



Governor's Council on the Prevention of Developmental Disabilities

FY 2012 Report



State of New Jersey
Chris Christie, *Governor*

Kim Guadagno, *Lt. Governor*

Department of Human Services
Jennifer Velez, *Commissioner*

Division of Developmental Disabilities

Governor's Council on the Prevention of Developmental Disabilities

Report for Fiscal Year 2012

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. It 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 2012 Activities

The Council met on a quarterly basis during Fiscal Year 2012 (see Appendix A). The Council and OPDD continue to collaborate and monitor New Jersey's developmental disability prevention programs throughout the state. In FY 2012, the Council focused on the following projects:

1. 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 among states with the oldest and most extensive industrial heritage, New Jersey contains a substantial amount of lead, and the potential to subject residents to the dangers of lead poisoning.

In FY 2012 the Interagency Task Force on the Prevention of Lead Poisoning (Lead Task Force) met three times (see Appendix B). It includes 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, and many local public health, housing, and social service agencies participate on the Lead Task Force, which also was responsible for DOH'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).

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

Prenatal exposure to alcohol is the most preventable cause of intellectual and other developmental disabilities. Too many women and men are not educated about the possible dangers of consuming even low levels of alcohol while pregnant. In FY 2012 the FASD Task Force met three times (see Appendix C). It is comprised of representatives from the Departments of Human Services, Department of Health, UMDNJ, Perinatal Addiction Prevention Programs, the FASD Diagnostic Centers, and local community health, addictions treatment, and social service agencies. The purpose of the FASD Task Force is to advise and promote education and disseminate information on prenatal alcohol and other perinatal addictions in and around New Jersey.

Office for Prevention of Developmental Disabilities (OPDD)

Based in the Department of Human Services' Division of Developmental Disabilities, OPDD works with the Governor's 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.

The OPDD funds partner agencies to engage in prevention education activities. The programs described below are statewide and are part of national initiatives:

1. Train the Trainer is a partnership program with UMDNJ – School of Osteopathic Medicine that educates community groups throughout the state about a broad array of prevention issues including lead poisoning, Pediatric HIV/AIDs, FASD and unintentional childhood injuries. It emphasizes knowledge about the specific substantive issue as well as utilization of effective communication skills. The intent of this project is to develop a network of trainers who can provide effective prevention education in their community. The program provides materials and technical support to these community educators. Over 500 individuals participated in the training in the past year, including approximately 150 adolescents. Grant amount - \$115,744

2. The New Jersey Coalition for Prevention of Developmental Disabilities (Coalition) is administered by The Arc of New Jersey. The Coalition works 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 accomplishes this goal through various means and publishes and distributes an on-line prevention newsletter on a bi-weekly basis to approximately 1,500 subscribers.

In addition, the Coalition organizes and helps 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 are used. These include 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 provides direct training to public health and social service professionals regarding prevention issues. Trainings have included FASD to Family Care Workers based in school systems as well as educational programs for the prevention of unintentional injuries and childhood lead poisoning. Grant amount - \$155,250

3. "Sex, etc." is a family life newsletter by and for adolescents and is written by the Network For Family Life Education at Rutgers University. Three issues of "Sex, etc." are written annually by New Jersey high school students, then published and distributed to teens throughout the state and the country. This newsletter contains accurate, up-to-date information about healthy behaviors, sexuality, the effects of drugs and alcohol, violence and prenatal health. It is written in a format and language that appeals and speaks to teens. Teachers are encouraged to use the newsletter for class discussion, essay and poster contests, and as a supplement to the Family Life curriculum. The program also sponsors a website for adolescents at <http://www.sexetc.org>. Approximately 46,000 copies of the magazine were circulated in FY 2012. Grant amount - \$25,000

4. The Fetal Alcohol Spectrum Disorders (FASD) Community Education Outreach program serves as a resource to New Jersey agencies and organizations involved in the prevention, education and diagnosis of FASD. This program is intended to ensure that agencies have access to up-to-date and comprehensive information. Sponsored and run by The Arc of Atlantic County, the program is responsible for developing, implementing and evaluating new prevention education approaches. The FASD Community Education Outreach staff train other FASD professionals in the use of these new approaches. This program educates participants in mandatory drunk driving programs about FASD. This unique setting is an effective place to educate about the dangers of consuming alcohol during pregnancy. 1,039 attendees received this training in FY 2012. Grant amount - \$80,000

In addition, the FASD Community Education Outreach program coordinated the FASD Task Force's public education campaign. Staff also conducted school-based FASD education in which 195 eighth-grade students participated. In total the Community Education Outreach program gave a total of 66 presentations reaching 1,570 individuals.

