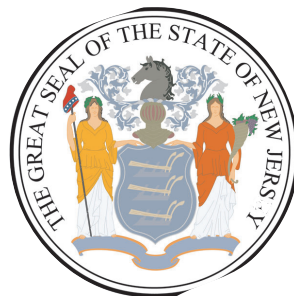




# **Governor's Council on the Prevention of Developmental Disabilities Report for Fiscal Year 2017**



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

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# Governor's Council on the Prevention of Developmental Disabilities Report for Fiscal Year 2017

**T**he 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, and 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 to 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.

Additionally, the Council includes New Jersey State Commissioners, or their designees, of the Departments of Human Services, Community Affairs, Education, Health, and Environmental Protection, as well as the Secretary of State, serving 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.

The Council reports annually to the Governor and the Legislature concerning the status of prevention programs in the state. Without compensation, public members of the Council, in partnership with the members of the FASD and other Perinatal Addictions Task Force and Lead Task Force, imbue this work with a high level of intensity and dedication.

## Fiscal Year 2017 Activities

During Fiscal Year (FY) 2017, the Council met quarterly and continued its effective work. 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 2016, the Council focused on the following projects:

### 1. Current Issues in Prenatal Care & Developmental Disabilities

Council members identified and started to consider action steps regarding matters that can affect the development of children as well as the kind - and quality - of prenatal care experienced by women in the State of New Jersey. Several guest speakers presented information on matters impacting issues of health and support for pregnant women. The following topics were reviewed:

- Fetuses exposed to opiates during pregnancy and neonatal abstinence syndrome (NAS); how New Jersey is confronting this national issue.
- Impact of homelessness on developmental disabilities; review of a statement from the U.S. Department of Health and Human Services, indicating that children growing up in poverty are at higher risk for malnutrition, childhood diseases, exposure to environmental health hazards and often receive inadequate health care.
- Newborn Screening updates pertaining to lists of new disorders recommended for screening in order for New Jersey to be consistent with the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services.
- Promotion of folic acid consumption among women of childbearing age, and a dramatic reduction in the incidence of neural tube defects, birth defects of the brain and spine.
- General discussions regarding the kind of information that is provided to obstetrics patients and how that information is related to them.
- Lead issues in New Jersey, and model programs intended to address the associated concerns of lead exposure.
- Water issues in New Jersey schools.
- Zika Virus updates from the New Jersey Department of Health.

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

Fetal Alcohol Spectrum Disorders (FASD), a developmental disability resulting from a fetus's exposure to alcohol 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 exposure of a fetus to 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 in September and December 2016 as well as during March and June 2017. Conference calls occurred in October and November 2016 and February and March 2017.

The FASDTF regularly monitored news and information pertaining to current research and programs, locally and nationally, regarding FASD. The FASDTF increased awareness in New Jersey about FASD as well as the numerous issues associated with perinatal addiction. During FY17, the following issues and initiatives were determined to be priority work items by the FASDTF:

- FASD Awareness Day/Month started on September 9th, 2016. The FASDTF observed this day and month with a variety of activities and actions intended to create awareness of FASD and maternal health in general. Articles appeared in New Jersey newspapers and on New Jersey news web sites. A number of these articles were authored by or included information provided by members of the Council. A proclamation honoring FASD Awareness Day was obtained from the Governor's office, demonstrating the importance of attending to FASD. A story on FASD was written for NJ Monthly Magazine by a NJ author and focused upon the impact of FASD on a particular family. Members of the Council provided information and feedback to the author for the magazine article.
- FASDTF members continued to provide feedback and support to the Southern New Jersey Perinatal Cooperative, the March of Dimes, and the Maternal Child Health Consortia on their FASD awareness "Coaster Campaign." This project involved the distribution of drink coasters with an FASD awareness message to bars and restaurants in New Jersey in order to promote FASD awareness. An image on the coasters provided a web link to consumer education materials through a QR code. The QR code connected viewers to prevention information on the National Organization on Fetal Alcohol Syndrome (NOFAS) website.
- FASDTF members worked with the Rutgers Center of Alcohol Studies and reviewed and discussed updating the "Be In the Know NJ" website. Progress has been made on developing a basic new design of the website. The OPDD will be exploring options pertaining to the agency or governmental entity that will update the website. Be In The Know NJ plays an important role in advertising and promoting FASD prevention information, FASD prevention activities, and FASD research. FASDTF members will continue to work on this matter in FY 18.
- The FASDTF considers the advancement of continuing professional education as critically important to NJ's plan for addressing FASD. Maximizing opportunities for professional access to free Continuing Education Units CEU's is an important tool. In order to address this training matter, a survey was sent to staff of all NJDOH Child Evaluation Centers to elicit input regarding plans for a professional education session. In partnership with the Department of Health, the FASDTF will develop a half-day seminar to be held in 2017.

