

Governor's Council on the Prevention of Developmental Disabilities



Report for Fiscal Year 2019



State of New Jersey

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



Department of Human Services

Carole Johnson, *Commissioner*

Division of Developmental Disabilities

Governor's Council on the Prevention of Developmental Disabilities

Report for Fiscal Year 2019

The 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 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 Interagency Task Force on the Prevention of Lead Poisoning, imbue this work with a high level of intensity and dedication.

Fiscal Year 2019 Activities

During Fiscal Year (FY) 2019, the Council met quarterly and focused on its mission. 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 2019, the Council focused on the following projects:

1. Current Issues in the Prevention of 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 affecting issues of health and support for pregnant women and child development. The following topics were reviewed:

- Early detection of autism and other developmental disabilities.
- Need for genetic evaluations of all children with autism.
- OB/GYN messages to women regarding the use of alcohol during pregnancy.
- General discussions regarding the kind of information that is provided to obstetrics patients and how that information is communicated.
- Utilization of marijuana for morning sickness and the cannabis industry promoting this practice.

- Opioid exposed babies and neonatal abstinence syndrome (NAS).
- Lead issues in New Jersey and model programs intended to address the associated concerns of lead exposure.
- Lead screening of pregnant and lactating women.
- The need for healthcare providers and community organizations to increase their awareness of cultural practices that can unknowingly put pregnant women at risk for lead poisoning. i.e. mixing soil with flour in the southern U.S.; ingesting soil from home countries; use of food, makeup and spices from home countries.
- Adverse Childhood Experiences (ACEs); how toxic stress effects the developing brain.
- As required by the New Jersey State Ethics Commission, Council members underwent Special State Officer Ethics Training.

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

The FASDTF met in August and December 2018 as well as during April 2019. Conference calls occurred in September and October 2018 and March 2019.

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 FY 19, the following issues and initiatives were determined to be priority work items by the FASDTF:

- FASD Awareness Day/Month started on September 9, 2018. The FASDTF worked with its partners to create awareness of FASD and maternal health in general. Some of these activities have targeted schools and university settings in order to focus on young people. 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 disseminate the information that people need for a safe and healthy pregnancy. A significant number of New Jersey citizens look to online information sites as a primary source for information. The FASDTF spent a significant portion of its time on the development of a new FASD information website. The creation of FASDNJ.org was the result of many hours of work by the numerous professionals that make up the FASDTF. Because of this work, New Jersey now has a website that can assist individuals and families with information regarding the prevention of FASD, FASD diagnostic information and the navigation of the varied FASD service systems within our state.
- During FY 18, a survey was sent to staff of all New Jersey Department of Health (DOH) 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 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. During FY 19, the FASDTF completed its work on this comprehensive guidebook. 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 19. 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 affect the lives of families. News outlets continue to feature reports about the country's aging water delivery infrastructure, which has detrimentally affected communities throughout the nation due to lead leaching 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 because 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 19, the Lead Task Force met in September 2018 and during November and April 2019. A conference call was conducted during September 2018. 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 19:

- New leadership for the Lead Task Force created an opportunity for the group to revisit its mission and purpose. Task force members broke into small groups, during meetings, to discuss topical issues and brainstorm about the best ways our state might address these concerns. Issues addressed include: Screening of children; reporting of data; enrollment of children with elevated blood lead levels in Early Intervention.
- The Lead Task Force heard from a number of speakers on subjects intended to assist them with their work. Speakers included:
 - Theresa Ruane from the Monmouth County Health Department. Ms. Ruane discussed the lead testing of pregnant women.
 - Jonathan Sabin, Director, Office for the Prevention of Developmental Disabilities regarding the history and role of the Governor’s Council on the Prevention of Developmental Disabilities and its task forces.
 - Siobhan Pappas from the Department of Health regarding current lead poisoning prevention issues in state government. Dr. Pappas provided updates pertaining to NJ DOH activities. These included:
 - Newark lead initiative regarding drinking water included outreach to pediatricians regarding the need to screen children, especially formula-fed infants.
 - NJ DOH is part of an interagency lead-in-drinking-water partnership between the Department of Environmental Protection, Department of Community Affairs, Department of Children and Families and Department of Education. These departments were examined variables (lead service lines, pre-1950/pre-1980 housing, child care centers, schools, and blood lead levels) to identify “hot spots” and develop collaborative interventions.
 - Both the Center for Disease Control and Prevention and the American College of Obstetricians and Gynecologists do not recommend routine screening of pregnant women---only when an assessment indicates risk. Exposures and risks differ between children and pregnant/lactating

women. For pregnant women, the risks typically do not include housing or occupational exposure. Usually the exposure includes pica issues and cultural practices (e.g. soil, Ayurvedic medications). Screeners need to understand that these issues affect the assessment and create limitations. Patients may not understand the definition of pica, and if the product is considered normal culturally then the patient may not interpret the product to be non-edible. NJ DOH has had several instances over the years in which we have had to seek medical guidance for breastfeeding mothers with elevated blood lead levels. General guidance is “breast is best,” and if necessary pump and discard until the mother’s Blood Lead Level (BLL) has dropped.

- National Childhood Lead Poisoning Prevention Week was observed from October 21-27, 2018. The NJ DOH posted information on its Facebook and Twitter accounts and webpages. Messages stressed the importance of increasing awareness of all lead hazards, educating residents about what they can do to prevent exposure, and encouraging parents to have their children tested. Messaging noted that in 2017, more than 200,000 New Jersey children were tested for lead exposure. Approximately 4,800 New Jersey children were identified with elevated blood lead levels (at or above 5 micrograms per deciliter). Additionally, NJ DOH stressed that all pediatricians in New Jersey are required to test children for lead at age one and two as part of their routine practice, and parents should ask if their children are due for testing. For uninsured and underinsured children less than six years, local health departments and community health centers provide free or low-cost testing.

4. 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.

Office for the Prevention of Developmental Disabilities Grant Funding

The OPDD funds agency projects that are intended to prevent developmental disabilities. FY 19 concludes the most recent OPDD funding cycle. FY 20 will start a new three year funding cycle. The OPDD Request for Proposal (RFP) subcommittee played a critical role in the selection of new projects to fund starting in July 2019. Members of the Council took part in a conflict of interest vetting process before serving on the subcommittee. This subcommittee reported to the Division of Developmental Disabilities (DDD) regarding the strength of proposals that were submitted in response

to the OPDD RFP. Subcommittee member expertise is an important component of the proposal review process and assists DDD in recognizing best practices and important issues influencing the prevention of developmental disabilities.

The new projects to be funded during fiscal years 2020 – 2022 are as follows:

- Parent Advocacy Network (SPAN) - \$184,975 per year
The *Empowering Women in Community Leadership for Healthier Families* project will prepare women of childbearing age as Peer Leader Liaisons (PLLs) to enhance existing state and community-based efforts to reduce the risk of preventable Intellectual/Developmental Disabilities (IDDs), specifically FAS/FASD and those caused by lead poisoning. SPAN will provide leadership training and education, to support and facilitate community engagement, for women of childbearing age for whom their children are at risk of elevated blood lead levels and/or at risk of being born with fetal alcohol syndrome (FAS)/fetal alcohol spectrum disorder (FASD). By the end of the third year, the project is expected to reach communities in nearly every county and develop the peer leadership skills of 315 to 420 diverse women. These women will participate in and have a voice in local and statewide decision-making and advocacy forums concerning FAS/FASD and lead poisoning prevention.
- Partnership for Maternal & Child Health of Northern NJ (PMCHNNJ) - \$185,000 per year.
In order to accomplish its objectives, the project will implement the National Organization on Fetal Alcohol Syndrome (NOFAS) K-12 Education and Prevention Curriculum in schools, after school programs, CBOs, and school districts serving target municipalities. During the first year of the proposed project, PMCHNNJ intends to reach schools where current Partnership programs exist, and will reach other schools and municipalities with a 15% increase in school recruitment goal for each year of the program. The K-12 curriculum addresses many important topics for school-aged students, such as: FASD, the consequences of prenatal alcohol consumption on human development, overall effects alcohol on human development, addictions, and acceptance of all people regardless of individual capabilities or disabilities. The curriculum provides FASD educational materials and lesson plans that can be implemented in classroom settings with age-appropriate information and activities, teacher background information about FASD, and a sample family letter explaining the planned unit of study.
- Rutgers School of Public Health - \$185,000 per year
The focus of this project will be young children, attending a large pediatric practice, whose parents report an early delay in social communication development, that is, children who are at greater risk of Autism Spectrum Disorder (ASD). Children's social communication development will be evaluated through use of a simple, standardized, validated questionnaire – the Psychological Development Questionnaire for Toddlers (PDQ-1) to be completed by parents

with children receiving pediatric care from the Rutgers—New Jersey Medical School (NJMS) Pediatric Continuity Care Clinic (PCCC). The PCCC is a medical anchor of Central Ward Newark. The PCCC serves as the community's first line of expertise with regard to detection of learning and developmental problems and in assisting families with special needs children. The population to be served by this project will be approximately 6,000 to 7,000 Newark-residing children between the ages of 18 and 24 months and their parents, served by the PCCC, in 2020 and 2021. Most of the screened children will be in the highest risk group for late evaluation, late diagnosis and late receipt of interventions. This project is intended to have a high impact on this population of children with ASD, who, on receiving timely autism screening, will go on to be served by their EIP.

The following programs concluded their funding during FY 19 (see Appendix C for Programmatic Reports for multiyear projects):

1. Department of Human Services, Division of Medical Assistance and Health Services (DMAHS) High-Risk for Lead Poisoning Communities/Newark-area schools - \$180,000 for one year

This joint venture between the OPDD and DMAHS was intended to provide targeted outreach via scholastic materials to Newark-area childcare centers and schools. The project provided outreach and education to people and communities in New Jersey municipalities (in particular the Newark-area) that were determined to be at greatest risk of having lead hazards. It created awareness of the associate dangers of lead hazards using scholastic materials, distributed through identified childcare centers and schools in the Newark-area. Additionally, specific attention and distribution of materials took place during Lead Poisoning Prevention Week.

