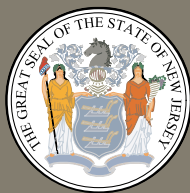




Governor's Council on the Prevention of Developmental Disabilities FY 2014 Report



State of New Jersey
Department of Human Services
Division of Developmental Disabilities

Chris Christie, Governor
Kim Guadagno, Lt. Governor
Elizabeth Connolly, Acting Commissioner

Governor's Council on the Prevention of Developmental Disabilities Report for Fiscal Year 2013

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 serves as an advisory body to the OPDD and makes recommendations to the Commissioner of the Department of Human Services regarding policies and programs to reduce or prevent the incidence of developmental disabilities in New Jersey.

The Council is comprised of twenty-five public members, who are appointed by the Governor. Members serve a three-year term. The Commissioners or their designees of the Departments of Human Services, Community Affairs, Education, Health and Environmental Protection, as well as the Secretary of State, serve as ex officio members. The Commissioners of the five departments sign an annual Interagency Agreement to participate on the Governor's Council and to work collaboratively with, and in support of, the OPDD.

Pursuant to Public Law 1987, Chapter 5, and amended by Public Law 2000, Chapter 82, the Council reports annually to the Governor and the Legislature concerning the status of prevention programs in the State.

FY 2014 Activities

The Council met quarterly during Fiscal Year (FY) 2014. The Council and OPDD continue to collaborate and monitor New Jersey's developmental disability prevention programs throughout the state. Efforts have included field visits, project meetings, and presentations to the Council by State and other institutions working in the field of prevention (see Appendix A). In FY 2014, the Council focused on the following projects:

1. Partners for Prevention Statewide Summit

The second annual Partners for Prevention Statewide Summit was held at the PSE&G Children's Specialized Hospital in New Brunswick, New Jersey on January 30, 2014. Seventy-six people were in attendance representing a variety of stakeholders such as: advocacy groups; health professionals; prevention programs; New Jersey Department of Health and Department of Human Services; disability specific organizations; and families. There was a proclamation read from Governor Christie in recognition of National Birth Defects Prevention Month and a letter was read from Congressman Leonard Lance regarding his work on The Premie Reauthorization Act.

The agenda included panel discussions on the following topics:

◆ Nutrition and Exercise

Michelle Brill, MPH, *Family and Community Health Sciences Educator, Rutgers University*

Garima Jain, Family Resource Specialist, Statewide Parent Advocacy Network

Peri L. Nearon, MPA, Director, *External Affairs & Strategic Initiatives, New Jersey Department of Health Division of Family Health Services*

◆ Genetics

Robin Godshalk, MS, MHA, CGC, *Genetic Counselor, Morristown Memorial Hospital*

George Lambert, MD, *Governor's Council for the Prevention of Developmental Disabilities, State of New Jersey*

Michael K. McCormack, Ph.D., FACMG, *Professor of Pathology, Rowan-SOM and Professor of Psychiatry, Rutgers-RWJMS, Chair, Governor's Council for Prevention of Developmental Disabilities, State of New Jersey*

◆ Toxins

Mike Gallo, PhD, DABT, *Fellow ATS Professor of Toxicology and Pharmacology Department of Environmental and Occupational Medicine, Rutgers-Robert Wood Johnson Medical School*

Mark A Maddalon, DPH, DABT USEPA- Region 2 Toxicologist

Gloria B. Post, Ph.D., *DABT Research Scientist, Office of Science, New Jersey Department of Environmental Protection*

In addition to the panel discussions, the barriers and challenges that healthcare providers see as part of their daily practice were highlighted. Edwin Guzman, MD, Chair, Department of Obstetrics and Gynecology, Saint Peter's University Hospital shared provider perspectives. Gary Weitzen, Director, Parents of Autistic Children shared his journey as the parent of child with autism spectrum disorder, including obstacles encountered by families when attempting to access services. The keynote address was presented by Susan Adubato, Ph.D., former Director of the Northern New Jersey Fetal Alcohol Spectrum Disorders Diagnostic Center, Rutgers University – New Jersey Medical School. Dr. Adubato received a commemorative plaque recognizing her lifelong contribution to educating health professionals, families and the community about fetal alcohol syndrome.