### **3. Interagency Task Force on the Prevention of Lead Poisoning**

Lead related issues gained attention in FY 17 in New Jersey and around the nation. Lead remains one of the leading preventable environmental health threats to New Jersey's children due to an extensive industrial heritage and high proportion of pre-1978 housing. Despite its ban for residential use in 1978, lead continues to impact the lives of families. Additionally, local and national news have featured stories about the effect of our aging water delivery infrastructure which has resulted in greater exposure to lead from our water sources.

The immediate impact of lead can be profound and may have multigenerational effects. New Jersey is the most densely populated state in the union and has an extensive industrial heritage. In our state, residents are at higher risk for elevated blood lead levels as a result of substantial amounts 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 in the Lead Task Force.

In FY 17, the Lead Task Force met in September and November 2016 as well as during January 2017. A conference call occurred during December 2016. Crystal Owensby, of the Department of Health (DOH) and Chairperson of the Lead Task Force, connected with the Council during each of their quarterly meetings in order to review current lead issues impacting the State of New Jersey. The following occurred:

- A meeting was held in September of all partner agency representatives. This gathering served as a kick-off meeting of the revitalized Lead Task Force. The agenda included a history of the Task Force; a presentation on mapping done by the DOH/DEP Environmental Public Health Tracking Network; and mentioned the DOH's new awareness campaign (#kNowLEAD) which was launched in late October during National Childhood Lead Poisoning Prevention Week.
- Lead Task Force members signed up for one or more strategic planning committees. These committees were tasked with determining progress made and the current status of activities outlined in the 2004 Elimination Plan of which the Task Force served as an advisory committee to the NJ DOH. In addition, the committees will determine new activities to focus efforts that support the NJ DOH's Population Health Action Team (NJ PHAT). NJ PHAT is comprised of several department Commissioners to ensure health in all policies, leveraging of resources and inter- and intra-departmental collaborations.
- The NJ DOH mapping and analyzing of lead data in collaboration with the NJ Department of Environmental Protection (DEP) for planning and evaluation purposes were reviewed. These mapping efforts have been focused on screening and elevated blood lead level rates, age of housing, and low to moderate income areas by municipality and block group to identify "hot spots". Stakeholders are being asked what data they would like mapped that would be useful to their work (e.g. by Legislative District).
- Notices of proposed rules amendments were monitored, such as:
  - o NJAC 8:51 which proposed that public health actions commence at a single capillary blood lead level of 5 ug/dL or greater (this is a change from a single venous blood lead level of 15 ug/dL or greater OR two venous blood lead levels 10-14 ug/dL).
  - o NJAC 8:51A that proposed that physicians who provide health care to children inform parents/guardians in writing of the blood lead level, its meaning, and how to prevent exposure when the child's blood lead level is 5 ug/dL or greater (this is a change from 10 ug/dL or greater).
- Participated in the #kNowLEAD campaign in which the childhood lead webpage was updated and given a more user-friendly URL name ([www.nj.gov/health/childhoodlead](http://www.nj.gov/health/childhoodlead)).
- Informed the public regarding the U.S. Food and Drug Administration's (FDA) safety warning and the Centers for Disease Control and Prevention (CDC) health advisory regarding the possibility of falsely low test results when venous samples are analyzed on a LeadCare analyzer. LeadCare analyzers provide a test result in 3 minutes and are used at the point of care in such settings as hospitals and provider offices, including some local health departments.

