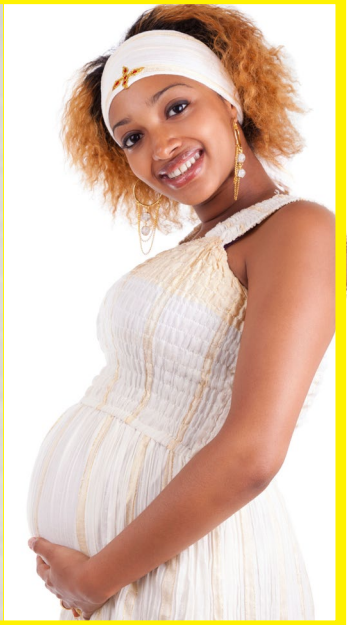

Governor's Council on the Prevention of Developmental Disabilities

FY 2015 Report

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

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

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Governor's Council on the Prevention of Developmental Disabilities

Report for Fiscal Year 2015

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 2015 Activities

During Fiscal Year (FY) 2015, the Council continued its successful work. It met quarterly during 2015. 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 2015, the Council focused on the following projects:

1. Newborn Screening

Led by Council Chair, Dr. Michael McCormack, Council members reviewed, discussed and supported the activities of New Jersey's Newborn Metabolic Screening Advisory Committee. Six additional genetic diseases have been added to the list of diseases screened under Emma's Law. Emma's Law mandates testing for Krabbe, Pompe, Gaucher, Niemann-Pick and Fabry. With the addition of the new diseases, New Jersey now tests for 60 different types of genetic disorders.

2. Current Issues in Prenatal Care & Developmental Disabilities

Council members identified and started to consider action steps to help improve the quality of prenatal care experienced by women in the State of New Jersey. Several guest speakers presented information on issues impacting the health of pregnant women. The following topics were reviewed:

- Prenatal screening techniques that are currently being utilized such as Non-Invasive Prenatal Testing (NIPT)
- Information provided to obstetric patients to promote healthy pregnancies. How are women receiving this information? "Text for Baby" cited as a good example of an App that has become popular and has the potential to improve outcomes for expecting mothers and young children.
- Fetal Alcohol Spectrum Disorders (FASD) and the number of OB/Gyns that continue to tell their patients that they may consume some alcohol during pregnancy.
- General discussions regarding the kind of information that is provided to OB patients and how that information is related to them.
- Neural tube defects and the importance of taking folic acid daily and eating a healthy diet of fortified and folate rich foods, prior to conception and throughout the first trimester.
- Addressing low income pregnant women's needs for basic necessities (housing, food, employment, etc.) is a critical component prior to starting intensive prenatal programs.
- Latinas not having adequate amounts of folic acid. Culturally sophisticated interventions, often using effective agency partnerships, can help address nutrition risk factors.
- Possible link between autism and traffic pollution. Following a review and discussion of current research, Council members agreed that more research is needed to draw any cause/effect conclusions.

3. New Jersey Task Force on Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions – Council Subcommittee

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 (FASDTF) 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 FASDTF met twice in July and once in November, 2014 as well as once during May, 2015. Conference calls occurred in September and October, 2014 and February, March and May of 2015.

The FASDTF reviewed their scope of work and decided to focus upon some specific, achievable aspects of the five year strategic plan rather than try to work on everything mentioned in the document. The following issues and initiatives were determined to be priority work items by the FASDTF:

- Facilitate action to disseminate and create awareness around the revised "A Pregnant Woman Never Drinks Alone" poster/flyer. This flyer was updated by the New Jersey Department of Health and is required by law to be posted in liquor stores as well as bars and restaurants in the state. It is also distributed to businesses by municipal health offices. The FASDTF identified and started to develop activities, including consumer education, in order to promote public awareness of the poster.
- Planning for FASD Awareness Day: 9/9/15. The National Organization on Fetal Alcohol Syndrome (NOFAS) Toolkit was used to provide guidance and content for these efforts. Input and ideas from the FASDTF helped Council leadership to best utilize the awareness activities described in the tool kit. Support from the Department of Human Services communications department was an important planning component.
- Introduce and connect the Task Force to regional winery associations and local breweries in order to address public awareness objectives. During FY 15, FASDTF members connected with the Southern NJ regional winery association. Although the association does not allow outside speakers at their meetings, they agreed to accept information that would be shared with members. Future small group work will focus on providing materials to share with these groups.
- The FASDTF reached out to the FASD Task Force in New Mexico for information about their successful FASD Prevention Beverage Coaster campaign in Albuquerque, which engaged bar owners. They are willing to share their design for a fee if the FASDTF should decide to duplicate this endeavor in NJ. The FASDTF, however, may wish to design its own coasters. The FASDTF identified the idea of possibly partnering with some of the state alcoholic beverage producers on this type of initiative.
- The FASDTF utilized links from the Department of Health to aid in the distribution of the National Birth Defects Prevention Packet.
- The FASDTF made plans around educating Early Intervention Treatment Providers. Webinars were identified as a possible educational forum. The training should be geared towards treatment modalities.
- Pursue inclusion of workshops on FASD at NJ Prevention Network Conference in March 2016.