2. Statewide Parent Advocacy Network (SPAN) *Prevention of Developmental Disabilities Project* - \$124,905 per year for two years

The primary goals of the SPAN OPDD FASD project included:

- Increasing the knowledge of youth ages 14 to 21 on FASD prevention and the social determinants of health that impact alcohol use by implementing an educational presentation targeting high school youth.
- Improving access to culturally, linguistically, and socio-economically relevant peer support for women at risk of alcohol use/abuse and of having a child with FASD. Goal to be achieved by collaborating with community organizations to provide enhanced peer-to-peer support groups targeting women of childbearing age to raise awareness on the social determinants of health; to learn prevention strategies to reduce the risk of FASD; and to link participants to available community resources and supports.
- The outcome analysis, presented in the final report, and submitted by an outside evaluator, noted that qualitative evidence suggests that the project was successful in achieving its dual goals of improving access to peer-to-peer

support for women at risk of alcohol use/abuse and of having a child with FASD; and increasing knowledge among youth regarding FASD prevention and general health. She notes that the high school presentations yielded similar positive, qualitative findings, with group discussion themes that suggested students learned the curriculum's key content including FAS/FASD; and risks associated with alcohol use; drug use; vaping; and smoking. The evaluator notes, however, that while these positive findings suggest the program was successful in meeting its intended goals, stakeholders should keep in mind that the type of qualitative methods used for this evaluation are generally considered limited in their ability to determine a program's actual effectiveness, from a scientific or evidence-based perspective. For this reason, designs that are more rigorous could be utilized in the future in order to provide more definitive evidence of the program's impact. She notes that in spite of these limitations, these findings, as a summary of the program participants' experiences and perspectives, provide important information and insight that may assist program leaders with making improvements when implementing similar programs in the future.

3. Spina Bifida Resource Network Fortify Your Future II Project - \$53,548 per year for two years

- The primary target population for the *Fortify Your Future II* program was: College students, with a secondary target population of Hispanic and low-income young women. This program was intended to change dietary habits to include healthier and folate-rich foods to improve health and to reduce chances of having children with disabilities. Secondly, it sought to educate on the dangers of alcohol consumption and risk of developmental difficulties.
- The second target population included young women in Hispanic communities and low-income communities and will augment the existing *Fortify Your Future/Fortifique Su Futuro* program.
- The project's outside evaluator reports that the project achieved its three main goals:
 - Prepare college students to serve as spokespeople on the importance of preconception health and reducing the risks for birth defects/developmental disabilities.
 - Increase awareness among their college peers about the need for healthy diets and behaviors before becoming pregnant to improve their health and reduce the risks of having babies with disabilities.
 - Increase healthy preconception diets and behaviors among young adults.

The evaluator notes that, based on pre-post test results, college students who participated in the Healthy Now Healthy Later train the trainer training successfully demonstrated increased knowledge and either met and/or exceeded the program's target benchmark. Additionally, these findings were supported by equally positive results from a test of knowledge administered to students who attended presentations given by their trained peers. During these

presentations, in which the majority of students successfully demonstrated knowledge of the program's key content areas, including: the importance of getting enough folic acid, calcium, and iron before getting pregnant; identifying foods that are high in calcium, iron, and folic acid; maintaining a healthy weight and the risks of binge drinking. Finally, the outside evaluator notes that this evaluation had some limitations, including the use of small convenience samples and reliance on self-reported information, which may result in a subjectivity bias. Therefore, care should be taken in extrapolating these findings to a broader population. However, the use of a mixed methods design that included multiple sources of quantitative and qualitative data may have mitigated this bias to some extent.

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 per year for three years

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 aimed 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 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 examine anatomical cerebellar development and function, behavioral measures of atypical cerebellar development, and early-life markers of infantile language. This project aimed to identify behavioral and biological markers that separately or in combination accurately identify, before age two, 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.

The agency reports testing of dozens of typically developing infants and approximately two-dozen children born prematurely. They report that novel research procedures have been developed as a direct result of OPDD funding. The agency reports having received many inquiries from labs at other universities and in other nations who wish to adopt their techniques for understanding a range of developmental phenomena. A concern throughout this project has been the agency's ability to recruit infant participants. They report that their ability to recruit and successfully test infants born prematurely with low birthweight has been challenging.

5. New Jersey Institute for Disabilities *Protection Against Zika/Protccion y Accion Contra Zika (PAZ) Project*- \$50,000 per year for three years

This project attempted to enhance the knowledge base of residents in Middlesex County who are at particular risk for contracting the Zika virus. The agency did 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. By bringing awareness of the dangers of the Zika virus and helping the community understand the ways that Zika is spread, this project intended to help impact the number of children born with developmental disabilities.

- The outside evaluator for this project notes that the results of her final evaluation confirms that the Protection Against Zika project achieved its goals and objectives. She notes that pre and post-tests confirmed that community trainings and dissemination of information had a “credible effect.” The NJ Institute for Disabilities will be continuing a modified Zika prevention program by utilizing agency discretionary funds. The evaluator noted several deviations from the original application including:
 - o A collaboration with Middlesex County College did not proceed as planned however, numerous other collaborations contributed to the program’s success.
 - o Staffing changes occurred but were addressed.
 - o The program scope was expanded to include South Asian Indian communities in central NJ.

6. Children’s Home Society of NJ Prevention of Developmental Disabilities Project - \$50,000 per year for three years

Project funding supported the “CARES for Her” preconception and prenatal health education program. CARES for Her was 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. This project attempted to accomplish its goals by delivering group education for women in central New Jersey (Mercer and Ocean Counties). It included one, three, and twelve session courses. Ultimately, these actions were intended to ensure more full-term healthy births and reduce unnecessary pre-term, low-birth babies with lifetime disabilities.

- The outside evaluator for Cares for Her reports that program completion rates were high in Mercer County but could have been improved in Ocean County. A significant percentage of the program participants in Mercer County were experiencing their first pregnancy. Conversely, the Ocean County participants were mostly individuals with a history of more than one pregnancy. The evaluator notes that at the time of intake, about one-quarter of the participants in the two Mercer County programs were not enrolled in prenatal care programs. For those that were, most began care in the first trimester of pregnancy and attended regularly.

- Access to care, lack of health insurance and inability to take time off from work were reasons given when prenatal care was inadequate. The project found that participants need encouragement to apply for NJ Family Care or Medicaid. Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) participation was low in Ocean County and SNAP enrollment was low for all programs. He recommends that effort should be focused on increasing enrollment and participation in these valuable programs. Other notable comments by the evaluator include:
 - o The birth weight of infants born to participating mothers compared favorably to county-wide data by race/ethnicity
 - o Consumer feedback was uniformly very positive.
 - o Extra effort needs to be applied to ensuring data collection is more complete, particularly with information regarding prenatal visits, substance use, and domestic violence.
 - o Program participants may need additional encouragement to complete the Client Satisfaction Questionnaire number Eight (CSQ-8) consumer satisfaction questionnaire.

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

This project trained home visitors and community health workers to utilize a modified version of the Screening, Brief Intervention, and 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 intended to train approximately 50 home visitors and community health workers, who would reach at least 500 clients annually. The funding also supported the creation of an FASD “toolkit” for distribution to home visitation clients. This toolkit included educational materials selected for linguistic and cultural appropriateness, which serves as a reference for clients. The projects outside evaluator reported the following:

- A total of 42 home visitors and community health workers attended the program trainings. Among home visitors/community health workers, who attended the training, a statistically significant increase was found in all four of the program's key competency areas, including: overall knowledge of the SBIRT method; comfort level with asking clients about their substance use; comfort level in beginning the conversation about substance use; and level of preparation to use the SBIRT technique with clients.
 - o 95% reported an increase in their comfort level with using the SBIRT method with clients.
 - o 100% reported being either *very likely* or *moderately likely* to use the SBIRT method with their clients.
 - o According to qualitative data, training participants were highly satisfied with the training, experienced it as very valuable, and planned to integrate what they learned into their professional practice, particularly with regard to improving communication with, and understanding their clients.

- Home visitors and community health workers distributed the program Toolkits and education to 561 clients.
 - o Clients' overall knowledge of FASD increased significantly, from an average score of 87 prior to receiving the program education to 97 afterwards (out of 100 possible points).
 - o 90% of participating clients reported an increase in their knowledge about the links between FASD and developmental disabilities.
 - o After receiving the program education, participating clients reported their plans to abstain from alcohol during pregnancy increased to 84%.

The evaluator noted that these positive results provide preliminary evidence for the program's effectiveness in achieving its short- and medium-term outcomes. She cautions that because an evaluation of the program's long-term outcomes, including actual behavior change and birth outcomes, was beyond the timeframe and scope of the current project, the extended impact of the program is unknown. Finally, the evaluator reports that the evaluation had some limitations, including the use of small convenience samples, which may not be generalizable to larger populations. In addition, the project relied primarily on self-reported information, which may have resulted in a subjectivity bias. For these reasons, she warns of extrapolating the results to the broader group of program participants. However, the use of a mixed methods approach that included multiple sources of quantitative and qualitative data may have mitigated this bias to some extent.

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

6/12/2019

- Healthy Spaces ACES Initiative
Aldina Hovde – NJ Chapter of American Academy of Pediatrics

3/13/2019

- Implications of Cannabis on Developing Fetus
Dr. Cheryl A. Kennedy – NJ Medical Marijuana Review Panel

12/12/2018

- Autism Surveillance in NJ
Dr. Walter Zahorodny – Rutgers, NJ Medical School

9/12/2018

- Child Evaluation Center Practice
Dr. Denise Aloisio – Jersey Shore University Medical Center

Appendix B

Governor's Council on the Prevention of Developmental Disabilities FY 2019 Membership

State of New Jersey Government Representatives

Jonathan Sabin	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, M.A., LDTC
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. Barbara May, RN, MPH
13. Michael McCormack, Ph.D., FACMG
14. Judith Morales, MSW, LCSW
15. Munir Nazir, MD
16. Beatriz Osterheld
17. Daniel Ranieri
18. Marlene Schwebel, JD,APN
19. Alyce M. Thomas, RD
20. Yvonne Wesley, RN, Ph.D.
21. Thomas Westover, MD
22. Jean Wiegner, CSNA
23. Leon Zimmerman
24. Ilise Zimmerman, MS

Staff

Jonathan Sabin, LSW

Director, Office for the Prevention of Developmental Disabilities

Appendix C

**OPDD Funded
Programmatic Reports for Multiyear Projects**

CARES for Her

The Children's Home Society of New Jersey

Final Program Report

Under Contract with the
New Jersey Department of Human Services
Division of Developmental Disabilities
Office for the Prevention of Developmental Disabilities

Leonard Feldman, Ph.D.

Data Support:
Dana Johnson
Ruth Ruggentaler-Cooper
Choresse Blue

August 2019

Summary

“Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. About one in six children in the U.S. have one or more developmental disabilities or other developmental delays.” Most developmental disabilities begin before a baby is born.¹

As a preventative, The Children’s Home Society of New Jersey has delivered CARES for Her, prenatal health education services to women living in Mercer and Ocean counties over a three-year period beginning July 2016. Services include primary prevention single session workshops, three session programs for women in the latter stages of their pregnancy and nine, 12 and 16-session prenatal education programs. CUNA for Latino women is offered in Mercer and Ocean counties. The Body and Soul Program is provided for African American women residing in Mercer County.