5. "Heads Up for Safety" is a broad-based public education effort sponsored by the Epilepsy Foundation of New Jersey. The purpose of the program is to increase public and professional awareness of preventable head injuries by promoting the wearing of helmets when riding a bicycle, scooter, skateboard, and in-line skates. A statewide poster contest is held in schools across the state. The posters are then displayed at the New Jersey Education Association's annual convention and teachers vote for the best poster. A ceremony is held at the State House to honor the poster-winning students, their families and their teachers. Approximately 2,000 individuals were touched by this program in FY 2012. Part of a national initiative, Heads Up for Safety also sponsors a website. Grant amount - \$20,000.

6. Small Grant Public Education Demonstration Programs OPDD provides small grants to community agencies that are developing, implementing and evaluating new models of prevention education. These initiatives mostly focus on unintentional injury prevention programs. The projects are primarily urban-based while one focuses on a rural area of New Jersey.

Operation Safe Actions For Everyone (S.A.F.E.) is sponsored by The Arc of Warren County. The project is educating children ages 4 - 14 in Warren County about ways to prevent unintentional injuries. Grant amount - \$25,157. The program components include:

- an age appropriate puppet show to children in preschool through second grade;
- sponsoring a modified Game of Life for students in grades three to eight;
- providing material and support to schools and other entities that participate in Operation S.A.F.E.; and
- participating in community safety events.

Safe Sitter, a nationally recognized program, is targeting youth between the ages of 11 -13 to teach them about safe and nurturing child care techniques with the goal of reducing the risks of childhood unintentional injuries. Sponsored by the Central New Jersey Maternal and Child Health Consortium, the program has recruited adolescents from the Trenton Public School District, the New Brunswick Public School District and the Boys and Girls Club of Perth Amboy to participate in the program. Many of these adolescents are responsible for caring for their younger siblings after school. The Safe Sitter program has been adapted to address the issues associated with inner city latch key children. Grant amount – \$25,600

The Safety Ambassador Program is a cross-age tutoring intervention in which 11th and 12th grade students teach 1st and 2nd grade students about injury prevention and risk awareness. Sponsored by the Robert Wood Johnson University Hospital Level One Trauma Center, 128 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. A Recognition Assembly was held for the Safety Ambassadors at the end of the school year. First and 2nd Graders at 16 school districts in Middlesex County learned about injury prevention from the teen-age Safety Ambassadors during the 2012 fiscal year. Grant amount – \$13,550.

Safety Education for Child Pedestrians is sponsored by UMDNJ – New Jersey Medical School. The Pedestrian Injury Prevention Partnership (PIPP) is partnering with elementary schools in Newark to educate children, ages 5 – 12, about pedestrian safety. The “Safety Education for Child Pedestrians” program uses a standard curriculum entitled, “WalkSAFE” to accomplish this goal. Information is also disseminated to schools to be sent home to families about pedestrian safety. During the past year, the PIPP Education Consultant trained over 600 preschool teachers and parents. Over 900 children participated in the school-based program. Grant amount – \$24,500.

Medical Student Education is supported by OPDD through collaborative work with the New Jersey FASD Training Center at UMDNJ-New Jersey Medical School. OPDD staff and team members from the New Jersey FASD Training Center together 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. The cost of this program is included as part the OPDD’s larger Train the Trainer project mentioned earlier in this document.

Child Health and Safety Information Resources were promoted and disseminated via the Advocates for Children of New Jersey (ACNJ) website. This project was intended to reduce serious, but preventable, unintentional injuries. Information regarding specific activities and health related issues are featured as well as links to organizations and their web sites are provided to allow the exploration of specific concerns. Grant amount – \$30,000.

Additionally, in FY 2012, ACNJ hosted three regional Kids Count forums. The purpose of these forums was to bring together government officials as well as providers for discussion on the well-being of children.

Appendix A

Meetings of the Governor's Council on the Prevention of Developmental Disabilities

July 2011 – Strategic Planning Session

This gathering focused on addressing the purpose of the Governor's Council. The group discussed questions that were designed to motivate the committee and solicit the group's best thinking for their work going forward. Questions and answers, explored during the session, were as follows:

Question – What is the primary mission of the Governor's Council?

