



Governor's Council on the Prevention of Developmental Disabilities FY 2013 Report



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

Chris Christie, Governor
Kim Guadagno, Lt. Governor
Jennifer Velez, Commissioner

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

The Governor's Council on the Prevention of Developmental Disabilities (Council) and the **Office for Prevention of Developmental Disabilities (OPDD)** were created by Public Law 1987, Chapter 5, as amended by Public Law 2000, Chapter 82. The Council serves as an advisory body to the OPDD and makes recommendations to the Commissioner of the Department of Human Services regarding policies and programs needed to prevent developmental disabilities.

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 must report annually to the Governor and the Legislature concerning the status of prevention programs in the State.

FY 2013 Activities

The Council met on a quarterly basis during Fiscal Year 2013. The Council and OPDD continue to collaborate and monitor New Jersey's developmental disability prevention programs throughout the state including presentations to the Council by State and other Institutions that are working in the field of prevention (see appendix A for the listing of the presentations). In FY 2013, the Council focused on the following projects:

1. Birth Defects Prevention Stakeholders Meeting & Activities

On January 24, 2013, stakeholders, including members of the Council as well as families, providers, state agencies, health and disability organizations, met to discuss the current status and outcomes of birth defects prevention activities in New Jersey. Participants discussed gaps and challenges, and developed recommendations to improve outcomes. Following an overview of the data, national and state initiatives, and New Jersey activities, as well as a summary of the results of an on-line survey, conducted prior to the forum, three workgroups were convened to focus on three audiences: Women of Childbearing Age, Providers of Services to Women of Childbearing Age, and the General Public. Meeting attendees worked on issues associated with their specific workgroup's focus. Council members intend to continue their involvement with the activities associated with the Birth Defects Prevention Stakeholders group. Ongoing project activities occurred via conference calls and included planning with specific Council members.

2. Fetal Alcohol Spectrum Disorder Legislation

Council members reviewed and discussed Alaska legislation that allows the diagnosis of FASD to be used as a mitigating factor during the sentencing portion of a trial. Council members met with a NJ State Assemblyman in order to discuss the possibility of this type of legislation in NJ. The Assemblyman was interested in this idea but had questions regarding the applicability of this type of legislation to other forms of developmental disabilities. Council members wish to dig deeper into the data associated with individuals with FASD that become involved with the legal system. Unfortunately, the lack of available records on this subject severely hampered the Council's efforts. The Council continues to explore this matter.

3. Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions Task Force (FASD Task Force)

Consumption of alcohol, while pregnant, is the most preventable cause of developmental disabilities. The mission of the New Jersey Task Force on FASD and other Perinatal Addictions is to prevent FASD and to promote effective, life-long interventions for individuals affected by prenatal exposure to alcohol and other substances.

The FASD Task Force was focused on a number of endeavors this fiscal year, including the completion of a new five-year plan, by way of the work of several subcommittees (Education and Training, Treatment Intervention, Screening of Women and Social Media). Among other accomplishments, some highlights of subcommittee work included:

- The Education subcommittee discussed and proposed methods to provide key information components to FASD educators for use in their FASD trainings. The methods that were reviewed were taken from the few papers on teaching and education regarding FASD. The Education Subcommittee uses the CDC curriculum for training, as well as the "reach to teach" suggestions for teachers, from the FASD Center of Excellence.
- The Screening of Women subcommittee promoted universal screening and brief interventions for alcohol, tobacco, substance use, mental health issues, and domestic violence, as a standard of prenatal care. The subcommittee is mostly comprised of Department of Health (DOH) Risk Reduction Coordinators. Risk Reduction Coordinators actively recruit and support prenatal care providers to screen patients using either the 4Ps Plus (screening for alcohol, tobacco and other drugs) or the PRA (Prenatal Risk Assessment). During FY 2013, approximately 33% of pregnant women (approximately 109,000 births in NJ annually) were screened and were offered a variety of programs and services. Additionally, obstetric providers were given referral assistance for women in need of services. It is important to note that the women that were screened primarily receive Medicaid or are uninsured. In most circumstances, commercially insured women are not screened by Obstetricians in private practice under the Department of Health Project. This lack of screening, among commercially insured women, poses a significant challenge regarding FASD education.