This report provides descriptive information about the CUNA and Body and Soul Program participants, the level of their participation in CUNA or Body and Soul and their compliance with healthy prenatal activities including prenatal visits, use of prenatal vitamins, participation in WIC and SNAP and the use of alcohol, drugs and tobacco products. The report also documents birth outcomes such as the length of the gestational period and birth weight and provides consumer feedback about the services provided.

Participant Characteristics

- The total level of service (LOS) was 728 women across all program components.
- Detailed data are reported for 226 Mercer County CUNA, 81 Mercer Body and Soul and 84 Ocean County CUNA participants.
- One-third of the CUNA participants in Mercer County were primigravida; and one-half of the Body and Soul participants were primigravida; 89 percent of the women in Ocean County CUNA were multigravida.
- 35 percent of the women in the Ocean County CUNA program were over 35 years of age, a factor for increased risk.
- 99 percent of Mercer County CUNA, 94 percent of Ocean County CUNA and 12 percent of Body and Soul participants were born outside the US.
- Over half of the CUNA mothers’ country of origin was Guatemala and 76 percent of the Ocean CUNA participants came from Mexico.
- Most Mercer County program participants attended or graduated high school while those in Ocean County mostly completed or attended grade school.
- CUNA participants were likely to be in a long-term relationship or married while the women attending Body and Soul were more likely to be single.

¹ <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>

- Anemia, diabetes, and infections were medical conditions typically being treated during pregnancy.
- The use of alcohol, drugs and tobacco appear underreported for the women in the two Cuna programs.
- A history of prior domestic violence appears to be underreported.
- Program participants appeared to have a social support network including parents, Husbands or partners and friends.
- Based on a measure of perceived social support, the program participants expressed a need for additional concrete and emotional/informational supports.

Program Participation

- The Mercer County women had a high program completion rate. The Ocean County CUNA participants have a significantly lower rate of program completion (63 percent).
- At the time of intake, 24 and 27 percent of the Mercer County CUNA and Body and Soul women respectively were not enrolled in prenatal care.
- One fifth of the women began prenatal care in the second or third trimester for the Body and Soul and Ocean CUNA programs.
- All prenatal appointments were reported to be kept in Mercer County for over 97 percent of the participants. The rate was 55 percent in Ocean County and 69 percent for Body and Soul participants.
- Charity care was the most frequent method of financing prenatal care for the women in the two CUNA programs. Medicaid and New Jersey family care were most often used by the women participating in Body and Soul.
- Prenatal vitamin usage was adequate for the Mercer County program participants but was very low in the Ocean County CUNA program (35 percent).
- WIC participation was very low among the Ocean County participants (17 percent).
- SNAP (Food Stamps) participation was low for the participants in all three programs.

Birth Outcomes

- The gestational period was full-term for almost all the births.
- The mean birth weight of program participants compared very favorably to year 2017 birth data by county and race/ethnicity.
- A significant number of the deliveries were planned or emergency cesarean sections.
- Only a very small percentage of newborns had a physical or mental disability at birth.
- Ten Mercer County CUNA, seven Body and Soul, and zero Ocean County CUNA participants had newborns placed in the Neonatal Intensive Care Unit.
- Two-thirds to three-quarters of these new mothers nursed their newborns.
- The gains on the social support measure were statistically significant for most subscales.

Consumer Feedback

- Consumer feedback indicated a uniformly high level of client satisfaction with the services provided by CARES for Her.
- A second form of consumer feedback allowed program participants to identify topics covered by the programs that they initially knew very little about, felt were most important to them, learned the most about, and would lead them to change their behavior or take other actions.

Recommendations

- A greater emphasis needs to be placed on improving data collection in some critical areas:
 - the month starting prenatal visits, the number of prenatal visits and the gestational period;
 - use and disuse of alcohol, drugs and tobacco products;
 - CSQ-8 consumer satisfaction questionnaires;
 - Service needs; and
 - Identification of providers for prenatal care in Ocean County.
- Clarify the reported barriers to prenatal care and work with future program participants to maximize those visits.
- A greater emphasis should be placed on encouraging longer-term breast-feeding as well as increasing participation in WIC and SNAP programs.
- Help program participants enroll in New Jersey Family Care or Medicaid as appropriate.
- Clarify the difference between planned and emergency cesarean sections and determine the reason for emergency cesarean sections.

Overview

The Children's Home Society of New Jersey has delivered CARES for Her, prenatal health education services to women living in Mercer and Ocean counties over a three-year period beginning July 2016. This report covers the period, July 1, 2016 through June 30, 2019. Services are funded in part by the New Jersey Division of Developmental Disabilities. The program targets immigrant and minority women with limited access to public health information and social networks. Participants have received knowledge and learned behaviors that promote healthy fetal development, prevent alcohol and substance abuse, and increase the likelihood of more full-term, healthy births, reducing unnecessary preterm, low birth weight babies with lifetime disabilities. "The cognitive and physical development of infants and children may be influenced by the health, nutrition, and behaviors of their mothers during pregnancy and early childhood.²"

The CARES for Her program, designed specifically for low-income women living with the stress of poverty, immigration issues and social isolation, directly addresses infant health disparities through education and monitoring of prenatal visits and the connection between mind and body while imparting crucial information on actions that effect infant development. For a three-year period, 728 women were served across all program components.

Programming was provided through linguistically and culturally appropriate programs. Services were delivered through three modules:

1. Single session workshops— these primary prevention workshops were designed for women who are not pregnant, including women who have recently delivered and are planning additional children and women who have previously delivered preterm. The topics were designed to arm the participants with knowledge to reduce the likelihood of future children having developmental disabilities. The staff in Mercer County provided 25 single session workshops for 207 individuals. Ocean County offered eight sessions for 44 participants.
2. Three session workshops – these workshops were offered to women in the second or third trimester of their pregnancy. In addition to the material covered in the single session workshops, content also included:
 - Nutrition (Rutgers SNAP-ed);
 - Preparing for your Baby;
 - Pregnancy and Post-Partum; and
 - Caring for your Baby.

² <https://www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health>

Mercer County provided four, three session workshops serving 69 individuals. Ocean County provided five, three session workshops for 17 women.

3. Nine, 12 and 16 session courses provided extended prenatal education to pregnant women. The descriptive and outcome data in this report relate to participants attending CUNA or Body and Soul. The primary goal of both programs was to promote healthy birth outcomes by having participants: avoid smoking, alcohol, and drugs during pregnancy; attend and receive adequate prenatal care; experience increased social support from a support network; and increase their knowledge about their health needs and the prenatal needs of their developing babies.

CUNA was delivered in Spanish and tailored to immigrant and other Spanish-speaking women who were relatively early in their pregnancies. CUNA is based on the March of Dimes Comenzando Bien curriculum. The Body and Soul curriculum, designed for African American women, was delivered in English and emphasized spirituality and stress reduction. CUNA served 226 mothers-to-be in Mercer County and 84 women in Ocean County. Body and Soul was provided to 81 women in Mercer County.

This report provides descriptive information about the characteristics of the mothers-to-be participating in CUNA (both counties) or Body and Soul. It reports on changes in levels of perceived social support and adequacy of prenatal care. Having a healthy pregnancy is one of the best ways to promote a healthy birth. Getting early and regular prenatal care improves the chances of a healthy pregnancy. The evaluation also presents birth outcomes data in comparison to a larger population (county-wide) of pregnant women. There is a discussion of consumer feedback, including feedback on what the women felt they learned, what information was most important to them and what behaviors may have been modified because of their participation in a pre-natal education program. A description of the participants follows organized by county and program. Most of the data are reported as percentages. Some of the descriptive data is not complete for all the participants due to database revisions or difficulty in collecting the information.

Description of Participants

About one-third of the Mercer County CUNA and half of the Body and Soul participants were pregnant for the first time. Eighty-nine percent of the Ocean County program had experienced a previous pregnancy. See Table 1.

Table 1. First Pregnancy

	CUNA (%) N=220	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=83
Primigravida	32	52	11
Multigravida	68	48	89

Typically, women who were multigravida and, in these programs, had a median of 3 previous pregnancies; some had up to 10 previous pregnancies (see Table2). The ratio of pregnancies to live births was 3:2 for CUNA, 3:1 for Body and Soul mothers, and 4:2 for CUNA in Ocean County.

Table 2. Median number and range of pregnancies, births and children living with the mother

	CUNA N=102	Body and Soul N=31	CUNA (Ocean County) N=47
Pregnancies	3 (2-10)	3 (2-8)	4 (2-9)
Births	2 (0-5)	1 (0-5)	2 (1-7)
Living with Mother	1 (0-5)	1 (0-5)	2 (0-6)

“One of the most common risk factors for a high-risk pregnancy is the age of the mother-to-be. Women who will be under age 17 or over age 35 when their baby is due are at greater risk of complications than those between their late teens and early 30s. The risk of miscarriage and genetic defects further increases after age 40³.” There were very few, very young program participants. However, 21 percent of the CUNA participants and 35% of the Ocean County participants were over age 35 at intake and would be considered in a higher risk group. These data are displayed in Table 3.

Table 3. Age at time of intake

	CUNA N=223	Body and Soul N=80	CUNA (Ocean County) N=83
Median Age	30	24	33
Range	15-48	15-43	16-46
Percent < 17 Years	1	1	1
Percent > 35	21	13	35

Country of Origin and Time in The United States

Ninety-nine percent of Mercer County CUNA, 94 percent of Ocean County CUNA and 12 percent of Body and Soul participants were born outside the US. Program participants come from Canada and a variety of Central American, South American and African countries including:

³ <https://www.webmd.com/baby/managing-a-high-risk-pregnancy#1>

- Argentina
- Canada
- Colombia
- Costa Rica
- Dominican Republic
- Ecuador
- El Salvador
- Ghana
- Guatemala
- Guyana
- Haiti
- Honduras
- Liberia
- Mexico
- Panama
- Peru
- Puerto Rico
- Trinidad and Tobago
- Venezuela

Over half of the CUNA mothers' country of origin was Guatemala and 76 percent of the Ocean CUNA participants came from Mexico.

Mercer County CUNA women not born in the US have been residents for a median of three years (1-20 yrs.). Body and Soul residents have been here for a median of 11 years (1-15 yrs.). Ocean CUNA participants have been living in the United States the longest with a median stay of 12 years (1-20 yrs.).

Table 4 displays the educational achievement of the program participants. Typically, Mercer County participants had high school degrees or participated in high school. Sixty-six percent of Ocean County CUNA participants had a grade school education or less (K-8).