4. Interagency Task Force on the Prevention of Lead Poisoning

Lead remains one of the leading environmental threats to the health of New Jersey's children due to an extensive industrial heritage and high proportion of pre-1978 housing. Lead was banned for residential use in 1978. The immediate impact of lead can be profound and may have multigenerational effects. 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, Rutgers University, and many local public health, housing, and social service agencies also participate on the Lead Task Force.

In FY 15, the Chairperson of the Lead Task Force, Crystal Owensby, Department of Health (DOH), met with the Governor's Council for the Prevention of Disabilities to review current lead issues impacting the State of New Jersey.

The following was discussed:

- Ms. Owensby updated the Council regarding DOH's Superstorm Sandy recovery work to educate residents, train professionals, and provide blood lead screenings and dust/soil sampling in nine of the most-affected counties.
- In February 2015, the NJ DOH commenced the rulemaking process to amend NJAC 8:51 (Childhood Lead Poisoning) and NJAC 8:51A (Screening of Children for Lead Poisoning). Specific public health interventions for lower blood lead levels (e.g. 5-9 µg/dL), which currently are not covered under regulation have not been determined. To date, the Federal Centers for Disease Control (CDC) has not issued recommendations on how to intervene at levels less than 10 µg/dL. Council Chair, Dr. Michael McCormack, requested that the Council be notified when the public comment period commences.
- Ms. Owensby clarified some points made in the February 28, 2015, Asbury Park Press article "Schools unaware of lead-poisoned kids". It is true that the NJ DOH does not notify schools of lead poisoned children. However, current forms used in childcare settings (CH-14 Universal Child Health Record) and schools (A-45 Health History and Appraisal form), as well as the IMM-8 (Standard School/Child Care Center Immunization Record) have designated space for a healthcare provider to include blood lead testing results.
- The NJ DOH provided comment on Senate Bill No. 2650, which calls for: a) documentation of students' blood lead test histories for entry into school or child care; b) school districts to adopt written policies for parent/staff education and teaching staff instruction on the effects of childhood lead poisoning; c) referral for special education services and enrichment opportunities for children with a blood lead level 5 µg/dL or greater; d) NJ DOH to identify children with blood lead levels 5 µg/dL or greater for referral to the NJ DOH's Early Intervention System; and e) ability to run reports on lead screenings by geographic location and kindergarten cohort. Ms. Owensby described the pros and cons of the legislation. For example: A lead poisoned 2 year old would not be considered lead poisoned if his/her blood lead level (BLL) has reduced to less than 10 µg/dL at age 6 upon entering school. However, since lead is a neurotoxin and has permanent effects, these effects may not be seen until the child enters the school/preschool setting (e.g. behavioral problems, learning disorders, developmental delays). Therefore, any child entering school that has a history of lead poisoning, regardless of the age at poisoning, should be assessed for special education services. As a lead poisoned 2 year old, the child would have been referred by the local health department performing case management to a local early intervention program (for ages birth-3 years) for assessment of service needs, and if indicated, entered into special child health services for the receipt of additional services.
- The NJ DOH as of October 2014, was awarded CDC funding to use surveillance data to guide local childhood lead poisoning primary prevention activities.
- Lastly, Ms. Owensby shared promising legislation (A2325 and S1279) that would make supplemental grants in aid ($10 million) in the form of an appropriation for the Lead Hazard Control Assistance Fund to DCA. This would reinstate the needed financial resources to allow the expedited abatement of residential units cited for lead hazards per NJAC 8:51 and related relocation of the household while the work is completed. As of June 25, the bill was passed by the Senate (28-9) and forwarded to the Assembly.

