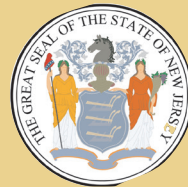




Governor's Council on the Prevention of Developmental Disabilities

Report for Fiscal Year 2016



State of New Jersey
Chris Christie, *Governor*
Kim Guadagno, *Lt. Governor*

Department of Human Services
Elizabeth Connolly, *Acting Commissioner*

Division of Developmental Disabilities



The New Jersey Department of Human Services (NJ DHS) complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. NJ DHS does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex. The NJ DHS:

- Provides free aids and services to people with disabilities to communicate effectively with us, such as: Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)
- Provides free language services to people whose primary language is not English, such as: Qualified interpreters
- Information written in other languages

If you need these services, contact Bonny E. Fraser, Esq., or if you believe that the NJ DHS has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance at: 222 South Warren Street, PO. Box 700, Trenton, New Jersey 08625-0700; phone: 609-777-2026; fax: 609-633-9610; Bonny.Fraser@dhs.state.nj.us.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.

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, 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 2016 Activities

During Fiscal Year (FY) 2016, 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:

- Genetic causes of birth defects and how they can be addressed by the promotion of New Jersey's newborn screening program.
- Educating medical professionals and the public about best practices for a healthy pregnancy.
- 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.
- The importance of the promotion of folic acid consumption in the Latina diet.
- The Healthy Babies are Worth the Wait campaign at the March of Dimes in order to encourage full-term pregnancies which result in healthier babies.
- General discussions regarding the kind of information that is provided to obstetrics patients and how that information is related to them.
- The New Jersey Catastrophic Illness in Children Relief Fund Commission (CICRFC) financial assistance program for New Jersey families whose children have medical costs otherwise uncovered by insurance, state or federal programs, or other sources.
- Medicaid programs for pregnant women including Presumptive Eligibility for Pregnant Women (PEPW) and New Jersey Supplemental Prenatal Care Program (NJSPCP) for applicants who are pregnant and otherwise eligible as pregnant women, except for their "lawfully present" or undocumented immigrant citizenship status.
- Lead issues in New Jersey, and model programs intended to address the associated concerns of lead exposure.
- Water issues in New Jersey, and information regarding the NJDEP drinking water program and implementation of the Lead and Copper Rule.
- Zika Virus: its origins, transmission and New Jersey's efforts to address mosquito control and reduce the possible spread of the virus.

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 (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 once in July and October 2015 as well as once during January and May 2016. Conference calls occurred in July, August and November, 2015.

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 the dangers of consuming alcohol while pregnant as well as best practices intended to reduce the impact of prenatal alcohol exposure in children. During FY16, the following issues and initiatives were determined to be priority work items by the FASDTF:

- FASD Awareness Day/Month occurred in September and included activities on September 9th, 2015. The FASDTF commemorated this day and month with a number of promotional actions and activities intended to create awareness of FASD. Several articles were featured in New Jersey newspapers and on New Jersey news web sites. A number of these articles included comments and messages from members of the Governor's Council. A proclamation honoring FASD Awareness Day was procured from the Governor's office, illustrating the importance of addressing FASD.
- Members of the FASDTF provided feedback and support to the Southern New Jersey Perinatal Cooperative, the March of Dimes, and the Maternal Child Health Consortia on a new FASD awareness "Coaster Campaign." When completed in FY 17, the project will distribute drink coasters with an FASD awareness message to bars and restaurants in New Jersey in order to promote FASD awareness and provide a web link to consumer education materials. The image on the drink coasters will include a "QR code" that will link coaster viewers to prevention information on the National Organization on Fetal Alcohol Syndrome (NOFAS) website. Bars and restaurants selling alcohol will be solicited for their participation in a pilot run of the coaster project which will be followed by a roll-out in September 2016.
- The Department of Health (DOH) released its new FASD prevention poster "A Pregnant Woman Never Drinks Alone." It was sent to all Class C licensed facilities (bars, liquor stores) in New Jersey. The FASDTF discussed possibilities for highlighting this effort during the September 2016 FASD Awareness activities.
- Members of the FASDTF collaborated with the Prenatal Committee of the State's Substance Exposed Infant (SEI) In-Depth Technical Assistance (IDTA) initiative Task Force. This group, with Substance Abuse and Mental Health Services Administration (SAMHSA) guidance and support, is focused on prenatal screening and other efforts to prevent the occurrence of substance affected infants and to promote treatment of women who expose their infants to opiates and other substances during pregnancy.
- The FASDTF reviewed and discussed updating the "Be In the Know NJ" website. Historically, this website has been utilized by the FASDTF to advertise and promote FASD prevention information as well as advertise partner activities such as professional education and FASD research. The site requires substantive work in order to make it current and useful. FASDTF members continue to review the site and create ideas for best ways to utilize this type of social media to advance its mission.
- Professional education is a primary concern of the FASDTF. The group discussed and reviewed opportunities for professional access to free Continuing Education Units CEU's. The availability of FASD oriented, professional education webinars is an ongoing concern. Members of the FASDTF noted that the CDC intends to collect data from practitioners on how staff is trained on the prevention, identification and treatment of FASD. There is hope that this may result in a broad approach to professional education.