Table 4. Educational Achievement

	CUNA (%) N=224	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=84
No Formal Schooling	<1	0	0
Some Grade School (K-8)	19	1	52
Completed Grade School	6	0	14
Some High School	18	23	12
Completed High School	25	46	13
AA Degree	4	1	1
Some College	9	20	6
Bachelor's degree	14	9	0
Some Graduate School	<1	0	0
Master's Degree	1	0	0
Some Post-Masters	<1	0	0
Ph.D.	<1	0	0
Declined to Answer	1	0	1
Total	100	100	100

Fifty-eight percent of the Mercer County CUNA participants reported living with a partner or spouse. The percentage was 24 and 66 percent for Body and Soul and Ocean County CUNA women respectively. Body and Soul Participants were more likely than the other two groups to be single (see Table 5).

Table 5. Marital Status

	CUNA (%) N=215	Body and Soul (%) N=79	CUNA (Ocean County) (%) N=84
Long Term Relationship	29	14	36
Married	34	9	33
Other	10	37	13
Separated or Divorced	1	1	0
Single	26	39	18
Total	100	100	100

Table 6 presents a list of a variety of health issues including anemia, infections, and diabetes. Infections the mother might have during pregnancy can lead to a developmental disability. For example, 25 percent of hearing loss in babies is due to maternal infections during pregnancy⁴. Of the 62 medical issues reported for CUNA cases, 23 percent were infections. For the Body and Soul mothers, 25 percent of the 48 medical issues reported were for anemia. Seventeen percent of the medical issues reported for CUNA Ocean, were for anemia. These findings point

⁴ <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>

up the need for early and regular prenatal care as well as education about the types of medical issues that can arise during pregnancy.

Table 6. Treated for medical conditions during pregnancy

	CUNA (%) N=62 Issues Reported	Body and Soul (%) N=48 Issues Reported	CUNA (Ocean County) (%) N=24 Issues Reported
Anemia	13	25	17
Anxiety	2	2	4
Asthma	0	2	0
Depression	10	11	13
Diabetes (before pregnancy)	11	8	8
Gestational Diabetes	13	2	13
High Blood Pressure (before pregnancy)	5	8	0
High Cholesterol	3	0	0
Infections	23	2	8
Other	8	27	8
Overweight/Obese	2	0	0
Pregnancy Induced High Blood Pressure	2	0	8
Problems with Placenta	3	0	8
Sickle Cell Anemia	0	4	0
Vaginal Bleeding	6	8	13
Total	100	100	100

Tables 7 and 8 provide data on some additional risk factors during and after pregnancy—substance abuse and domestic violence. It is possible that this data represents an undercount and thus may not be reliable. Seven participants in CUNA and three participants in Body and Soul acknowledged being victims of domestic violence in the year before this pregnancy. No one in the Ocean CUNA program reported past domestic violence. This is likely an undercount as national statistics indicate a domestic violence rate of 36 percent over the course of a women’s life.⁵

⁵ *National Intimate Partner and Sexual Violence Survey, 2010 Summary Report. National Center for Injury Prevention and Control, Division of Violence Prevention, Atlanta, GA, and Control of the Centers for Disease Control and Prevention.*

Table 7. History of Substance Abuse and Tobacco Before Pregnancy

	CUNA (%) N=221	Body and Soul (%) N=80	CUNA (Ocean County) (%) N=84
Alcohol Use	33	33	2
Drug Use	1	26	None Reported
Tobacco Use	2	22	None Reported

Table 8. Prior History of Domestic Violence

	CUNA (%) N=219	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=82
Prior Domestic Violence	2	8	0
No History	98	82	100

As seen in table 9, parents, partners, friends and relatives form the foundation of a mothers-to-be support networks. The 226 Mercer CUNA program participants identified from none to four supports; an average of 1.2 people. The 81 Body and Soul mothers-to-be named from none to six supports for an average of 2.3 people in their support network. In Ocean County 84 participants named from none to four supports for an average of one support person to rely on (see Table 9).

Table 9. Social Support Network

	CUNA (%) N=292 Supports	Body and Soul (%) N=187 Supports	CUNA (Ocean County) (%) N=110 Supports
Father	2	9	2
Friend	4	12	13
Husband	7	1	9
Mother	10	23	7
Other	1	3	3
Partner	54	27	57
Relatives	13	10	7
Sibling	9	15	2
Total	100	100	100

Social Support Survey

To measure changes in perceived social support, a 19 item, multi-dimensional social support survey developed for the Rand Medical Outcomes Study⁶ was employed, pre- and post-intervention, after it was translated into Spanish. The survey measures the availability of four types of functional social support, i.e., interpersonal relationships that serve particular functions. The four dimensions include:

- Emotional/informational support;
- Tangible (concrete) support;
- Positive social interaction; and
- Affectionate support.

The social support items with the lowest scores or highest need (in ascending order) on the pre-test, by program are listed in Table 10.

Table 10. Social Support Needs

CUNA	Body and Soul	CUNA (Ocean County)
Someone to help with daily chores if you were sick	Someone who understands your problems	Someone to prepare your meals if you were unable to do it yourself
Someone to prepare your meals if you were unable to do it yourself	Someone to help you if you were confined to bed	Someone to help you if you were confined to bed
Someone to give you information to help you understand a situation	Someone to give you good advice about a crisis	Someone to help with daily chores if you were sick
Someone to share your most private worries and fears with	Someone to take you to the doctor if you needed it	Someone to take you to the doctor if you needed it
Someone to help you if you were confined to bed	Someone to help with daily chores if you were sick	Someone to give you information to help you understand a situation

These were areas where the participants reported the least likelihood of support. In CUNA and Body and Soul, three of the five items with the lowest scores were for tangible support or concrete assistance. Two needs are for emotional and informational support. In Ocean County CUNA, four of the social support items are for tangible support and one is for emotional and informational support.

The items that constitute this measure of social support can be rated from 1 (“None of the Time”) to 5 (“All of the Time”) with 5 being the highest or most positive score.

All the scale items are then combined into four summary indices for the four types of functional social support (as described above) and an overall index. The highest deficit (lowest mean

⁶ https://www.rand.org/health/surveys_tools/mos/social-support.html

scores) were for tangible (concrete) support followed by emotional and informational support and the need for positive social interaction (Table 11).

The pre-test scores for the summary indices will be compared to the post-test scores in a later section of the report.

Table 11. Social Support Summary Indices (Means)

	CUNA N=160	Body and Soul N=66	CUNA (Ocean County) N=61
Affectionate Support	4.4	4.0	3.8
Positive Social Interaction	4.2	3.9	3.5
Emotional and Informational Support	3.8	3.8	3.4
Tangible Support	3.6	3.7	3.3
Overall Support Index	3.9	3.8	3.4

Table 12 displays the expressed service needs of program participants. These included: Family Success Center programming, Early Head Start, and a variety of concrete services by women in the Mercer County CUNA program. Women in the Ocean County CUNA program reported a need for tangible services, Family Success Center programming, and referral to other agencies. Housing assistance was most important to Body and Soul participants.

Table 12. Service Needs

	CUNA (%) N=33 Service Needs	Body and Soul (%) N=32 Service Needs	CUNA (Ocean County) (%) N=218 Service Needs
Child Care	0	3	1
Concrete Services (food, clothing, utilities)	12	6	27
Early Head Start	21	9	0
Emergency food, clothing	0	3	0
Employment Assistance	3	3	0
English as a Second Language	0	0	2
Family Success Center	30	6	28
Financial Assistance	0	3	2
Housing Assistance	0	19	0
Immigration Assistance	0	0	0
Medical Needs	3	3	0
Other	15	34	2
Referral to other agencies for services	3	6	35
SNAP	0	0	0
WIC	12	3	2
Total	100	100	100

Program Participation

As displayed in tables 13 and 14, most participants attended 12 session programming. CUNA is 12 sessions and a subset, “Comenzando Bien” is run in nine sessions. Body and Soul is generally 12 sessions with a subset, “Becoming a Mom” run in nine sessions. Sixteen session programming began in January 2019 for CUNA in Mercer County. Additional workshops and a hospital tour were included in the sixteen sessions. The group completion rate was highest for the Body and Soul participants at 83 percent. CUNA in Ocean County had the lowest completion rate at 63 percent.

Table 13. Program Sessions

	CUNA (%) N= 218	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=78
Nine Sessions	27	44	26
Twelve Sessions	58	56	74
Sixteen Sessions	15	0	0
Total	100	100	100

Table 14. Program Completion Rate

	CUNA (%) N=191	Body and Soul (%) N=58	CUNA (Ocean County) (%) N=27
Completed All Sessions	76	83	63
Did Not Complete All Sessions	24	17	37
Total	100	100	100

A critical aspect of care while pregnant involves regular pre-natal visits (PNV) to assess the health of the mother and growing fetus. The CARES for Her program works with program participants to encourage the selection of a provider early in the pregnancy along with regular visits to that provider during and after the pregnancy. At intake, 20 to 25 percent of Mercer County participants did not see a provider for prenatal visits. Most women began their prenatal visits during the first trimester of their pregnancy. However, 21 and 22 percent of the Body and Soul and Ocean CUNA mothers-to-be respectively, waited until the second or third trimester (see Table 15). Comparatively, in 2017, in Mercer County, the percentage of Hispanic mothers-to-be in the population who waited until the third trimester to begin prenatal care was 7 percent. For African Americans, the percentage was 10 percent. In Ocean County, 5 percent of pregnant women waited until the third trimester to begin care⁷.

⁷ <https://www-doh.state.nj.us/doh-shad/query/builder/birth/PNCtri3Cnty/PNC.html>

Prenatal Visits

Table 15. Prenatal Visit Participation at Intake and Trimester when Care Started

	CUNA (%) N=220	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=83
Attending Prenatal Visits at Intake	73	76	95
No Prenatal Visits	27	24	5
Total	100	100	100
Prenatal Visits Started:			
First Trimester	91	79	78
Second Trimester	9	19	20
Third Trimester	0	2	2

The participants in the Mercer County CUNA program had a good track record of keeping their prenatal appointments. The Ocean County program had a significantly lower prenatal visitation rate. Body and Soul participants had the largest percentage (18 percent) of women not keeping their appointments at all (as displayed in Table 16).

Table 16. Level of Participation for Prenatal Visits

	CUNA (%) N=100	Body and Soul (%) N=49	CUNA (Ocean County) (%) N=51
All Appointments Kept	97	69	55
Most Appointment Kept	0	12	27
Some Appointments Kept	0	0	4
Minimum Appointments Kept	0	0	12
No Appointments Kept	3	18	2
Total	100	100	100

Table 17 displays reported barriers to completing prenatal visits. Mercer County program participants identified lack of access and lack of insurance as the major reasons for not completing prenatal visits. Ocean County participants identified conflict with work schedules and lack of time as the major reasons for failed visits.