#### **4. Office for the Prevention of Developmental Disabilities Grant Funding**

Council members take part in a conflict of interest vetting process prior to serving on the Office for the Prevention of Developmental Disabilities (OPDD) Request for Proposal (RFP) subcommittee. This subcommittee reports 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)**

The Office for Prevention of Developmental Disabilities is based in the Department of Human Services' Division of Developmental Disabilities and works with the Council and its Task Forces to pursue a 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 17:

#### **1. Youth Consultation Services - \$125,000**

The LifeChoices project is a statewide, intellectual/developmental disabilities prevention and risk reduction project. Goals included:

- Prevention of Fetal Alcohol Spectrum Disorders (FASD)
- Improve teens' and women's understanding of the maternal and fetal harms related to alcohol consumption.
- Identify drinking during pregnancy through screening assessments and conduct brief intervention and/or referral for treatment.

LifeChoices applies Life Course Theory as its model of care for several at-risk target populations along three crucial points of a female's potential reproductive life span: Preconception (sexually active teens); Prenatal (pregnant women); and Inter-conception (first-time mothers who could conceive again).

#### **2. Statewide Parent Advocacy Network (SPAN) - \$124,905**

The project's target population is women of childbearing age, especially women who are pregnant and are at risk of drinking alcohol during their pregnancy. SPAN works to increase knowledge and capacity of at least 100 health care providers, including primary care providers, home visitors, etc., on FASD, the importance of and how to use effective screening tools, and available community resources and supports, through an on-line training course. They continue to improve access to culturally, linguistically, and socio-economically relevant peer-to-peer support for women at risk of alcohol use/abuse and of having a child with FASD in collaboration with community-based providers that serve the most at risk women of childbearing age. Peer-to-peer training is utilized as well as focus groups.

#### **3. Spina Bifida Resource Network - \$53,548**

The primary target population for the Fortify Your Future II program is college students, with a secondary target population of Hispanic and low income young women. This program will change dietary habits to include more healthy and folate-rich foods in order to improve health and to reduce chances of having children with disabilities. Secondly, it also will educate on the dangers of binge drinking and its relation to unintended pregnancies and risk for developmental difficulties. The second target population will include young women in Hispanic communities and low income communities and will augment the existing Fortify Your Future/Fortifique Su Futuro program.

#### **4. Isles Inc. - \$50,000**

This lead poisoning prevention project targets the prevention of lead exposure to newborns and young children through training, testing, remediation, and public education. The project features the training of home visitors, lead testing in lower income households, and public education around the dangers of environmental lead. Lower income families, living in Trenton, are targeted. Isles Inc. intends to train home visitors in the Healthy Homes for Community Health Workers (CHW) course. They plan to support one home visiting organization by training staff members as lead dust sampling technicians and provide additional coaching and support to teach home visiting staff how to address home maintenance issues that may result in lead entering the home environment. Isles also plans to deliver public education to community members regarding lead and other home health issue and how to protect children.

#### **5. Rutgers – RWJ Medical School - \$66,000**

The hypothesis of this project is that folic acid supplementation prior to and during pregnancy changes the risk of autism, that this risk is modified by functional variants in dihydrofolate reductase (DHFR) including the DHFR 19bp intron 1 deletion, and that this risk may further be modified by variants in other folate-related alleles. The results of this study are thought to likely have implications on a number of developmental disorders; specifically, any developmental disorder where folate/folic acid metabolism has been implicated. This may include disorders/conditions such as pre-term delivery, low birth weight, pregnancy loss, neural tube defects, congenital heart defect, and chromosome disorders, as well as autism. Project leaders will use whole genome sequencing data for 500 unrelated individuals available through the Database of Genotypes and Phenotypes (dbGaP) for the first aim. They will use up to 2626 trios (mother, father child) from the Simons Simplex Collection (SSC) that have maternal folic acid supplementation and Genome Wide Association (GWAS) Data genotype data available for the second and third aims.