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

Fetal Alcohol Spectrum Disorders (FASD), a developmental disability resulting from alcohol consumption during pregnancy, is 100% preventable. The mission of the New Jersey Task Force on Fetal Alcohol Spectrum Disorders and other Perinatal Addictions is to provide education regarding the causal relationship between the consumption of alcohol and other substances during pregnancy and the incidence of Fetal Alcohol Spectrum Disorders (FASD), and to promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

The NJ Task Force on FASD met in July and December, 2013 and March, 2014.

The following topics of discussion and action items occurred during the course of FY 2014:

- ◆ Rutgers Center of Alcohol Studies – The Center offers continuing education classes, a summer institute, and state funding for some licenses. They work with the Certification Board, as well. The Center is working with the NJ FAS Education and Training Center to provide an FASD Certification program, as well as on-line courses. Laura Fenster Rothschild, Psy.D., Educational Director for the Center of Alcohol Studies, discussed Center programs and opportunities for partnership between the Center and the Task Force.
- ◆ 2013 FASD Professional Summit – The NJ Task Force on FASD assisted in the planning and promotion of this nationally recognized Summit. (See details below.)
- ◆ Be In the Know Five-Year Strategic Plan – The following subcommittees met to discuss goals associated with FASD education; treatment of individuals with FASD; screening of women at high risk for alcohol-exposed pregnancy; and the use of social media to expand knowledge of FASD. The following high-priority issues were identified:
 - Revision of the *Be In The Know* Five-Year Plan
 - a. Task Force discussion focused on prioritization of goals and objectives; upcoming activities; and review of objectives and activities that have been completed and/or are currently underway through funded projects such as the Perinatal Addictions Prevention project and the FASD Diagnostic Centers.
 - b. Professional education and consumer education were identified as priority activities.
 - i. Professional groups targeted for training include providers of Early Intervention services (PT, OT, Speech, Behavioral), and Mental Health and Child Behavioral Health service providers.
 - ii. Training topics include:
 - ▶ How to recognize FASD as a possible diagnosis
 - ▶ What Works (treatment guidelines ie: Families Moving Forward)
 - ▶ Effects of Alcohol on the Central Nervous System (infant, toddler, young child)
 - ▶ Family Education Strategies
 - iii. Workshop formats including expert panels

3. 2013 FASD Professional Summit - BACK (AND) TO THE FUTURE: 1973-2013 - 40 years of prenatal alcohol exposure and FASD

Members of the Council were involved actively in the planning and promotion of this event, which celebrated the 40-year anniversary of the foundational clinical reports regarding Fetal Alcohol Syndrome (FAS) by Drs. Kenneth Jones and David Smith, in 1973. Held at the Atlantic City Convention Center September 26-27, 2013, this premier event provided an overview of the historical context and international research regarding prenatal alcohol exposure and FASD. It also included a detailed explanation of the brain damage that occurs as a result of prenatal alcohol exposure. Presenters reviewed gender-related issues and interventions for women who use alcohol prenatally. Additionally, event participants were educated about the most recent findings in the special topic areas of nutrition, intervention with young children, and criminal justice.

Summit attendees included: physicians, medical students, nurses, social workers, psychologists, psychiatrists, allied health personnel, addiction prevention and treatment providers, child welfare, administrators, school personnel, legal and justice systems personnel, families and individuals living with FASD, and professionals who work with families.

Summit Presentations

- ◆ *The Fetal Alcohol Spectrum Disorder: 35 Years and Beyond*
Kenneth Lyons Jones, MD
- ◆ *Prenatal Alcohol Use: Identification and Intervention*
Grace Chang, MD
- ◆ *FAS: Beyond Morphology*
Luther Robinson, MD
- ◆ *FASD and Nutrition: Fueling Protection and Recovery against the Damaging Effects of Prenatal Alcohol Exposure*
Jennifer Thomas, Ph.D
- ◆ *Identification and Treatment of FASD in Young Children*
Claire Coles, Ph.D.
- ◆ *Special Topics in FASD for Adolescents and Adults: Forensic Assessment*
Natalie Novick Brown, Ph.D.