Table 17. Barriers to Prenatal Visits

	CUNA (%) N=23 Barriers	Body and Soul (%) N=12 Barriers	CUNA (Ocean County) (%) N=31 Barriers
Conflicts with Work	4	0	42
Don't know where to go	0	17	0
How treated	9	0	0
Lack of Access	35	8	0
Lack of Child Care	0	0	10
Lack of Insurance	17	33	6
Lack of Interest	0	0	6
Lack of Money	0	17	3
Lack of Support	0	8	10
Lack of Time	4	0	16
Lack of Transportation	4	0	3
Language Barrier	9	0	3
Other	17	17	0
Total	100	100	100

Maternity services at Capital Health in Hopewell was the was the major provider in Mercer County. Maternity service providers in Ocean County were not detailed (see Table 18).

Table 18. Provider for Prenatal Care

	CUNA (%) N=201	Body and Soul (%) N=78	CUNA (Ocean County) (%) N=73
Capital Health	94	70	0
None – Need Referral	2	3	0
Other	1	13	97
Princeton Medical Center Prenatal	1	1	0
Private OBGYN	1	13	1
Monmouth Medical Center	0	0	1
Total	100	100	100

As Table 19 shows the New Jersey Hospital Care Payment Assistance Program (Charity Care), essentially, no insurance, constitutes 52 and 67 percent of the insurance coverage for Mercer and Ocean County CUNA participants respectively. Body and Soul participants were more apt to rely on Medicaid or New Jersey Family Care.

Table 19. Mother's Insurance Status

	CUNA (%) N=214	Body and Soul (%) N=74	CUNA (Ocean County) (%) N=84
Affordable Care Act	0	0	1
Applied, waiting response	4	3	1
Charity Care	52	1	67
Medicaid	8	35	17
Medicare	1	1	0
NJ Family Care	8	32	1
None— need to apply for insurance	26	7	13
Private Insurance	0	20	0
Total	100	100	100

Compliance with the use of prenatal vitamins was high in the two Mercer County programs but less so in Ocean County (see Table 20).

Table 20. Mother's Use of Prenatal Vitamins

	CUNA (%) N=222	Body and Soul (%) N=78	CUNA (Ocean County) (%) N=83
Always	86	81	35
Never	9	9	18
Rarely	2	0	11
Sometimes	3	10	36
Total	100	100	100

"The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides Federal grants to States for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk. Research has shown that the WIC Program has been playing an important role in improving birth outcomes and containing health care costs."⁸

WIC participation has been shown to: lead to longer pregnancies; fewer premature births; lower incidence of moderately low and very low birth weight infants; and fewer infant deaths⁹.

⁸ <https://www.fns.usda.gov/wic/about-wic-how-wic-helps>

⁹ Ibid.

About one-fifth of the mothers-to-be are not participating in Mercer County. WIC participation in Ocean County was extremely low at 17 percent (as in Table 21).

Table 21. WIC Program Participation

	CUNA (%) N=221	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=84
Don't Know if Eligible	5	1	1
Not Participating	19	19	82
Not Eligible	1	0	0
Yes – Participating	75	80	17
Total	100	100	100

The Supplemental Nutrition Assistance Program, formerly known as the Food Stamp Program, provides food-purchasing assistance for low- and no-income people. The program served 75.4 percent of those eligible for benefits in New Jersey in 2014¹⁰. Comparatively, participation levels at 6 to 30 percent for the CUNA and Body and Soul Programs is very low.

Table 22. SNAP Participation – Food Stamps

	CUNA (%) N=218	Body and Soul (%) N=81	CUNA (Ocean County) (%) N=84
Don't Know if Eligible	3	2	1
Not Participating	58	91	56
Not Eligible	19	0	13
Yes – Participating	20	6	30
Total	100	100	100

Birth Outcomes

Birth outcomes were measured in terms of the length of gestation, birth weight, NICU stays, and problems at birth. Program data are compared to county population level birth outcome data by race/ethnicity.

Type of Delivery

Table 23 displays the type of delivery experience by program participants. In 2017 the New Jersey C-section rate was 37.4 percent, the 10th highest in the country.¹¹ The Mercer County rate in 2017 was 34.9 percent and Ocean County's rate was 20.9 percent. Reducing cesarean births among low-risk (full-term, singleton, and vertex presentation) women is a goal of the

¹⁰ <https://www.fns.usda.gov/ops/snap-community-characteristics-new-jersey>

¹¹ https://www.cdc.gov/nchs/pressroom/sosmap/cesarean_births/cesareans.htm

Healthy People 2020 initiative¹². The rate of Cesarean births in 2017¹³ for Hispanic women in Mercer County was 30.7 percent. In Ocean County the rate for Hispanic women was 33.9. This compares favorably to the CUNA data in both Mercer and Ocean Counties. The rate for Black-non-Hispanic women in 2017 was 38.6 percent. The participants in Body and Soul had a 32 percent rate for caesarian births.

Table 23. Type of Delivery

	CUNA (%) N=217	Body and Soul (%) N=68	CUNA (Ocean County) (%) N=55
Vaginal	75	68	91
Planned C-Section	10	10	4
Emergency C-Section	15	22	5
Total	100	100	100

Length of Gestation

As in Table 24, most singleton births were full-term with a gestational period of over 39 weeks for Mercer and Ocean County CUNA programs. The mean gestational age for body and soul participants was almost 39 weeks.

Table 24. Gestational Period

	CUNA (%) N=195	Body and Soul (%) N=61	CUNA (Ocean County) (%) N=55
Very Pre-Term (< 32 weeks)	0	5	0
Pre-Term (<37 weeks)	4	5	0
Full Term	96	90	100
Total	100	100	100
Mean Gestational Age	39.2	38.8	39.6
Median Gestational Age	39.0	40.0	40.0
Range	33-42	28-41	38-40

Seven Mercer County CUNA moms delivered prematurely. Six Body and Soul babies were considered pre-term. No Ocean County CUNA deliveries were pre-term.

¹² <https://www.healthypeople.gov/>

¹³ <https://www-doh.state.nj.us/doh-shad/query/result/birth/MODCesarean/MOD.html>

Birthweight

Pediatricians have long been familiar with the increased risk of mortality and early morbidity of babies born very small or very early. These babies have a greater risk of dying throughout the first year of life. In addition, they are more likely to have a range of morbidities, particularly neurological, respiratory, and gastrointestinal.

In the last 20 years or so, there has been increasing evidence that size at birth is also associated with later health, particularly with the chronic degenerative diseases that are major causes of death in middle and later life. The best documented are the relations between smaller size at birth and higher death rates from coronary heart disease and stroke. Smaller size at birth is also related to increased levels of cardiovascular risk factors such as hypertension, type II diabetes mellitus, and hyperlipidemia¹⁴.

Over 90 percent of program participants delivered normal weight babies. A comparison can be made with New Jersey County population data. The latest New Jersey State Department of Health data is for 2017¹⁵. The data is organized by county and race/ethnicity. CARES for Her participant birthweights compared favorably (see Table 25).

Table 25. Birth weight by program with a comparison to population data

	CUNA (%) N=202	Body and Soul (%) N=55	CUNA (Ocean County) (%) N=56
Very Low Birth Weight (< 1,500 gms)	0	5	0
Low Birth Weight (>=1,500 and <2,500 gms)	3	4	0
Normal Birth Weight (>= 2,500 gms)	97	91	100
Mean Birth Weight in grams	3,292	3,175	3,492
Range in grams	1,673-4,536	1,134-4,422	3,090-4,082
Comparison with Population Data	Mercer	Mercer	Ocean
Total births in 2017	N=1,175	N=985	N=868
Mean Birth Weight by County and Race	3,241	3,127	3,254

A one-sample t-Test compared the state averages to the program data. The difference in birth weights was not statistically significant in Mercer County. The mean birthweight for the Ocean

¹⁴ <https://fn.bmj.com/content/86/1/F7>

¹⁵ <https://www-doh.state.nj.us/doh-shad/home/Welcome.html>

County CUNA babies was, however, statistically significantly higher than the County average $t(55) = 10.32, p = .01$.

Physical or Mental Disability at Birth

As displayed in Table 26, a very small percentage of newborns in Mercer County had a physical or mental disability at birth. None were reported from CUNA in Ocean county.

Table 26. Physical or Mental Disabilities at Birth

	CUNA (%) N=213	Body and Soul (%) N=64	CUNA (Ocean County) (%) N=57
Yes	2	3	0
No	98	97	100
Total	100	100	100

NICU Usage

Table 27 displays the percentage of babies needing care in a Neonatal Intensive Care Unit (NICU). There were ten Mercer CUNA, seven Body and Soul and no Ocean County CUNA participants with newborns needing placement in a NICU.

Table 27. Neonatal Intensive Care (NICU)

	CUNA (%) N=210	Body and Soul (%) N=59	CUNA (Ocean County) (%) N=56
Yes	5	11	0
No	95	89	100
Total	100	100	100

Breastfeeding

“Breastfeeding, with its many known health benefits for infants, children, and mothers, is a key strategy to improve public health. The American Academy of Pediatrics recommends that infants be exclusively breastfed for the first 6 months with continued breastfeeding alongside introduction of complementary foods for at least 1 year.¹⁶”

¹⁶ <https://www.cdc.gov/breastfeeding/data/reportcard.htm>

Table 28. Breast-Feeding

	CUNA (%) N=220	Body and Soul (%) N=68	CUNA (Ocean County) (%) N=83
Breastfeeding Only	64	73	67
Breastfeeding and Formula	65	43	28
Formula Only	7	9	9

Among infants born in 2015 in the United States, 4 out of 5 (83.2) started to breastfeed, over half (57.6) were breastfeeding at 6 months, and over one-third (35.9) were breastfeeding at 12 months. New Jersey data for infants born in 2015 indicate that 82.8 percent were ever breast fed. At six months, 57.6 percent were breast feeding and at 1 year, 36.1 percent were breast fed.¹⁷ As can be seen in Table 28, breast-feeding is not a universally accepted practice with newborns. What makes this of more concern is the drop-off in breast feeding that is likely to occur over time, mirroring the state data. The data also suggests some ambivalence with nursing as many of the mothers-to-be seem unable to choose between only breastfeeding or combining breastfeeding with formula.

Social Support Outcomes

At the end of each program cycle, the social support measure was administered a second time to each of the CUNA and Body and Soul participants. As can be viewed in Table 30, there was a gain in all the support measure's subscales and in the measure of overall support. Using a paired t-Test, the gains in the indices were found to be statistically significant for all the subscales and overall support except for Body and Soul Affectionate support.