#### **6. Princeton University Dept. of Psychology & RWJ Medical School - \$50,000**

This project provides funding for the Princeton Baby Lab to purchase an eye blink conditioning apparatus, plus personnel support, in order to measure infant learning processes associated with typical vs. atypical cerebellar functioning. This venture aims to establish extremely early life markers to identify infants at risk for developmental disabilities (DDs) that include language, learning, memory, cognitive, and motor delays and deficits associated with cerebral palsy, schizophrenia, and autism spectrum disorders. This project is intended to increase the accuracy with which young children are identified for screening, evaluation, and enrollment in early intervention services. Using a cohort of infants born prematurely, project leaders will examine anatomical cerebellar development and function, behavioral measures of atypical cerebellar development, and early-life markers of infantile language. Relative to the general population, prematurity confers an increased risk of 4- to 80-fold for a range of DDs. This project aims to identify behavioral and biological markers that separately or in combination will accurately identify, before age 2, one or more subtypes of children at risk for DDs, and evaluate the value of these risk markers or profiles for improving early identification and determination of which individuals would benefit from early interventions.



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**7. New Jersey Institute for Disabilities - \$50,000**

This project will attempt to enhance the knowledge base of residents in Middlesex County who are at particular risk for contracting the Zika virus. The agency intends to do this via community training sessions, engagement with faith based organizations, and utilization of social media, as well as through the distribution of materials. “NOZika” information will be disseminated throughout the community. By bringing awareness of the dangers of the Zika virus and helping the community understand the ways that Zika is spread, this project could help impact the number of children born with developmental disabilities.

**8. Children’s Home Society of NJ - \$50,000**

Project funding will support the “CARES for Her” preconception and prenatal health education program. CARES for Her is intended to teach pregnant women, and women in their reproductive years, behaviors that promote healthy fetal development, including avoiding alcohol and substance use, managing stress and anxiety, ensuring adequate intake of folic acid and vitamins, and knowing the signs of early labor and what to do. CARES for Her will attempt to accomplish its goals by delivering group education for women in central New Jersey (Mercer, Ocean and Monmouth Counties). The CARES for Her project will include one, three, and twelve session courses. Ultimately, these actions are intended to ensure more full-term healthy births and reduce unnecessary pre-term, low-birth babies with lifetime disabilities.

## **Appendix A**

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

**6/14/2017**

- NOZika Project  
Venus Majeski, Institute for Disabilities

**3/8/2017**

- Newborn Screening Update  
Scott Shone, NJ Department of Health
- Cares For Her Project  
Karen Courtney, Children's Home Society

**12/14/2016**

- Impact of Homelessness on Developmental Disabilities  
Michael McCormack, Rutgers Medical School

**9/14/2016**

- Fetuses Exposed to Opiates During Pregnancy – Department of Health  
Mary Knapp
- Life Choices FASD Prevention Program  
Diane Squadron & Amanda Poling, Youth Consultation Services

# **Governor's Council on the Prevention of Developmental Disabilities**

## **FY 2017 Membership**

### **State of New Jersey Government Representatives**

Elizabeth M. Shea, JD - Department of Human Services

Mary M. Knapp, MSN, RN - Department of Health

Kenneth Richards - Department of Education

Alice D'Arcy, PP/AICP - Department of Community Affairs

Gloria Post, Ph.D., DABT - Department of Environmental Protection

Kelly Boyd - Department of State

### **Public Members**

1. Dorothy Angelini, MSN
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
9. Lynne Levin, OTR/L
10. Artea Lombardi
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12. Michael McCormack, Ph.D., FACMG
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16. Alyce M. Thomas, RD
17. Yvonne Wesley, RN, Ph.D.
18. Jean Wiegner
19. Leon Zimmerman
20. Ilise Zimmerman, MS

### **Staff**

Jonathan Sabin, LSW - *Director, Office for the Prevention of Developmental Disabilities*