- Retain primary prevention focus (public information) by identifying critical issues of developmental disabilities prevention
- Provide advocacy & support for effective prevention policy
- Identify and reduce barriers to accessing prevention services

Question – Is the current mission of the Governor's Council appropriate and adequate?

- Absolutely
- Voted "no" to the inclusion of secondary prevention (prevention efforts aimed at at-risk populations) or tertiary prevention (rehabilitation or treatment) to the current Governor's Council mission

Question – How does the Governor's Council fulfill its mission?

- Gather and review information on the causes of DD and engages in dissemination
- Facilitate task forces and sub-committees (task force reports to the Governor's Council)
- Recommend/advise on legislative action in conjunction with DHS
- Provide & report on scientific data and information
- Represent Governor's Council on other bodies and reports back to Governor's Council
- Advise OPDD
- Plan and strategize
- Conduct symposia & other conference/educational sessions with OPDD staff in collaboration with other groups

Question – Should the ways in which the Governor's Council fulfills its mission change?

- Have council be more directly involved with OPDD grantees
- Provide technical assistance to grantees
- Produce summary of small grants currently being funded
- Assure that small projects disseminate findings and approaches for replication
- Evaluate process & progress of grantees
- Encourage and support efforts by State agencies to make the general public aware of environmental issues – PSAs (replicate NYS model)

Question – Are there other entities involved with prevention activities (contacts where we currently have collaboration/membership/liaison)?

- The Arc – central and local offices
- Coalition for Prevention
- Safe Kids
- Advocates for Children of NJ (ACNJ)
- Maternal & Child Health Consortia and the Department of Health & Senior Services
- March of Dimes
- Some local boards of health

Discussion – Other entities not involved or weak involvement (targets for future contact/collaboration)

- Autism community
- Brain Injury Association of NJ
- Intoxicated Driver Resource Center
- Drug & Alcohol Abuse
- Family Planning agencies
- NJ Environmental Federation
- Pre-natal clinics
- Medical associations & groups
- Text for babies (check it out) CDC
- Web pages – prevention

September 2011 – General Meeting

In addition to regular agenda items, the Council received a presentation from Council member Judith Morales entitled Guidelines for Screening Pregnant Women, Pain Management, Methadone & Infants in Withdrawal & Guidelines for Breastfeeding & Drug-Dependent Women.

- New Jersey hospitals do not have standardized evidence-based guidelines in place to address the co-occurring medical needs of women that are both pregnant and simultaneously using substances. In an effort to improve pregnancy outcomes in the health care delivery environment, evidence-based guidelines focusing on the screening, assessment, and treatment of substance-abusing pregnant women and their neonates were developed. Each draft was reviewed by physicians nationally recognized in the field of obstetrics, and addiction in the treatment of newborns exposed to alcohol, methadone, and other drugs.
 - o **The Guidelines include:**
 - ◆ *“Substance Abuse Screening in Obstetrics”* includes recommendations to screen all patients entering care utilizing standardized screening tools designed to identify past and current use; presents signs and symptoms of withdrawal, scientific explanations for handling false positives and obtaining accurate urine toxicology, and when to obtain urine toxicology’s and blood serums to eliminate false accusations.
 - ◆ *“Pain Management for Chemically Dependent Women in Obstetrics”* includes pain assessment, non-pharmacological comfort measures, analgesia for labor, anesthesia for surgery, prevention of withdrawal.
 - ◆ *“Methadone Intervention for the Chemically Dependent Woman in Obstetrics”* addresses treatment for Opioid dependent patients not currently maintained on methadone and those currently not enrolled in a treatment program as well as patients currently enrolled in Methadone treatment program.
 - ◆ *“Medical Management and Care of the Drug-Exposed Neonate”* focuses on an appropriate nursery environment, the assessment for Neonatal Abstinence Syndrome and pharmacological treatment options.
 - ◆ *“Breastfeeding”* addresses how to approach mothers willing to breastfeed who have a history of substance use.