Summit Workshops

- ◆ Integrating CHOICES in Your System of Care
- ◆ Communicating About Alcohol Use During Pregnancy and FASDs Through Social Media: Making It Work For You;
- ◆ FASD Through the Lifespan: Changing Presentations, Changing Interventions;
- ◆ Working More Effectively with Families

4. Interagency Task Force on the Prevention of Lead Poisoning

Lead remains the leading environmental threat to the health of New Jersey's children. As the most densely populated state, New Jersey has an extensive industrial heritage that has put residents at higher risk for lead poisoning as a result of substantial levels of lead contamination. The mission of the New Jersey Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) is to:

- ◆ reduce childhood lead poisoning;
- ◆ promote lead-safe and healthy housing;
- ◆ support education and blood lead screening; and
- ◆ support interagency collaboration.

Lead Task Force members include representatives from state agencies charged with addressing the health and environmental problems caused by exposure to lead, including the Departments of Human Services, Community Affairs, Environmental Protection, and Health. The U.S. Environmental Protection Agency, UMDNJ (now Rutgers University), and many local public health, housing, and social service agencies also participate on the Lead Task Force. Notably, the Lead Task Force was responsible for the Department of Health's New Jersey Child Lead Poisoning Elimination Plan, for which New Jersey received lead prevention funds from the U.S. Centers for Disease Control and Prevention (CDC).

In FY 14, members of the Lead Task Force continued their participation in Superstorm Sandy recovery work. \$13.2M in funding from the New Jersey Department of Human Service's Social Services Block Grant, Superstorm Sandy Recovery, was appropriated to support New Jersey Department of Health related projects from September 1, 2013 through June 30, 2015. Projects include public education and professional development; targeted blood lead screening; and support of HomeTrax, a centralized repository of data regarding housing hazards that may impact residents' health, including lead-based paint.

In FY 14, the Lead Task Force also addressed and/or participated in:

- ◆ Childhood Lead Poisoning Prevention Week (October 21-27)
- ◆ Updates from State of New Jersey Departments in receipt of Superstorm Sandy Recovery funding from HUD (Community Development Block Grant) and DHHS (Social Services Block Grant)
- ◆ NJ Department of Health, Division of Family Health Services, Child and Adolescent Health Program, Child Health, for Lead Poisoning Prevention and Healthy Homes \$13,216,900
 - Public Education and Professional Development (a series of mini presentations for members of the general public; full-day trainings for home visitors/inspectors; outreach to primary care providers)
 - Targeted Blood Lead Screening (use of LeadCare II point-of-care blood lead analyzers; funding for case management/environmental investigation of children with lead poisoning; outreach to households with children identified as having blood lead levels 5-9 ug/dL)
 - Healthy Homes database (to note housing conditions and occupant behaviors, referrals to community-based resources)

5. Office for the Prevention of Developmental Disabilities Grant Funding

Following a conflict of interest vetting process, a number of Council members volunteered to serve on an Office for the Prevention of Developmental Disabilities (OPDD) Request For Proposal subcommittee, which reported to the Division of Developmental Disabilities (DDD) regarding the strength of submitted proposals. Subcommittee member expertise was an important component to the proposal review process and assisted DDD in recognizing best practices and important issues impacting the prevention of developmental disabilities.

Office for the Prevention of Developmental Disabilities (OPDD)

Based in the Department of Human Services' Division of Developmental Disabilities, the Office for Prevention of Developmental Disabilities (OPDD) works with the Council and its Task Forces. OPDD is charged with implementing, monitoring and evaluating community prevention education programs that receive support from its annual state appropriation.

Funding for Prevention Initiatives

The OPDD funds partner agencies to engage in prevention education activities. The following programs were funded during FY 14:

- 1. Safe Kids New Jersey** (Central Jersey Family Health Consortium) (Service Area: Statewide) Safe Kids New Jersey is a program intended to decrease the death and disability rates due to unintentional injury in children ages 14 and under. Program initiatives addressed the most serious accidental risk areas for children including motor vehicles (Children In and Around Cars); pedestrian safety (Walk This Way); all-sports helmet safety (Heads You Win); drowning prevention (Kids Don't Float); sports and play injury prevention (Get Into the Game with Safety); and safety in the home (Home Safe Home).