¹⁷ Ibid.

Table 30. Changes in Perceived Social Support (Pre- and Post-Intervention)

	CUNA N=117	Body and Soul N=38	CUNA (Ocean County) N=52
Emotional/Informational 1	3.7	3.7	3.3
Emotional/Informational 2	4.3**	4.1*	4.0**
Tangible1	3.5	3.7	3.1
Tangible2	4.1*	4.1*	3.9**
Affectionate1	4.4	4.0	3.8
Affectionate2	4.7**	4.2	4.4**
Social Interaction1	4.1	3.8	3.4
Social Interaction2	4.5**	4.2*	4.2**
Overall Support1	3.9	3.8	3.4
Overall Support2	4.4**	4.2**	4.1**

* p< .05

**p<.01

In order to reduce the paperwork burden on program participants, program staff began administering a 6-item version of the social support measure as opposed to the 19-item version. The 6-item measure showed “strong internal consistency and scale reliability.” Thus, the reduced scale is useful in measuring global social support¹⁸.

Twenty-six pre- and post- short form questionnaires were administered. The average pre-score was 3.8 and the average post-test score was 4.5. The improvement in the global measure of social support was statistically significant (t (25) =-2.82, p=.009).

Consumer Feedback

All consumers are given an opportunity to anonymously critique the services they received while participating in the various programs of the Children’s Home Society of New Jersey. The results of that feedback from CUNA and Body and Soul participants is presented below. The CSQ-8 is a multi-lingual client satisfaction survey¹⁹. Fifty-seven CARES for Her participants completed the survey. The results are displayed in Table 31 and are uniformly excellent.

¹⁸ Holden, L., Lee, C., Hockey, R., Ware, R., and Dobson, A. (2014). Validation of the MOS Social Support Survey 6-item (MOS-SSS-6) measure with two large population-based samples of Australian women. *Quality of Life Research*. 23. 2849-2853. <http://library.sgu.ru/ftp/QL/art%253A10.1007%252Fs11136-014-0741-5.pdf>

¹⁹ <http://www.csq scales.com/csq-8.htm>

Table 31. Consumer Satisfaction

Client Satisfaction	Rating	N=57 (%)
How would you rate the quality of service you received?	Percent “Excellent” or Percent “Good”	89 9
Did you get the kinds of service you wanted?	Percent “Yes, Definitely” or Percent “Generally”	82 16
To what extent has our program met your needs?	Percent “Almost All” or Percent “Most Needs Met”	63 37
If a friend were in need of similar help, would you recommend our program to him or her?	Percent “Definitely” or Percent “I think So”	91 7
How satisfied are you with the amount of help you have received?	Percent “Very Satisfied” or Percent “Mostly Satisfied”	75 16
Have the services you received helped you to deal more effectively with your problems?	Percent “Helped a Great Deal” Or Percent “Helped Somewhat”	81 18
In an overall, general sense, how satisfied are you with the service you have received?	Percent “Very Satisfied” or Percent “Mostly Satisfied”	88 12
If you were to seek help again, would you come back to our program?	Percent Definitely or Percent “I Think So”	93 5

A second feedback form – in two versions for CUNA and Body and Soul – is completed by the CARES for Her women. These forms provide a self-report on: 1) topics that the mothers-to-be knew little about; 2) felt were very important to learn about; 3) had a knowledge gain on specific topics; and 4) indicated the likelihood of initiating a behavioral change or taking some other action due to participation in CUNA or Body and Soul (see Tables 32 to 43).

Table 32. CUNA Feedback Form

What Participants Knew Prior to Attending CUNA

N=90	A Great Deal (%)	Some Knowledge (%)	Very Little (%)
Navigating the medical system	6	29	65
Finding a safe place for information and support	3	36	61
Identifying the physical and psychological impact of pregnancy on a woman and her family	8	43	49
Postpartum care and pediatric care	8	46	47
Reading to a young child	10	46	44
Caring for a newborn understanding the need for vitamins and other supplements	17	41	42
Keeping a baby safe	14	46	40
Disciplining a young child	12	49	39
Breast-feeding	18	46	37
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	12	51	37
Understanding the effects of drugs, alcohol and smoking on a baby	26	40	34
Feeding a baby	18	48	34
Identifying the common discomforts of pregnancy and ways to cope	8	60	33
The importance of medical and prenatal care	23	49	28
Having a healthy pregnancy	15	60	26
The reasons for eating better during pregnancy	28	53	19

Table 33. What Participants Felt Were the Most Important Topics in CUNA

N=90	Very Important and Helpful (%)	Somewhat Important and Helpful (%)	Not Important (%)
Caring for a newborn understanding the need for vitamins and other supplements	91	7	2
The importance of medical and prenatal care	90	8	2
The reasons for eating better during pregnancy	89	9	2
Having a healthy pregnancy	89	9	2
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	89	10	1
Postpartum care and pediatric care	88	7	5
Feeding a baby	88	10	2
Breast-feeding	87	10	3
Disciplining a young child	84	13	2
Keeping a baby safe	83	15	2
Finding a safe place for information and support	81	16	3
Navigating the medical system	81	17	2
Identifying the physical and psychological impact of pregnancy on a woman and her family	81	13	6
Understanding the effects of drugs, alcohol and smoking on a baby	81	14	4
Reading to a young child	80	16	4
Identifying the common discomforts of pregnancy and ways to cope	78	20	2

Table 34. What Participants Learned the Most About After Attending CUNA

N=68	Gained a Great Deal of Knowledge (%)	Gained Some Knowledge (%)	Gained No Knowledge (%)
Understanding the effects of drugs, alcohol and smoking on a baby	91	9	0
Keeping a baby safe	90	10	0
Breast-feeding	90	9	1
The reasons for eating better during pregnancy	87	13	0
Having a healthy pregnancy	85	15	0
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	85	15	0
Identifying the common discomforts of pregnancy and ways to cope	82	18	0
The importance of medical and prenatal care	82	18	0
Feeding a baby	81	19	0
Reading to a young child	79	19	2
Identifying the physical and psychological impact of pregnancy on a woman and her family	78	22	0
Navigating the medical system	77	23	4
Finding a safe place for information and support	75	25	0
Caring for a newborn understanding the need for vitamins and other supplements	73	25	2
Disciplining a young child	72	27	1
Postpartum care and pediatric care	66	33	1

Table 35. What Topics Participants Felt Would Lead Them to Change their Behavior due to CUNA

N=68	Definitely Change Behavior or Take Other Actions (%)	Possibly Change Behavior or Take Other Actions (%)	Will Not Change my Behavior (%)
Understanding the effects of drugs, alcohol and smoking on a baby	88	7	5
The importance of medical and prenatal care	88	9	3
Breast-feeding	85	6	9
Keeping a baby safe	85	7	7
Navigating the medical system	82	14	4
Postpartum care and pediatric care	82	15	3
The reasons for eating better during pregnancy	81	15	4
Caring for a newborn understanding the need for vitamins and other supplements	81	13	6
Having a healthy pregnancy	81	13	6
Disciplining a young child	79	16	5
Identifying the physical and psychological impact of pregnancy on a woman and her family	79	16	4
Reading to a young child	78	16	6
Identifying the common discomforts of pregnancy and ways to cope	76	19	4
Feeding a baby	76	18	6
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	75	21	4
Finding a safe place for information and support	72	27	1

Body and Soul Feedback Form

Table 36. What Participants Knew Prior to Attending Body and Soul

N=25	A Great Deal (%)	Some Knowledge (%)	Very Little (%)
What to tell your provider about your contractions	16	29	54
Checking for contractions	17	29	54
What are the signs of preterm labor	25	37	37
Nurturing my soul	17	58	25
The importance of nutrition and folic acid	46	33	21
Other types of mind-body techniques	25	54	21
Prescription drug use during pregnancy	50	29	21
How to prepare the body for pregnancy	21	58	21
What stress means for pregnancy outcomes	25	58	17
How to prepare the mind for pregnancy	33	50	17
Types of stress pregnant women face	25	62	12
Fetal alcohol syndrome (FAS)	58	29	12
The connection between mind body and soul	21	67	12
Healthy weight gains during pregnancy	46	42	12
How to manage stress	17	75	8
Meditation and stress reduction	29	62	8
What is meditation	37	58	4
The benefit of exercise during pregnancy	29	67	4
How do alcohol, tobacco and other drugs affect the developing baby	83	17	0
Illegal drug use and pregnancy	87	12	0

Table 37. What Participants Felt Were the Most Important Topics in Body and Soul

N=25	Very Important and Helpful (%)	Somewhat Important and Helpful (%)	Not Important (%)
How to prepare the body for pregnancy	92	8	0
What are the signs of preterm labor	92	4	4
How to manage stress	87	13	0
What stress means for pregnancy outcomes	87	13	0
What to tell your provider about your contractions	87	13	0
How to prepare the mind for pregnancy	87	13	0
The importance of nutrition and folic acid	83	12	4
Types of stress pregnant women face	83	17	0
Nurturing my soul	83	17	0
Meditation and stress reduction	83	12	4
Checking for contractions	83	12	4
Fetal alcohol syndrome (FAS)	79	12	8
Prescription drug use during pregnancy	79	12	8
The connection between mind body and soul	79	17	4
Other types of mind-body techniques	79	16	4
How do alcohol, tobacco and other drugs affect the developing baby	75	8	17
The benefit of exercise during pregnancy	75	17	8
Illegal drug use and pregnancy	71	12	16
Healthy weight gains during pregnancy	71	25	4
What is meditation	62	33	4

Table 38. What Participants Learned the Most About After Attending Body and Soul

N=17	Gained a Great Deal of Knowledge (%)	Gained Some Knowledge (%)	Gained No Knowledge (%)
The importance of nutrition and folic acid	100	0	0
What is meditation	100	0	0
The benefit of exercise during pregnancy	94	6	0
The connection between mind body and soul	94	6	0
Meditation and stress reduction	94	6	0
Types of stress pregnant women face	93	7	10
How do alcohol, tobacco and other drugs affect the developing baby	87	6	6
How to prepare the mind for pregnancy	87	13	0
Illegal drug use and pregnancy	87	6	6
Nurturing my soul	87	13	0
What to tell your provider about your contractions	86	14	0
What are the signs of preterm labor	85	15	0
What stress means for pregnancy outcomes	81	12	6
Fetal alcohol syndrome (FAS)	81	12	6
How to prepare the body for pregnancy	81	19	0
Healthy weight gains during pregnancy	81	19	0
Other types of mind-body techniques	79	21	0
How to manage stress	75	19	6
Prescription drug use during pregnancy	75	25	0
Checking for contractions	64	36	0