December 2011 – General Meeting

During this meeting, the Governor’s Council received several presentations from a guest speaker as well as OPDD grant recipients in addition to their regular business items:

- Lori Feldman-Winter, a pediatrician from Cooper University Hospital discussed the benefits of breastfeeding for both mother and child. There was a long discussion regarding the issue of breastfeeding and drug use. At this time there are no guidelines concerning breastfeeding and drug use.
- Diana Starace presented a Power Point on the Safety Ambassador Program at RWJ University Hospital – Level 1 Trauma Center. The focus of the project is to educate high school and elementary school children about safety and injury prevention. The high school students develop an interactive educational session to be presented to elementary school classes.
- Sharon Clancy presented a Power Point presentation on the Safety Education for Child Pedestrians program at U.M.D.N.J. – Medical School – Level 1 Trauma Center. This program is based on the Walk Safe curriculum. The project focuses on pedestrian safety for elementary school students in grades 1 – 5.

- A motion was made to reestablish the Governor's Council Executive Committee. The Council approved the motion.
- The Council received information regarding the status of the 2012 – 2013 OPDD RFP.
- OPDD staff provided the council with information regarding the status of Council reappointments and vacancies.

March 2012 – General Meeting

The Governor's Council received several presentations during this meeting and received updates regarding old and new projects including:

- Jeannette Weikel, from the Arc of Warren County, presented a Power Point presentation on the Operation S.A.F.E. project. This program provides safety education on unintentional injuries to children ages 4 – 14.
- Velva Dawson, from the Central Jersey Family Health Consortium, gave a Power Point presentation on the Safe Sitter program. The project is a six session course that teaches adolescents, ages 12 and 13, about safe childcare techniques and responsibilities, including CPR instruction.
- **Interagency Task Force on the Prevention of Lead Poisoning** – Crystal Owensby, Chair of the Interagency Task Force on the Prevention of Lead Poisoning, provided an update on the Lead Task Force's activities.
- Scott Shone and Suzanne Karabin, from the Department of Health, presented a Power Point presentation that provided an overview of the new laboratory facility and the improvements made to the collection, analysis, matching and recording of data for newborn metabolic screening.
- Jerisa Maseko, from the Arc of New Jersey, provided a Power Point presentation on the proposed FASD Statewide Media Blitz campaign. The Governor's Council was supportive of this endeavor.
- Susan Adubato provided an update on the **Fetal Alcohol Spectrum Disorder (FASD) Task Force**. The FASD Task Force 5 year strategic plan is being updated. In honor of the 40th anniversary of the report identifying FAS, the FASD Task Force would like to plan a commemorative conference.

June 2012 – General Meeting

During this meeting, the Governor's Council reviewed and discussed a variety of prevention related matters including:

- An FASD education Public Service Announcement done through a media campaign with the Department of Human Services.
- Open positions on the council for new members
 - o Council members term of services expiration date – Council members discussed concerns related to expired terms of service
- Office for the Prevention of DD Grants
 - o 5 Applications were approved
 - o 7 Applicants received letters that their projects were not chosen
 - o Another RFP on Lead issues was being issued and the dead line was June 15th. These contracts would be able to be in full effect by July 2012.
 - o Also discussed – how should we handle the grantees coming to present their programs to the council? Council members were in agreement that they would like to meet with the grantees.
- Announcement that the Office for Prevention has a new Director, Jonathan Sabin.

Appendix B

Meetings of the Interagency Task Force on the Prevention of Lead Poisoning

October 6, 2011:

- Received a presentation by a federal Region 2 representative of the Environmental Protection Agency's (EPA) amendment to the Renovation, Repair and Painting (RRP) Rule.
- State Department representatives shared the impact of Federal and State budget cuts or level funding.
 - The Department of Community Affairs' Lead Hazard Control Assistance Fund received the largest loss of State funding thereby eliminating financial assistance to relocate lead poisoned children and their families. Additionally, financial assistance to property owners to perform abatement work no longer received funding.
- The Department of Health (DOH) provided a summary of the Lead Poisoning Prevention/Healthy Homes work plan components and anticipated Year 1 deliverables.
- Attendees shared their plans for National Childhood Lead Poisoning Prevention Week (October 23-29, 2011).
- Attendees participated in guided discussions regarding the Task Force's:
 - Mission
 - Strengths, weaknesses, opportunities and threats
 - Attendees' expectations
 - Format of meetings
 - Tasks

January 12, 2012:

- A needs assessment survey was conducted between the October and January meeting dates regarding Lead Task Force membership. The results were presented to the attendees.
- Discussion regarding the CDC's adoption of the recommendations from the Advisory Committee on Childhood Lead Poisoning Prevention (ACCLPP). Their report, Low Level Lead Exposure Harms Children: A Renewed Call for Primary Prevention was issued on January 4, 2012.

