

# Governor's Council on the Prevention of Developmental Disabilities



## Report for Fiscal Year 2018



**State of New Jersey**

Phil Murphy, *Governor*    Sheila Oliver, *Lt. Governor*

**Department of Human Services**

Carole Johnson, *Commissioner*

***Division of Developmental Disabilities***

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# Governor's Council on the Prevention of Developmental Disabilities Report for Fiscal Year 2018

**T**he Governor's Council on the Prevention of Developmental Disabilities (Council) and the Office for the 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 25 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, and 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 Fetal Alcohol Spectrum Disorder and other Perinatal Addictions Task Force and Lead Task Force, imbue this work with a high level of intensity and dedication.

## Fiscal Year 2018 Activities

During Fiscal Year (FY) 2018, the Council met quarterly and maintained 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 2018, 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).
- Non-Invasive Prenatal Testing for the Prevention of Genetic Diseases and Birth Defects.
- Newborn Screening updates pertaining to lists of new disorders recommended for screening for New Jersey to be consistent with the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services.
- The Council took time to create bylaws to codify the way it executes its mission.
- As required by the New Jersey State Ethics Commission, Council members underwent Special State Officer Ethics Training.
- Council members discussed the declining population rates for individuals with down syndrome in several countries.
- 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.

### 2. 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 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 promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

The FASDTF met in August, September and December 2017 as well as during March and June 2018. Conference calls occurred in November 2017 and June 2018.

The FASDTF remains engaged with community organizations and policy professionals regarding news and information pertaining to current research best practices and programs, locally and nationally, regarding FASD. The FASDTF worked with its partners to increase awareness in New Jersey about FASD and perinatal addiction among the public and healthcare professionals. During FY18, the following issues and initiatives were determined to be priority work items by the FASDTF:

- FASD Awareness Day/Month started on September 9, 2017. 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. Some of these activities have targeted colleges to focus on young adults. In addition, Grand Rounds for physicians and other health professionals were scheduled. 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. The Governor's Office issued a proclamation honoring FASD Awareness Day demonstrating the importance of these awareness activities.
- The FASDTF understands the importance of a strong online presence to properly disseminate the information that people need for a safe and healthy pregnancy. A significant number of New Jersey citizens look to news and online information sites as a primary source for information. The FASDTF continued working to update the BeInTheKnowNJ.org website.
- The FASDTF considers the advancement of professional education as critically important to NJ's plan for addressing FASD. 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. The results of the survey indicated a need for additional information/training regarding treatment services available to individuals with FAS/FASD. Additional information was requested pertaining to transition to community supports from state school systems as well as the role of state government agency partners. To help address this need, the FASDTF began work on a comprehensive guidebook that is intended to assist anyone in need of FASD related services to find their way through New Jersey's state system of programs and services for individuals with FASD. It will be a starting point for anyone interested in developing an understanding of the way New Jersey has arranged its governmental services for individuals and families affected by FASD.

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

Lead related concerns continued to be prominent issues in New Jersey and the nation during FY 18. Lead is 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. News outlets continue to feature reports about the country's aging water delivery infrastructure, which has detrimentally impacted communities throughout the nation due to lead leeching from aging pipes.

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 on the Lead Task Force.

In FY 18, the Lead Task Force met in October 2017 and during February, April and June 2018. The Department of Health (DOH), with the Council reviewed current lead issues impacting the State of New Jersey during each meeting. The following issues and items received attention from the Lead Task Force during FY 18:

- Three Regional Lead and Healthy Homes Coalitions sponsored the statewide conference “Take the Lead on Lead” with nearly 200 attendees representing a variety of work settings and professional disciplines. The conference included a keynote by Green and Healthy Homes Initiative’s Executive Director Ruth Ann Norton and ten breakout sessions including: U.S. EPA and HUD rules regarding lead in drinking water and housing; the national action drive Find It, Fix It, Fund It; a local initiative to create healthy and sustainable families and communities; mapping to enhance primary prevention; overview of the anticipated adoption of NJ DOH child blood lead screening and public health intervention rules; the role of pediatric health care providers in preventing, identifying and managing children’s elevated blood lead levels; and, a joint federal strategy to decrease childhood lead exposures and health impacts.
- The NJ DOH’s rules N.J.A.C. 8:51 (local health department actions when a child has an elevated blood lead level (EBLL)) and N.J.A.C.8:51A (screening children for EBLLs) were adopted resulting in an anticipated quadrupling of the number of children to receive services by local health departments.
  - o N.J.A.C. 8:51 requires at a single venous blood lead level of 5 ug/dL or greater to commence nurse case management and at two venous blood lead levels 5 – 9 ug/dL one to four months apart or a single venous blood lead level of 10 ug/dL or greater to commence an environmental investigation.
  - o N.J.A.C. 8:51A health care providers are required to inform parents in written plain language the blood lead level screening result, its meaning, and how to prevent exposure when the child’s blood lead level is 5 ug/dL or greater.
- The NJ DOH issued a Notice of Funding Availability/Request for Proposals that resulted in 24 local health departments being awarded upwards of \$10 million for an initial budget period January-June 2018 as part of a January 2018-June 2020 project period. The Childhood Lead Exposure Prevention Projects (CLEPP) are anticipated to be allocated \$10 million annually to increase statewide screening, conduct nurse case management and environmental inspections, and build local capacity through staff training and the purchase of required equipment (e.g. consumer analyzers, LeadCare II point-of-care blood lead analyzers).
- National Childhood Lead Poisoning Prevention Week was observed from October 22-28, 2017. The NJ DOH posted information on its Facebook and Twitter accounts and webpages. The Regional Lead and Healthy Homes Coalitions shared the outcomes of their outreach activities and educational events which included a variety of settings (e.g. churches, child care centers, libraries, WIC, health care sites) conducted through health fairs, parent workshops, professional trainings, and information distribution.
- Guest speaker Elyse Pivnick from Isles, presented national policy-based best practices that could be implemented in NJ. Many of these policies were shared with Legislative representatives from non-profit agencies such as Isles and have resulted in proposed bills (e.g. required inspections of one and two rental housing units, required blood lead testing upon initial entry to school).
- Green and Healthy Housing Initiative (GHHI) staff shared the work their agency has done at the national level. The NJ DOH established a relationship with GHHI to provide technical assistance to the CLEPP. GHHI described the work done to date and future assistance to build local capacity.