- The Treatment subcommittee began to search for a small cadre of professionals, with whom they can work, including psychologists, counselors, social workers, and psychiatrists, to treat individuals with prenatal alcohol exposure. While the Diagnostic Centers can diagnose FASD, there seems to be very few professionals, in NJ, trained or interested in doing interventions with this vulnerable population.
- The Social Media subcommittee continued to use the “Be In The Know” website to inform the public about FASD prevention. They also attempted to increase the use of various social media platforms (Pinterest, Twitter, etc.). This subcommittee intends to increase the use of webinars and podcasts on the “Be In The Know” website.

A number of speakers presented to the FASD Task Force during FY 2013. They included:

- Celine Fortin from The Arc of NJ regarding its work and how it can assist the Task Force in various counties.
- Pauline Lisciotta from DOH described the Special Child Health Registry, and how the case managers can assist families regarding referral for services in the NJ counties.
- Philip Mastroini, from DCF, described what the department will look like, once changes to services for children with developmental disabilities occurred at the state level.
- Mary Knapp from the NJ Birth Defects Registry (NJBDR), described the NJBDR and how FAS still is not being entered into the registry, and how important it is that families register. In order to boost registration, advocates continue to ask diagnostic centers to designate a person to be responsible for registering individuals that have been recently diagnosed. Physicians, at the centers, will need to communicate diagnostic information with the registration staff.
- Shirla Simpson and Barbara Lee from the NJ Council on DD discussed the various programs under their council

The FASD Task Force welcomed two new members during FY 2013:

- Shirla Simpson is the Deputy Director for the NJ Council on Developmental Disabilities (NJCDD).
- Laura Fenster Rothschild, Psy.D is from the Center of Alcohol Studies at Rutgers.

4. Interagency Task Force on the Prevention of Lead Poisoning

Lead remains the leading environmental threat to the health of New Jersey’s children. As the most densely populated state in the Union, and one of the states with the oldest and most extensive industrial heritage, a substantial amount of lead contamination is present in New Jersey, with the potential to subject residents to the dangers of lead poisoning. “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.”

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

Task Force members participated in Superstorm Sandy recovery work following the Department of Health/Division of Family Health Services/Child and Adolescent Health Program being selected to receive \$13.2M in funding, commencing September 1, 2013 and ending June 30, 2015. The source of funding is the NJ Department of Human Service’s Social Services Block Grant, Superstorm Sandy Recovery. The funding will go toward: public education and professional development, targeted blood lead screening, and support of HomeTrax, which will serve as a centralized repository of housing hazards data that may impact residents’ health including lead-based paint.

The Lead Task Force refined the task list that was developed at previous meetings. The tasks for completion in CY2013 included:

- Developing a 1-page information sheet for recruitment and retention of Lead Task Force members.
- Updating the State agencies contact list with roles and responsibilities.
- Summarizing outcomes from the 2004 NJ Childhood Lead Poisoning Prevention (CLPP) Elimination Plan.
- Outline current funding levels and real/perceived impacts of decreased lead prevention funding.

The Regional CLPP Coalitions, funded through the State appropriation to the Task Force, shared their plans for national CLPP Week which was observed October 21-27, 2012.

5. Office for the Prevention of Developmental Disabilities Grant Funding

Members of the Council provided assistance to the OPDD for the FY 14 Request for Letters of Interest (RLI). Following a vetting process that excluded members of the Council for possible conflicts of interest, a number of Council members volunteered to serve on an OPDD RLI subcommittee. Subcommittee members provided feedback to DDD staff regarding the strength of proposals submitted to the OPDD. Subcommittee member expertise was an important component to the proposal review process and assisted DDD in recognizing best practices and important issues impacting the prevention of developmental disabilities. Following DDD's selection of program funding for FY 14, Council members engaged in a discussion of ways to improve future RLI's so as to advance the quality of the proposals that are submitted. Meetings have been scheduled to continue to evaluate the grant process. Council members' feedback included:

- Improving the process of how agencies are informed about the availability of funding.
- Providing technical assistance to agencies on how to prepare a proper proposal in response to an RLI.
- Proposing to focus future RLI's upon more specific needs.
- Making the development of the next RLI more data driven.
- Increasing examination and focus on the types of programs and projects that the state wants/needs.

Office for Prevention of Developmental Disabilities (OPDD)

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

Web Site

The Council provided significant feedback and expertise regarding the renovation of the OPDD web site. Early in FY 13 the OPDD received some comments, from an interested party regarding the information included on the OPDD web site. The OPDD Director requested that the Council provide a comprehensive evaluation of the web site's information in order to determine if the content was in need of an update. Following the Council's review, it was determined that an overall update of the website would be helpful. The updated web site now includes current links to information and resources available through State of NJ web sites, as well as web links to the Center for Disease Control (CDC), USEPA, and the National Institute of Health (NIH).