Grant amount - \$125,000

- 2. Safety Ambassador** (Robert Wood Johnson University Hospital, Level I Trauma Center) (Target populations: elementary [1st and 2nd grade] and high school [11th and 12th grade] students in Middlesex County) This school-based injury prevention program was intended to address traumatic brain injury. It provided students with the knowledge, skills and understanding necessary to become safe and responsible citizens, through the use of educational methodologies and practical exercises that heighten awareness of the potential for traumatic brain injury. It also included prevention strategies to decrease unintentional childhood injuries related to transportation and falls among elementary school participants.

Grant amount: \$43,240

- 3. The New Jersey Fetal Alcohol Spectrum Disorders (FASD) Education and Training Center** (Rutgers-NJMS) (Service Area: Statewide) This program provided trainings for medical and allied health personnel on prenatal alcohol exposure and Fetal Alcohol Spectrum Disorders. The focus was education and intervention for women of child-bearing age, and early diagnosis where exposure to alcohol has already occurred. The program maintained the beintheknownj.org website. An on-line course and Certificate program was also piloted.

Grant amount: \$124,640

- 4. Operation Stop Think & Act Responsibly** (The Arc/Warren County Chapter) (Service Area: Warren, Sussex, Hunterdon, and Morris counties) This project focused on low-income preschool children and pregnant women with the goal of educating participants about preventing and reducing the occurrence of intellectual and developmental disabilities. Strategies included the distribution of safety devices to low-income families. Activities included puppet shows targeting the prevention of unintentional injuries to children in Head Start programs, day cares and elementary schools. Middle and high school children were educated about the prevention of FASD and TBI/Secondary Impact Syndrome. Home Visitor volunteers provided information about the prevention of FASD and other related topics that can lead to intellectual and developmental disabilities. Additional materials and information were provided regarding drug use and smoking. Training to athletes/coaches about Secondary Impact Syndrome was provided through a conference/in-service. Bike helmets and car booster safety seats were also distributed to families who are at 100% of the federal poverty level.

Grant amount: \$40,000

- 5. Back to Basics – Childhood Lead Poisoning Prevention** (Family Health Initiatives) (Service Area: Cumberland, Salem and Atlantic Counties) The intention of this project was to reduce the incidence of developmental and cognitive disabilities due to exposure to paint and non-paint lead sources found in and around the home among its target audience of pregnant women and children (newborn – age 5). The agency focused on doing this through the delivery of childhood lead poisoning prevention education to pregnant women and parenting families. A primary tool utilized in this endeavor was a renovated tobacco control education vehicle, redesigned to resemble the interior of a home that family members could enter and interact with. The van contained multiple examples of traditional and non-traditional lead hazards found in and around the home. The agency also conducted lead safe home repair workshops and educated pregnant women living within Atlantic City on the identification and reduction of potential harm from lead hazards in the home. Additionally, the agency developed a new “Partnership Against Lead” collaboration with at least 10 family day care providers.

Grant amount: \$80,000

- 6. Get the Lead Out (GLO)** (The Arc/Warren County Chapter) (Service Area: Warren, Sussex, Morris and Hunterdon Counties) The goal for GLO was to educate pregnant women, expecting fathers, women of child bearing years and children between pre-school and 2nd grade about the prevention of lead poisoning. Participants were provided with age appropriate prevention information to reduce the incidence of intellectual and developmental disabilities caused by lead poisoning. The agency presented puppet shows targeting the prevention of lead poisoning to children in Head Start programs and day cares in Warren, Sussex, Morris and Hunterdon Counties. Education was provided to Home Visitor Volunteers about the prevention of lead poisoning that can lead to intellectual and developmental disabilities. Additional instruction was given to pregnant women, expecting fathers and women of child bearing years at WIC offices and other forums that cater to expecting parents. Lead detection test kits were also provided to low-income families.

Grant amount: \$18,363

- 7. Dangers of Lead Exposure** (Partnership for Maternal and Child Health of Northern NJ) (Bergen, Passaic, Essex, Hudson, Morris, Union, Sussex and Warren Counties) The purpose of this project was to reduce the incidence of intellectual and developmental disabilities caused by lead exposure during pregnancy and childhood. The agency provided small group lead education workshops to pregnant women, and lead poisoning prevention information via the web and social media.