Table 39. What Topics Participants Felt Would Lead Them to Change their Behavior in Body and Soul

N=14	Definitely Change Behavior or Take Other Actions (%)	Possibly Change Behavior or Take Other Actions (%)	Will Not Change my Behavior (%)
Prescription drug use during pregnancy	100	0	0
The importance of nutrition and folic acid	100	0	0
The benefit of exercise during pregnancy	100	0	0
Other types of mind-body techniques	100	0	0
What stress means for pregnancy outcomes	92	8	0
How to manage stress	92	8	0
How do alcohol, tobacco and other drugs affect the developing baby	92	0	8
Fetal alcohol syndrome (FAS)	92	0	8
Illegal drug use and pregnancy	92	0	8
How to prepare the body for pregnancy	92	8	0
Healthy weight gains during pregnancy	92	8	0
The connection between mind body and soul	92	0	8
What is meditation	92	8	0
Meditation and stress reduction	92	8	0
Checking for contractions	92	8	0
How to prepare the mind for pregnancy	85	8	8
Types of stress pregnant women face	85	15	0
Nurturing my soul	85	8	8
What are the signs of preterm labor	85	8	8
What to tell your provider about your contractions	85	8	8

Ocean CUNA Feedback Form

Table 40. What Participants Knew Prior to Attending Ocean CUNA

N=40	A Great Deal (%)	Some Knowledge (%)	Very Little (%)
Navigating the medical system	2	42	55
Finding a safe place for information and support	2	47	50
Reading to a young child	12	57	30
Identifying the physical and psychological impact of pregnancy on a woman and her family	7	67	25
Caring for a newborn understanding the need for vitamins and other supplements	30	47	22
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	12	70	17
Breast-feeding	41	44	15
Understanding the effects of drugs, alcohol and smoking on a baby	37	47	15
Disciplining a young child	21	67	13
The importance of medical and prenatal care	38	49	13
Postpartum care and pediatric care	20	67	12
Having a healthy pregnancy	32	55	12
Identifying the common discomforts of pregnancy and ways to cope	20	70	10
Keeping a baby safe	32	57	10
Feeding a baby	44	49	7
The reasons for eating better during pregnancy	27	65	7

Table 41. What Participants Felt Were the Most Important Topics in Ocean CUNA

N=40	Very Important and Helpful (%)	Somewhat Important and Helpful (%)	Not Important (%)
Disciplining a young child	80	20	0
Keeping a baby safe	77	23	0
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	77	22	0
Feeding a baby	77	22	0
Caring for a newborn understanding the need for vitamins and other supplements	77	22	0
Breast-feeding	75	25	0
The reasons for eating better during pregnancy	75	25	0
The importance of medical and prenatal care	75	25	0
Having a healthy pregnancy	75	25	0
Understanding the effects of drugs, alcohol and smoking on a baby	75	25	0
Postpartum care and pediatric care	72	28	0
Reading to a young child	72	27	0
Navigating the medical system	70	30	0
Identifying the common discomforts of pregnancy and ways to cope	70	30	0
Finding a safe place for information and support	68	32	0
Identifying the physical and psychological impact of pregnancy on a woman and her family	67	33	0

Table 42. What Participants Learned the Most About After Attending Ocean CUNA

N=37	Gained a Great Deal of Knowledge (%)	Gained Some Knowledge (%)	Gained No Knowledge (%)
Identifying the physical and psychological impact of pregnancy on a woman and her family	89	9	3
Identifying the common discomforts of pregnancy and ways to cope	89	8	3
Understanding the effects of drugs, alcohol and smoking on a baby	89	6	6
Having a healthy pregnancy	89	6	6
Feeding a baby	86	11	3
The importance of medical and prenatal care	86	11	3
Finding a safe place for information and support	83	14	3
Postpartum care and pediatric care	83	11	6
Breast-feeding	83	14	3
Keeping a baby safe	83	11	6
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	83	14	3
The reasons for eating better during pregnancy	83	14	3
Caring for a newborn understanding the need for vitamins and other supplements	80	14	6
Navigating the medical system	80	20	0
Disciplining a young child	37	60	3
Reading to a young child	14	71	14

Table 43. What Topics Participants Felt Would Lead Them to Change their Behavior from Ocean CUNA

N=37	Definitely Change Behavior or Take Other Actions (%)	Possibly Change Behavior or Take Other Actions (%)	Will Not Change my Behavior (%)
Breast-feeding	97	3	0
Finding a safe place for information and support	94	6	0
Identifying the common discomforts of pregnancy and ways to cope	94	6	0
Postpartum care and pediatric care	94	6	0
Keeping a baby safe	94	6	0
Lifestyle and eating behaviors you change to have a healthier pregnancy and baby	94	6	0
The reasons for eating better during pregnancy	94	6	0
Feeding a baby	94	6	0
The importance of medical and prenatal care	94	6	0
Caring for a newborn understanding the need for vitamins and other supplements	94	6	0
Having a healthy pregnancy	94	6	0
Navigating the medical system	91	9	0
Identifying the physical and psychological impact of pregnancy on a woman and her family	91	9	0
Understanding the effects of drugs, alcohol and smoking on a baby	91	6	3
Disciplining a young child	79	21	0
Reading to a young child	77	20	3

Findings

The Children's Home Society of New Jersey delivered CARES for Her, prenatal health education services to women living in Mercer and Ocean counties over a three-year period beginning July 2016. Services include primary prevention single session workshops, three session programs for women in the latter stages of their pregnancy and nine, 12, or 16 session prenatal education programs. CUNA for Latino women was offered in Mercer and Ocean counties. The Body and Soul Program was provided for African American women residing in Mercer County.

The three-year level of service was 728 women across all program components including one- and three-session programs and 9, 12, and 16-week prenatal educational programs using the CUNA or Body and Soul curricula.

Program completion rates were high in Mercer County but could be improved in Ocean County. A significant percentage of the Body and Soul program participants were experiencing their first pregnancy. Conversely, the Ocean County CUNA participants were mostly multigravida. The Ocean County women tended to be older and had a lower educational level. The CUNA participants in Mercer and Ocean Counties were more likely to have a husband or partner than the Body and Soul participants. Most participants appeared to have some type of support network but indicated a need for more tangible (concrete) and emotional/informational support. The level of alcohol, drug and tobacco usage and exposure to domestic violence prior to pregnancy appears to be under-reported.

At the time of intake, about one-quarter of the participants in the two Mercer County programs were not enrolled in prenatal care programs. For those that were, most began care in the first trimester of pregnancy and attended regularly. Access to care, lack of health insurance and inability to take time off from work were reasons given when prenatal care was inadequate. Participants, particularly in CUNA need encouragement to apply for NJ Family Care or Medicaid. WIC participation was low in Ocean County and SNAP enrollment was low for all three programs. Effort should be focused on increasing enrollment and participation in these valuable programs.

The birth weight of infants born to participating mothers compared favorably to county-wide data by race/ethnicity. Few newborns had physical or mental disabilities and only a small number needed special care in the NICU after birth. Perceived social support measurably increased by the end of the program cycle. Post-partum, 64 to 73 percent of mothers nursed their infants.

Consumer feedback was uniformly very positive.

Extra effort needs to be applied to ensuring data collection is more complete, particularly with information regarding prenatal visits, substance use, and domestic violence. Program participants may need additional encouragement to complete the CSQ-8 consumer satisfaction questionnaire.

New Jersey Institute for Disabilities - #NoZika
Final Evaluation Report

Gloria Aftanski, President
United Way of Central Jersey

October 15, 2019

Introduction

This document presents the final evaluation report of #NoZika, the Zika virus awareness program of the New Jersey Institute for Disabilities, as funded by the NJ Department of Human Services, Division of Developmental Disabilities, Office for the Prevention of Developmental Disabilities. There will also be comparisons of data between the final and interim reports.

Program Description

The New Jersey Institute for Disabilities (NJID) created a multi-faceted bilingual project to help prevent developmental disabilities caused by the Zika virus: *News & Options about Zika/Noticias y Opciones sobre Zika*, now known as #NoZika.

The audience of #NoZika is wide-ranging since the virus is transmitted by mosquito vector and sexual activities. The initial targeted community was those people with ties to countries where Zika is prevalent, specifically the Caribbean, Central and South America. In the third year of the program, the scope of the program was expanded to target the large South Asian Indian population which is a large demographic in central New Jersey. This group has strong ties to India and frequently travel to visit family and friends. The Zika virus emerged in great numbers in India in 2018 and it was the same strain as the virus in Brazil, which had devastating consequences. The Indian government response was swift and effective in containing the spread of the virus, however, it was essential that the awareness message was disseminated to this community prior to any travel or visits with family and friends.

The goal of the project is to educate the community on all aspects of Zika virus to facilitate the prevention of developmental disabilities. The objectives are:

- #1 Increase *knowledge*, identify prevention strategies; awareness of pregnancy risks
- #2 Saturate *the community* with sound information on all aspects of Zika, particularly effects on pregnant women/fetuses; possibility of vaccine availability

To create an awareness and educate the community about the little known Zika virus and its potential consequences, NJID developed three major initiatives which have measureable indicators:

1. Bilingual, Spanish/English public training sessions (Pre & Post testing)
2. Distribution of a wide variety of newly-created Zika awareness materials (documented number of distribution sites and events)
3. Social media initiatives (Reporting metrics of various platforms)

The primary goal of #NoZika is that the community becomes informed of the existence of Zika virus, how it is transmitted and ways to prevent the virus. Additional goals include fostering collaboration among human service providers, faith-based community and various levels of government; alerting health care providers, working with the targeted community to the prevalence and consequences of the Zika virus and publicizing any new developments as related to Zika vaccines.

The outcomes of #NoZika activities focused on the dissemination of information: the information was presented in easy to understand formats, using various social media platforms, in relatable language and the delivery of information in non-traditional settings.

Evaluation Methods

#1 Bilingual Community Training Programs - Pre & Post Tests:

Simple questionnaires were developed to assess the existing scope of knowledge of Zika virus and the knowledge gained by participating in training sessions. The questions were formulated to establish a baseline of basic information concerning the vulnerability to Zika virus, methods of transmission, prevention of transmission and potential consequences.

