Trauma Center, began with a "Safety Summit" at RJW University Hospital in New Brunswick in October, 2009. Approximately 100 students from several Middlesex County high schools attended this kick-off event. At the Safety Summit, the adolescents were trained about injury prevention and safety. Pairs of high school students then developed lesson plans that they delivered over the past year to a total of about 5,000 Middlesex County elementary school students. At the end of the school year, a Recognition Assembly was held for the Safety Ambassadors.

Safety Education for Child Pedestrians is sponsored by the New Jersey Trauma Center - Level One Trauma Center, UMDNJ - New Jersey Medical School. One of the Trauma Center's programs, the Pedestrian Injury Prevention Partnership (PIPP), is partnering with elementary schools in Newark to educate children, ages 5 – 12, about pedestrian safety. The "Safety Education for Child Pedestrians" program uses a standard curriculum entitled "WalkSAFE" to accomplish this goal. Information about pedestrian safety also is disseminated to schools for home delivery and family use/education.

Small Grant Public Education continued...

Table 1 provides a summary of all the educational and prevention-related events that were supported by OPDD:

AGENCY	ISSUE	AUDIENCE	# OF PERSONS
OPDD	FASD	- Medical students, Health professionals	2,000
	Lead	- Preschool teachers, children	1300
	Train-the-Trainer	- Health & Social Service professionals	500
Coalition for Prevention	FASD Pregnant Pause	- High school students, young adults	5,000
	Quarterly Newsletter	- Health professionals, Educators	10,000
	Lead Toolkit	- Preschool Educators	1,000
	Injury Prevention	- Children, Educators	1,000
Safe Kids	Unintentional Injuries	- Children, Parents, Professionals	10,000
Child Health Month	Child Health Resource	- Parents, Health Professionals	1,000
	Healthy Lifestyles Newsletter	- Parents, Educators	10,000
	Families Toolkit	- Parents	5,000
Rutgers Family Life Ed.	Adolescent Issues	- Adolescents, Teachers	500,000
Epilepsy Foundation	Brain Injuries	- Students, Teachers	2,000
The Arc of Atlantic Cty	FASD	- Students, Educators, Drunk Drivers	1,500
The Arc of Warren Cty	Injuries, Child Abuse	- Children, Teachers	3,000
UMDNJ - NJMS	Pedestrian Injuries	- Children, Teachers	3,500
CNJMCHC	Baby Sitting Safety	- Adolescents	100
RWJ Trauma Center	Injuries	- Adolescents, Children	5,000