3. Interagency Task Force on the Prevention of Lead Poisoning

Lead remains as a significant concern to the health of New Jersey's children. Lead can be found in a variety of sources including: paint in homes built before 1978; water pumped through leaded pipes; imported items including clay pots and certain consumer products such as candies, make-up and jewelry as well as particular imported home remedies.¹

Lead exposure can be profound and may have multigenerational effects. The mission of the New Jersey Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) is to:

- Raise awareness about childhood lead poisoning;
- promote lead-safe and healthy housing;
- support education and blood lead screening; and
- support interagency collaboration to advance policy that reduces lead poisoning.

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 16, the Governor's Council for the Prevention of Disabilities asked the Chairperson of the Lead Task Force, Crystal Owensby, Department of Health (DOH), to review current lead issues and responsive initiatives underway in her department. The following was discussed:

- Superstorm Sandy funding priorities to address lead and other environmental hazards as NJ continued to clean up from the storm and rebuild housing.
- The DOH creation of geographic information system (GIS) maps that go beyond county and municipality levels so that specific neighborhoods can be targeted for screening and primary prevention activities.
- The monitoring of NJ legislative bills related to lead for possible advocacy by public members of the Lead Task Force.
- The DOH's continuing work on the rule making process for NJAC 8:51A (screening of children for elevated blood lead levels) and NJAC 8:51 (public health interventions performed by local health departments in cases of elevated blood lead levels in children).
- Reinvigorating the Lead Task Force with a June 2016 meeting including:
 - o Adding new agency representatives from the affordable housing, child advocacy, and environmental justice fields.
 - o Having a large "kick off" event in September 2016 that would include a review of the history of lead in NJ and that of the Lead Task Force.
 - o Creating a description of each State department with the responsibilities of lead-related programs to enhance networking and referrals.
 - o Creating a resource directory to refer professionals and consumers to appropriate state, regional and local agencies.

¹. https://www.cdc.gov/nceh/lead/acclpp/lead_levels_in_children_fact_sheet.pdf

4. Office for the Prevention of Developmental Disabilities Grant Funding

Following a conflict of interest vetting process, 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 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 16:

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. Family Guidance Center, Prenatal Screening Project - \$141,500

Having concluded its funding cycle, this is the final year of a DHS – Division of Mental Health & Addiction Services partner project, during 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. A lead screening is also employed which will result in a referral for blood testing for individuals determined to be at risk for lead exposure. Also available to further assess smoking patients is a carbon monoxide monitor to measure the level of carbon monoxide in the patient's breath as well as a device to measure the patient's lung age. These monitoring tools are used with the patient to assist with smoking cessation and to provide awareness of the effects that smoking has on their 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.

4. 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.

5. 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.

Appendix A

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

6/8/2016

- NJ response to Zika
Dr. Edward Lifshitz, Medical Director, Communicable Disease Service, NJ DOH
- NJ DEP Drinking Water Testing
Dr. Gloria Post, NJ DEP

3/9/2016

- Lead Prevention Project
Peter Rose, Emily Puskar & Elyse Pivnick, Isles Inc.

12/9/2015

- Medicaid and Prenatal Care – Division of Medical Assistance and Health Services
Julie Chase, Charlene South and Louise Patterson

9/9/2015

- March of Dimes Programs – Prevention of Developmental Disabilities
Laurie Navin, March of Dimes
- NJ Catastrophic Illness in Children Relief Fund Commission (CICRFC)
Claudia Marchese, Executive Director

Governor's Council on the Prevention of Developmental Disabilities FY 2016 Membership

State of New Jersey Government Representatives

Dawn Apgar, PhD, LSW, ACSW - 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
11. Barbara May, RN, MPH
12. Michael McCormack, Ph.D., FACMG
13. Mariam Merced, MA
14. Judith Morales, MSW, LCSW
15. Ana Rivera, MSW, LCSW
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*