Funding for Prevention Initiatives

The OPDD funds partner agencies to engage in prevention education activities. The programs described below are funded by the OPDD:

1. **The New Jersey FASD Education and Training Center** (UMDNJ – School of Osteopathic Medicine) (Now Rutgers-New Jersey Medical School) (Service Area – Statewide) UMDNJ provides training for medical and allied health personnel, throughout NJ, on prenatal alcohol exposure and Fetal Alcohol Spectrum Disorders. The trainings emphasize knowledge about specific substantive issues as well as utilization of effective communication skills. The goal of this project has been to train NJ medical and allied health practitioners to: more accurately understand the importance of preventing prenatal alcohol use; effectively screen for and diagnose FASD; provide case management and direct referrals to prevent further secondary disabilities.

FASD Education is supported by OPDD through collaborative work with the New Jersey FASD Training Center at UMDNJ-New Jersey Medical School. Team members from the New Jersey FASD Training Center educate medical students, physicians, nurses and other allied health professionals, juvenile and criminal justice system personnel, adolescents, prospective parents and others about the dangers of consuming alcohol during pregnancy.

Grant amount - \$124,706

2. The New Jersey Coalition for Prevention of Developmental Disabilities (Coalition) (Arc of New Jersey) (Service Area – Statewide) The Coalition worked to mobilize individuals and agencies/organizations in a cooperative effort to educate and promote prevention of developmental disabilities among the public and private sectors. It accomplished this goal through various means and published and distributed an on-line prevention newsletter on a bi-weekly basis to approximately 1,500 subscribers.

In addition, the Coalition organized and helped to sponsor Pregnant Pause events in each county. Pregnant Pause is a national program to educate prospective parents about the importance of not drinking alcohol during pregnancy. Each county event is designed to meet its residents' needs and a variety of approaches were used. These included sponsoring Mother and Daughter luncheons, holding special events in malls and at Toys-R-Us, supporting baby showers for pregnant adolescents, and partnering with colleges to educate students about FASD.

The Coalition also provided direct training to public health and social service professionals regarding prevention issues. FASD trainings have included Family Care Workers based in school systems as well as educational programs for the prevention of unintentional injuries and childhood lead poisoning.

Grant amount - \$125,000

3. Operation Stop Think and Act Responsibly (STAR) (Arc of Warren) (Service Area – Warren, Sussex, Hunterdon & Morris) This project includes collaboration with the Northwest New Jersey Community Action Partnership (Norwescap). The goal for Operation S.T.A.R. is to educate young children and adults of child-bearing age about the prevention and reduction of the occurrence of intellectual and developmental disabilities. The focus is on the prevention of unintentional injuries, FASD and Traumatic Brain Injury/Secondary Impact Syndrome. To achieve these goals, Operation STAR included:

- The presentation of puppet shows targeting the prevention of unintentional injuries to children in the 22 Head Start programs in Warren, Sussex and Hunterdon Counties. These programs also were offered to day cares and elementary schools in all the primary counties plus Morris County. This program component reached 546 children.
- Educating 315 middle and high school children about the prevention of FASD and TBI/Secondary Impact Syndrome.
- Educating 20 Home Visitor Volunteers about the prevention of FASD and other related topics that can lead to intellectual and developmental disabilities re: drug use, smoking, etc. These Home Visitor Volunteers reached approximately 250 low-income families.
- Providing training to 21 nurses, administrators, athletes/coaches, and social service staff regarding Secondary Impact Syndrome through a conference/in-service.
- Distributing 150 bike helmets/car booster safety seats to families who are at 100% of the federal poverty level.

Grant Amount - \$39,996

4. Get The Lead Out (GLO) (Arc of Warren) (Service Area – Warren, Sussex, Hunterdon & Morris) This project also includes collaboration with Norwescap. The goal for GLO has been to educate pregnant women, expectant fathers, women of child bearing years and children starting at the age of 4 through the 2nd grade about the prevention of lead poisoning and to provide them with age appropriate prevention tips to reduce the incidence of intellectual and developmental disabilities caused by lead poisoning. The program accomplished the following during FY 13:

- A puppet show targeting the prevention of lead poisoning was presented.
- A presentation to Home Visitation volunteers.
- 590 people were seen at WIC programs and provided with Lead Poisoning prevention information.
- 120 lead detection tests were distributed to low-income families residing in Warren, Sussex, Hunterdon and Morris counties.
- Lead poisoning information was disseminated at 4 health fairs.