Grant amount: \$40,000

- 8. Educating Health Providers on Communication of Prevention Messages** (Statewide Parent Advocacy Network (SPAN) (Service Area: Statewide) The purpose of this project is to strengthen the capacity of at least 50 healthcare provider practices (including at least 15 Federally Qualified Health Centers) to effectively communicate culturally, linguistically, and socio-economically relevant prevention messages to their female patients of childbearing age (especially those women at greatest risk of having a child with birth defects/developmental disabilities), with the long-term goal of positively impacting the behavior of such women in ways that reduce birth defects that cause developmental disabilities. Trainings are delivered to healthcare providers, including FQHCs, in their offices. Follow-up education is conveyed via webinars and other informational resources to women and members of the public.

Grant amount: \$125,000

- 9. Fortify Your Future/Fortifique Su Futuro** (Spina Bifida Resource Network) (Service Area: Statewide) This project raises awareness among adolescent girls and young women of childbearing age, especially in Hispanic communities, of the need for Folic Acid and other vitamins before becoming pregnant. This agency provides bilingual educational materials to girls and young women with special emphasis on reaching Hispanics/Latinas. The importance of Folic Acid is emphasized. Recipes for traditional dishes are provided that include folate rich foods. The staff at health centers, clinics and other organizations serving women particularly Hispanics/Latinas are trained about the benefits of Folic Acid.

Grant amount: \$52,412

- 10. Latina Group Pregnancy Program** (Hunterdon Medical Center Foundation) (Service Area: Hunterdon County) The purpose of this project is to increase access to prenatal care and increase positive birth outcomes. The agency engages at-risk, pregnant Latina women in Hunterdon County. Women are grouped into cohorts. Each cohort meets as a group at Philips Barber Family Health Center for all prenatal care. Each prenatal session includes a medical exam and participants are taught evidence-based health information in a discussion format.

Grant amount: \$35,000

- 11. Parents Learning And Nurturing (PLAN) Program** (Jewish Family & Children's Services of Greater Mercer County) (Service Area: Mercer County) This project provides in-depth information and education to at-risk, expecting Latino parents about preventing intellectual and developmental disabilities. A new component to the existing parenting program will include information regarding how to reduce the incidence of intellectual and developmental disabilities in children. Information includes: genetic testing, Folic Acid, nutrition, smoking, alcohol, safe medications, vaccination and the importance of immunization, lead, and the prevention of head injuries including sport safety.

Grant amount: \$16,560

Appendix A

Presentations to the Governor's Council on the Prevention of Developmental Disabilities

6/11/2014

- ◆ *Advances in Understanding the Genetics of Autism/Related Disorders*
Dr. Linda Brzustowicz , Rutgers University Department of Genetics

3/12/2014

- ◆ *CJFHC "Safe Kids" Program*
Carol Ann Giardelli, Central Jersey Family Health Consortium

12/11/2013

- ◆ DOH Reproductive and Perinatal Health Grants
Sandra Schwarz, NJ Department of Health

9/11/2013

- ◆ *Newborn Metabolic Screening*
Scott Shone, NJ Department of Health Newborn Screening
- ◆ *Robert Wood Johnson Level 1 Trauma Presentation*
Diana Starace & Carol Lavitt, Robert Wood Johnson Level 1 Trauma Center

Governor's Council on the Prevention of Developmental Disabilities FY 2014 Membership

Government Representatives

Dawn Apgar, Ph.D., LSW, ACSW	Department of Human Services
Sandra Schwarz, RNC, MS	Department of Health
Kathleen Ehling, MAT, JD	Department of Education
Alice D'Arcy, PP/AICP	Department of Community Affairs
Gloria Post, Ph.D., DABT	Department of Environmental Protection
Elizabeth Vouk	Department of State

Public Members

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2. Jeananne Arnone, RN, BS
3. Thomas Baffuto
4. Deborah Davies, Ph.D.
5. Mary DeJoseph, DO
6. Carol Ann Hogan, M.S. Ed.
7. William Holloway, Ph.D.
8. George Lambert, MD
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17. Deborah Spitalnik, Ph.D.
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20. Jean Wiegner
21. Leon Zimmerman
22. Ilise Zimmerman, MS

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