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 (RFP) subcommittee, which reported to the Division of Developmental Disabilities (DDD) regarding the strength of proposals that were submitted in response to the OPDD annual RFP. Subcommittee member expertise was an important component of 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 works with the Council and its Task Forces to pursue their common charge; the prevention of developmental disabilities in the State of New Jersey. One of the OPDD's tasks is implementing, monitoring, and evaluating community prevention 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 15:

1. **Rutgers, Center of Alcohol Studies –** $124,992 – This program was intended to develop and implement a multi-tiered approach to provide education and resources in the area of FASD to early childhood educational teams, including daycare providers, classroom teachers, and school nurses. These entities will increase their knowledge of the range of presentations of FASD, their ability to identify warning signs, their efficacy making proper referrals for assessment and diagnose and make the proper referrals for treatment. This is intended to increase the educational team's ability to provide in-school support for students with a potential diagnosis.
2. **Jewish Family and Children's Services of Greater Mercer County –** $40,000 – Year 2 of Parents Learning and Nurturing (PLAN) program. This program provided women of childbearing age, their partners, and the health care professionals who serve them with bilingual (English & Spanish) education and training on the prevention of preventable developmental disabilities. PLAN has three main components: outreach and education, development of a formalized bilingual curriculum that can be replicated, and a media campaign targeting Spanish language public access television programs.
3. **Statewide Parent Advocacy Network (SPAN)** – $125,000 – Year two of this project provided training and follow-up support to 75 healthcare provider practices, including at least 25 Federally Qualified Health Centers (FQHCs) and at least two practices in every county, to strengthen their capacity to effectively communicate effective prevention messages to diverse women of childbearing age and their commitment to communicating such messages to their patients on an ongoing basis as part of routine care. It also connected at least 75 diverse women, needing assistance in implementing health promotion/prevention actions, to support from Family Resource Specialists, aimed to improve birth outcomes and reduced risk of developmental disabilities.
4. **Spina Bifida Resource Network** – $52,412 – The purpose of the second year of Fortify Your Future/ Fortifique Su Futuro was to raise awareness among older teens and young women of childbearing age, especially in Hispanic communities, of the need for folic acid and other vitamins before becoming pregnant. Young women received educational materials on the benefits of folic acid for better health and preventing birth defects, along with recipes and other information on preparing healthy, folate-rich meals for different cultures.

5. **Hunterdon Medical Center Foundation** – $35,000 – This second year project targeted at-risk pregnant Hispanic/Latino women residing in Hunterdon County, NJ and helped them obtain early and adequate prenatal care. The program provided early coordinated medical care and educated mothers about health topics that influence a positive pregnancy, delivery, healthy child, and a strong family unit in a group setting, which provides a comfortable and supportive environment. The goals of the program were to increase access to early prenatal care and to increase positive birth outcomes.

6. **Family Guidance Center, Prenatal Screening Project** – $98,263 – This is a program expansion of a Division of Mental Health and Addiction Services' project through which prenatal clients are screened by Family Guidance Center counselors. Clients are screened for substance abuse, tobacco use, and domestic violence using the Perinatal Addictions Prevention Project screening tool (4 P's Plus). Once a problem is identified during the screening, further assessment is conducted. Along with the 4 P's Plus, each opened patient has the following assessments completed as needed: Addiction Severity Index (ASI), Level of Care Index (LOCI), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), Mood Disorder Questionnaire (MDQ), Alcohol Use Disorders Identification Test (AUDIT), Drug Abuse Screening Test (DAST), and a tobacco assessment. Also available to further assess patients who smoke are a carbon monoxide monitor to measure the level of carbon monoxide in the patient's breath and a device to measure the patient lung age. These monitoring tools are used to assist the patient with smoking cessation and to provide awareness of the effects that smoking has on the patient's health. Once patients are assessed, if there is a need for a higher level of care for substance abuse or mental health treatment, or if other social service needs are identified the patients are referred to outside agencies. A new additional screening that will be introduced for the FY15 contract is a Lead Screening which will result in a referral for blood testing for individuals determined to be at risk for lead exposure.