April 5, 2012:

- Presentation by Southern New Jersey Perinatal Cooperative staff of a Healthy Homes survey they conducted in eight southern counties with over 700 completed surveys from residents. The information on the surveys was then developed into action sheets. The draft action sheets were evaluated using focus groups to determine the usefulness of the recommendations and user-friendliness (reasonableness of the actions, low literacy). The action sheets are intended for use by health, social services, and housing home visitors.
- The draft mission statement was refined. Future "tasks" the Task Force should undertake in 2012/2013 were brainstormed.

Appendix C

Meetings of the Fetal Alcohol Spectrum Disorder Task Force

August 3, 2011

- During this meeting, Dr. McCormack (Chair of the Governor's Council on the Prevention of Developmental Disability) officially announced Dr. Susan Adubato as the new Chair for the FASD Task Force. He gave a brief overview of what was happening in the state re: OPDD and the Governor's Council. Dr. Adubato discussed 2 micro grants that she was awarded. FASD Task Force Committee reports included:
 - o A report on the continuation of the Comcast Public Service Announcements, through Sept, 2011, in all regions of NJ. Discussed other venues for the PSAs.
 - o Website: - the website is changing to make it easier to navigate, with information bullets, PSAs, webinars and podcasts available from agencies and organizations around the US. The media subcommittee still, on their own time, reviews all questions, comments and information to be put on the website;
 - o Discussions: The DSM 5 is still debating if FASD will be included. Two journal articles were given to the Task Force – one on FASD and the Law and one on recent developments in imaging in FASD.

December 7, 2011

- Almost the entire meeting was devoted to the development of a new 5 year plan. The group discussed accomplishments from the 2007 plan.
 - o For the new plan, the Task Force established 4 subcommittees: Education and Training, Prenatal and Child Screening, Treatment and Services and a new subcommittee- media. Discussions centered on what direction the Task Force needs to take for the future as well as involving other groups/NJ leaders to assist us in the plan.
- The Task Force decided to continue to offer free informational events through workshops, conferences, and health fairs. The primary educators from the Task Force were members of the Diagnostic Centers, the Maternal Child Health Consortiums (MCH), and the NJ FASD Education and Training Center.
- The MCHs continued to work with the various substance treatment centers and all medical facilities and hospitals to institute the 4 Ps Plus Screening Tool and universal screening of women.
- The Task Force increased awareness of NJ Diagnostic Centers.
- New Jersey's Birth Defects registry's numbers remain low.
- Not yet accomplished: a single point of entry for information and referral for women and children, and an established core of trained professionals who treat individuals with FASD.

April 25, 2012

- This meeting included an up-date from each of the new subcommittees regarding the new Five Year Plan, as well as FASD updates from the statewide work of the Task Force members.
 - o State PSAs were still running, and the FASD website was being updated. The meeting also featured 2 speakers from DMHS women's treatment services, as well as the state representative working on the transition for DYFS, DDD and Children and families.

Governor's Council on the Prevention of Developmental Disabilities FY 2012 Membership

Government Representatives

<i>Name</i>	<i>Department</i>
Dawn Apgar	Human Services
Sandra Schwartz	Health
Kathleen Ehling	Education
Alice D'Arcy	Community Affairs
John Bojanek	Environmental Protection
Wendy Galloway	State

Public Members FY 2012 – Present

1. Dorothy Angelini, MSN
2. Jeananne Arnone, RN, BS
3. Thomas Baffuto
4. Morris Cohen, MD
5. Deborah Davies, Ph.D
6. Mary DeJoseph, DO
7. Carol Ann Hogan, M.S., Ed.
8. William Holloway, Ph.D
9. George Lambert, MD
10. Marlene Lao-Collins
11. Lynne Levin
12. Lula Linder, MSW
13. Artea Lombardi
14. Barbara May, BSN
15. Michael McCormack, Ph.D, FACMG
16. Kevin McGovern, Esq.
17. Mariam Merced, MA
18. Judith Morales, MSW, LCSW
19. Munir A. Nazir, MD
20. Fred Patterson
21. Ana Rivera, MSW, LCSW
22. Deborah Spitalnik, Ph.D
23. Alyce M. Thomas, RD
24. Yvonne Wesley, RN, Ph.D
25. Jean Wiegner
26. Leon Zimmerman
27. Ilise Zimmerman, MPH