- Peter Chen of ACNJ presented findings from the annual NJ Kids Count and Newark Kids Count reports and Ben Haygood, Housing & Community Development Network of NJ provided a highlight of current proposed NJ legislation.
  - o The NJ Kids Count report is part of a state-by-state effort, spearheaded by the Annie E. Casey Foundation, that provides comprehensive data about child well-being to policymakers, advocates, grant-makers and the public to help inform critical decisions for children and families. The report describes New Jersey in terms of family economic security, food insecurity, child care, education, child health and protection. The Newark Kids Count report includes the same data points in addition to a special section on childhood lead.

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

Council members take part in a conflict of interest vetting process before 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 is an important component of the proposal review process and assists 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 18:

##### **1. Statewide Parent Advocacy Network (SPAN) Prevention of Developmental Disabilities Project - \$124,905**

The project's target population is school age children and women of childbearing age, especially women who are pregnant and are at risk of drinking alcohol during their pregnancy. SPAN conducts outreach to youth by building networks and collaborative relationships with school administrators, school nurses, social workers, child study teams, specialized teachers and community programs that have access to diverse youth. SPAN conducts outreach to women through professional collaboration with community-based organizations, health centers, provider groups, County Councils for Young Children, NJ's Maternal Child Health networks, Family Support Organizations, and Community of Care Consortium activities. SPAN also conducts direct outreach through SPAN programs and activities such as the NJ Parent to Parent network and SPAN's prevention programs. Outreach is conducted through SPAN's diverse social media platform and website; program information is targeted to youth and women on SPAN's program webpages. Outreach materials are disseminated in hard copy as well as digitally to parents, professionals and/or different organizations.

## **2. Spina Bifida Resource Network Fortify Your Future II Project- \$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 healthier and folate-rich foods to improve health and to reduce chances of having children with disabilities. Secondly, it also will educate on the dangers of drinking and risk of 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.

## **3. Rutgers – RWJ Medical School Department of Neurology Prevention of Developmental Disabilities Project - \$66,000**

The hypothesis of this project is that folic acid supplementation before 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.

## **4. Princeton University Dept. of Psychology & RWJ Medical School Division of Neonatology Cerebellar Dysfunction and Infant Cognition as Very Early Markers for Predicting and Preventing Developmental Disabilities Project - \$50,000**

This project provides funding for the Princeton Baby Lab to purchase an eye blink conditioning apparatus, plus personnel support, 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.



**5. New Jersey Institute for Disabilities Protection Against Zika/Protccion y Accion Contra Zika (PAZ) Project- \$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.

**6. Children’s Home Society of NJ Prevention of Developmental Disabilities Project - \$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.

**7. Partnership for Maternal/Child Health of North Jersey Perinatal Addictions and Prevention Project - \$50,000**

This project will train home visitors and community health workers to utilize a modified version of the Screening, Brief Intervention, Referral, Treatment (SBIRT) model to discuss alcohol use during pregnancy and the link between Fetal Alcohol Spectrum Disorders and developmental disabilities with their clients. The agency will train approximately 50 home visitors and community health workers, who will reach at least 500 clients annually. The funding will also support the creation of an FASD “toolkit” for distribution to home visitation clients. This toolkit will include educational materials selected for linguistic and cultural appropriateness, which will serve as a reference for clients.

## Appendix A

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

6/13/2018

- **Special State Officer Ethics Training**  
Sherry Wilson, *NJ State Ethics Commission*

3/14/2018

- **OPDD Project – Princeton U. & Rutgers Medical School Eye Blink Project**  
Casey Lew-Williams, *Princeton University*

12/13/2017

- **OPDD Project – Analysis of autism risk, folic acid supplementation and DHFR**  
Edward Stenroos, *Rutgers University*

9/13/2017

- **New Options for Non-Invasive Prenatal Testing for the Prevention of Genetic Diseases and Birth Defects**  
Elena Ashkinadze, *Rutgers Medical School*

# **Governor's Council on the Prevention of Developmental Disabilities FY 2018 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*

Jennifer Underwood, *Department of Community Affairs*

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

Rowena Madden, *Department of State*

## **Public Members**

1. Dorothy Angelini, MSN
2. Jeananne Arnone, RN, BS
3. Caroline Coffield, Ph.D.
4. Mary DeJoseph, DO
5. Forest Elliot
6. Fran Gallagher
7. Carol Ann Hogan, M.S. Ed.
8. William Holloway, Ph.D.
9. Martin Johnson
10. George Lambert, MD
11. Lynne Levin, OTR/L
12. Artea Lombardi
13. Barbara May, RN, MPH
14. Michael McCormack, Ph.D., FACMG
15. Judith Morales, MSW, LCSW
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17. Beatriz Osterheld
18. Daniel Ranieri
19. Marlene Schwebel
20. Alyce M. Thomas, RD
21. Yvonne Wesley, RN, Ph.D.
22. Thomas Westover, MD
23. Jean Wiegner, CSNA
24. Leon Zimmerman
25. Ilise Zimmerman, MS

## **Staff**

Jonathan Sabin, LSW

*Director, Office for the Prevention of Developmental Disabilities*