7. **Newborn Screening Projects with the NJ Department of Health** – $55,500 – The NJ DOH Newborn Screening Program administered by the Newborn Screening Service (NBS) implemented the following projects:

   - *Newborn Screening education posters for birthing facilities* – Posters that include the NJ Newborn Screening logo surrounded by text in 21 languages that says "Ask about your baby's Newborn Screening tests" were distributed throughout the state.
   - *Translation of pre-test parent information brochure into 21 languages* – Utilizing OPDD funds, pre-testparent educational brochures were translated into 21 languages and were made available on line for on-demand printing by birthing facilities and families. These brochures cover basic Biochemical, Hearingand Pulse Oximetry screening information and are modeled after a general Newborn Screening information brochure developed by the Health Resources and Services Administration (HRSA) in 2013.
   - *Newborn Screening educational material for pediatricians* – Utilizing OPDD funds, the NBS sent this educational material to all of the State's pediatricians, birthing hospitals, and other stakeholders.
   - *Newborn Screening blood spot collection training material for birthing facilities* - An issue faced by all newborn screening programs is the quality of specimens collected by hospitals and doctors. Recently, the Clinical Laboratory Standards Institute (CLSI) released an updated version of their guideline and DVD entitled "Blood Collection on Filter Paper for Newborn Screening Programs" and "Making a Difference Through Newborn Screening: Blood Collection on Filter Paper". Utilizing OPDD funds, the NBS purchased 85 copies of the guideline and DVD for each hospital and midwife practice to use as part of their continuing education for nurses and phlebotomists.
   - *Improving the newborn screening (NBS) specimen transportation and tracking system* – OPDD funds were used to configure and distribute a new tracking system for hospitals. Implementation of this system increases the program's ability to track packages containing NBS specimens and allow for identification of lost packages within 24 hours of shipment. Moreover, the new system will reduce the time from collection of specimens to receipt in the laboratory by defaulting to Saturday and holiday delivery schedules.

8. **Smoking Cessation Project** – $100,000 – This partnership project with the Department of Health Office of Tobacco Control focused on the reduction of smoking in New Jersey. This collaboration supported a two week supply of Nicotine Replacement Therapy (NRT) products to all qualified New Jersey residents and in the future to provide a four week supply of NRT patches to all qualified callers interested in quitting tobacco use. Relapse tobacco use callers were also able to qualify for subsequent NRT kits (four week supply) up to four times a year. Smoking during pregnancy is of particular concern because it can cause tissue damage in the unborn baby, particularly in the lung and brain. Tobacco smoke also contains other chemicals that can harm unborn babies. Mothers who smoke are more likely to deliver their babies early. Preterm delivery is a leading cause of death, disability, and disease among newborns. In addition, one in every five babies born to mothers who smoke during pregnancy has low birth weight. Mothers who are exposed to secondhand smoke while pregnant are also more likely to have lower birth weight babies.

9. **Health & Wellness Guide** – $75,000 – The OPDD supported this Division of Disability Services (DDS) project. This guidebook provides recommendations intended to assist individuals with disabilities on how to live a healthy life. Often people with disabilities are overlooked when it comes to promoting public health communications. Messages of prevention are emphasized in this guide, including accident prevention and healthy choices to prevent illness, addiction and secondary conditions. This guide was distributed at several statewide disability conferences as well as via the DDS website and DHS Facebook page.

10. **Bicycle Helmets** – $27,123 – This statewide project was executed with assistance from the Department of Transportation (DOT) and the Department of Children & Families (DCF). After their first year of life, unintentional injuries are the most common cause of death among children and are the most common way in which children acquire developmental disabilities. Low-income families are less likely to use safety devices such as bicycle helmets, often due to lack of money or lack of transportation to obtain safety devices. Children are at significant risk of dying or becoming disabled due to unintentional injuries. Utilizing OPDD funding, the DOT and DCF distributed 4,515 children's bike helmets at special events in order to promote bike safety and prevent head injuries. These efforts were targeted toward low income communities.

Appendix A

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

6/10/2015

- Evaluation of Fetal Alcohol Spectrum Disorders (FASDs) Using New Jersey's Birth Defects Registry
  Janice O. Okeke, Intern, Department of Health
- Educating Health Providers on Communication of Prevention Messages
  Diana Autin, Malia Corde & Pamela Kelley, Statewide Parent Advocacy Network (SPAN)

3/11/2015

- American Congress of Obstetricians and Gynecologists (ACOG)
  Dr. Thomas Westover, NJ Section of ACOG

12/10/2014

- Understanding the Neuroscience Of Autism
  Dr. Sam Wang, Princeton University Neuroscience Institute

9/10/2014

- Study of Perfluorinated Chemicals (PFCs) in NJ Drinking Water
  Dr. Gloria Post, NJ Department of Environmental Protection
- Latina Group Pregnancy Program
  Dr. Cindy Barter, Hunterdon Medical Center

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