Grant amount - \$18,483

5. The Safety Ambassador Program (Robert Wood Johnson Hospital) (Service Area – Middlesex) This program is a cross-age tutoring intervention in which 11th and 12th grade students teach 1st and 2nd grade students about injury prevention and risky behaviors. Administered by the Robert Wood Johnson University Hospital Level One Trauma Center, 170 high school students were trained to give the Safety Ambassador presentation. The adolescents were trained about injury prevention and safety. Pairs of high school students developed lesson plans that they delivered to elementary school students. Presentations were given to first and second grade students at Middlesex County school districts. Eighteen elementary schools participated in this year's program. A Recognition Assembly was held for the Safety Ambassadors at the end of the school year. The program has demonstrated an influence in safety knowledge and behavior among students.

Grant amount - \$43,240

6. Safe Kids New Jersey (Central Jersey Family Health Consortium (CJFC)) (Service Area – Statewide) continued to expand its statewide education program aimed at reducing the incidence of developmental disabilities by decreasing unintentional injuries among children ages 14 and under. Their strategies address the most serious accidental risk areas for children including: motor vehicles (*Children In and Around Cars*), pedestrian safety (*Walk This Way*), all-sports helmet safety (*Heads You Win*), drowning prevention (*Kids Don't Float*), sports/ play injury prevention (*Get Into the Game with Safety*) and home safety (*Home Safe Home*).

Grant amount - \$125,000

7. Back to Basics (Family Health Initiative) (Service Area – Cumberland, Salem & Atlantic) targets pregnant mothers, new moms, and families with young children using a variety of outreach strategies. An important component of the Back to Basics program is the Promotores de Salud outreach feature which focuses on reaching out to the Hispanic community. Another special aspect is the use of an interactive van that has been renovated to resemble the interior of a home. Individuals and families can enter the van and interact with multiple examples of traditional and non-traditional lead hazards found in and around the home. In addition to the interactive van, Back to Basics featured the following:

- Lead and Pregnancy Education – addresses both potential lead exposure hazards and pregnancy specific practices that expose pregnant mothers to lead. A total of 93 educational activities, serving 1075 participants occurred during FY 13. 177 lead detection kits were distributed across Atlantic, Cumberland and Salem Counties, of which 32 were found to be positive. 14 of the positive lead detections were found to be hazardous positive.
- Renovate Right – educates individuals conducting home renovation or repair activities either in their own home or the home of another person or family. It is designed to educate participants about lead safe work practices that they can use to protect both themselves and inhabitants of the home undergoing renovation or repairs. Workshops were held in Atlantic, Cumberland and Salem Counties serving a total of 82 participants.
- General Lead Education – is intended to increase knowledge about potential sources of lead exposure, practices for reducing risk, and opportunities for determining if a child is contaminated or if a child has been exposed to lead. Workshops were held throughout Atlantic, Cumberland and Salem Counties.

Grant amount - \$80,000

Appendix A

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

12/12/2012

New Jersey Department of Health and the Statewide Parent Advocacy Network (SPAN)

- Presentation on the Birth Defects Registry: Partners for Prevention

6/12/2013

Arc of Warren

- Presentation on the Star & Glo Programs

3/13/2013

Governor's Council member, Judy Morales

- Prescription Drug Abuse & Pregnancy Presentation

Governor's Council on the Prevention of Developmental Disabilities FY 2013 Membership

Government Representatives

<u>Name</u>	<u>Department</u>
Dawn Apgar, Ph.D., LSW, ACSW	Human Services
Sandra Schwarz, RNC, MS	Health
Kathleen Ehling, MAT, JD	Education
Alice D'Arcy, PP/AICP	Community Affairs
Gloria Post, Ph.D., DABT	Environmental Protection
Wendy Galloway	State

Public Members FY 2012 – Present

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. Kevin McGovern, Esq.
14. Mariam Merced, MA
15. Judith Morales, MSW, LCSW
16. Ana Rivera, MSW, LCSW
17. Deborah Spitalnik, Ph.D.
18. Alyce M. Thomas, RD
19. Yvonne Wesley, RN, Ph.D.
20. Jean Wiegner
21. Leon Zimmerman
22. Ilise Zimmerman, MS

Staff

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