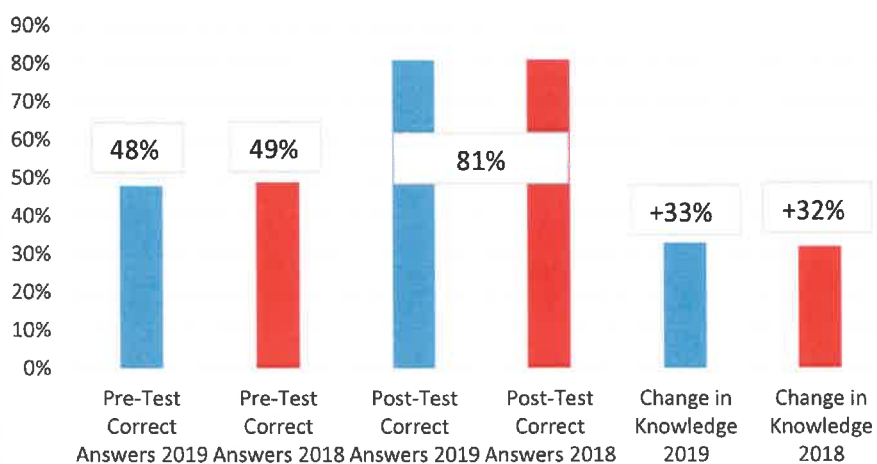
The post-test synthesis shows a significant increase in knowledge in all categories of knowledge.

#NOZika Pre Test/Post Test Synthesis	Pre-Test Correct Answers		Post-Test Correct Answers		Change in Knowledge	
	2019	2018	2019	2018	2019	2018
Who can get Zika?	73%	74%	76%	76%	3%	2%
How does a person get Zika?	57%	30%	75%	76%	18%	46%
Does everyone who gets Zika show symptoms?	29%	46%	50%	61%	21%	15%
Out of 5 people who get Zika, how many show symptoms?	19%	15%	92%	92%	73%	77%
Can you prevent Zika?	43%	53%	75%	92%	32%	39%
How can you prevent Zika?	57%	61%	98%	92%	41%	31%
What are the risks for the fetus if a pregnant woman gets Zika?	58%	69%	99%	84%	41%	15%
Overall Average Pre/Post Test Correct Answers	48%	49%	81%	81%	33%	32%

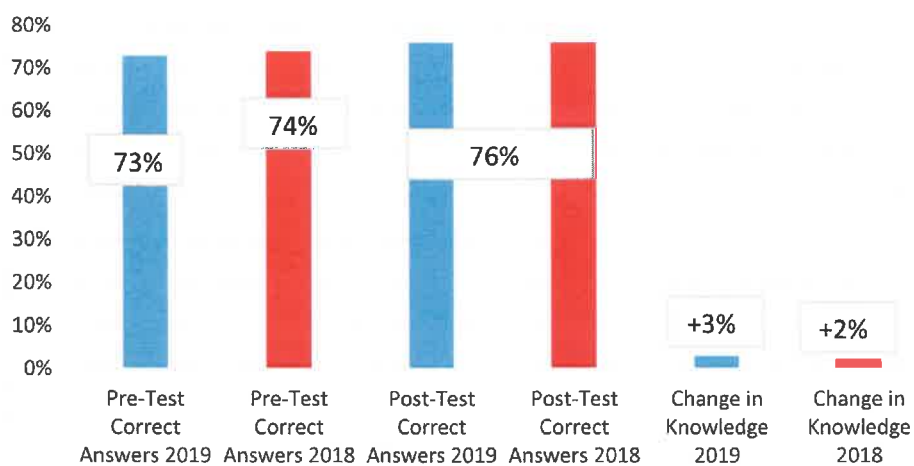
Correct Answers:

- Who can get Zika: Male/Female Adults/Children Unborn
- How does person get Zika: Mosquito Bites, Sexual activity, blood transfusion, mother to unborn child
- Out of 5 people who get Zika, how many show symptoms: 1
- Can you prevent Zika: yes
- How can you prevent Zika: mosquito control, condoms,
- What are risks for fetus if a pregnant woman gets Zika: birth defects; delays; disabilities

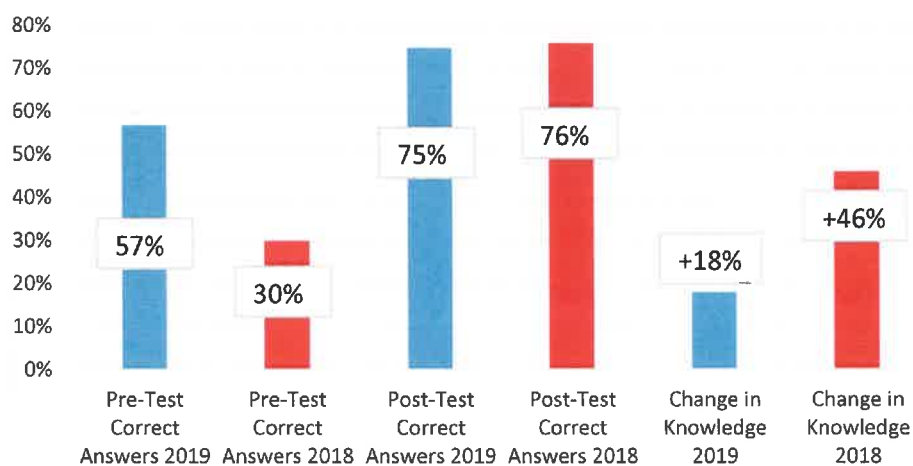
Overall Average Pre/Post Test Correct Answers



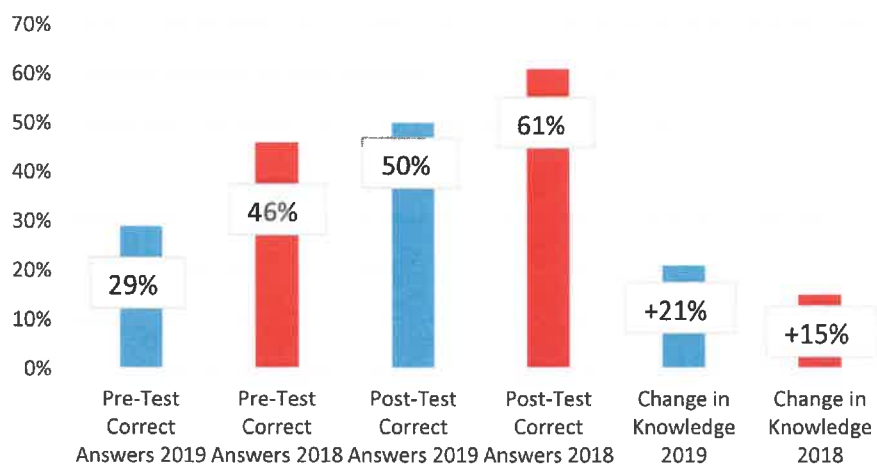
Who Can Get Zika?



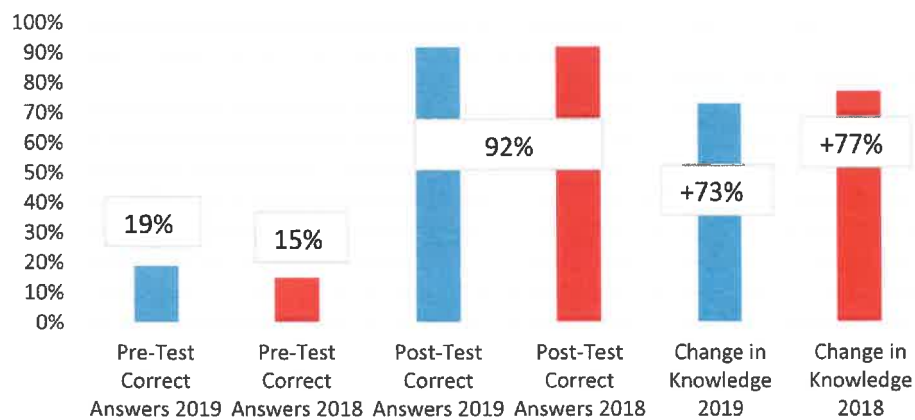
How Does a Person Get Zika?



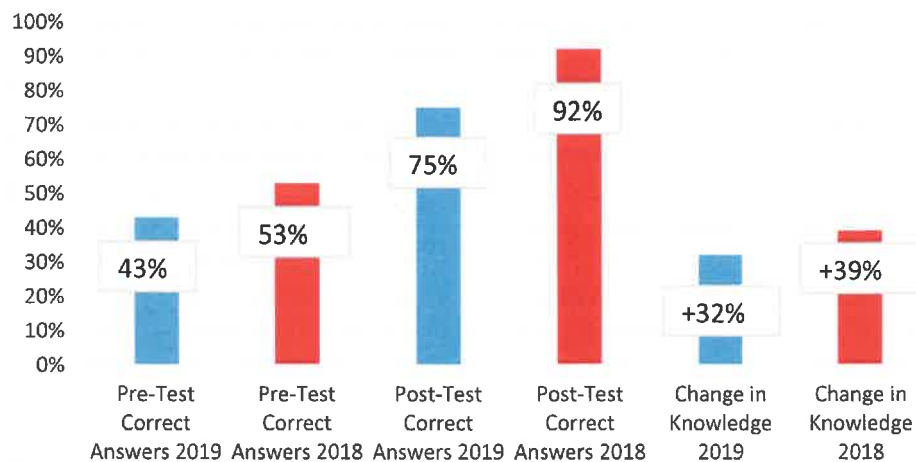
Does Everyone Who Gets Zika Show Symptoms?



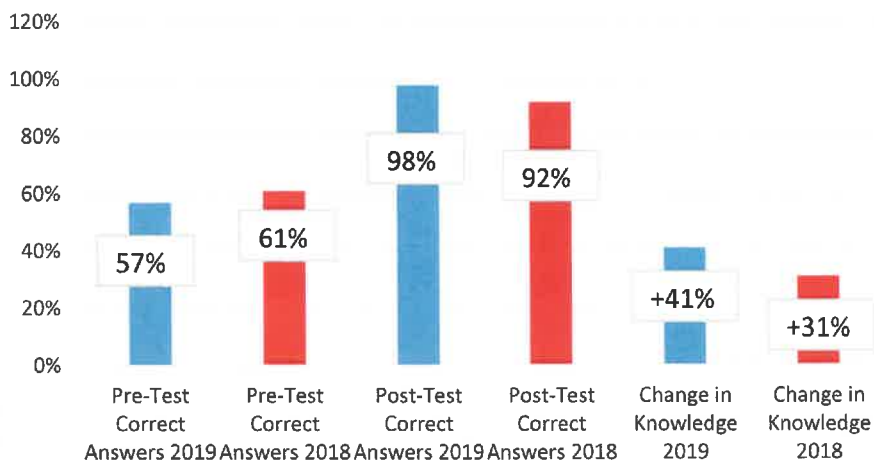
Out of 5 People Who Get Zika, How Many Show Symptoms?



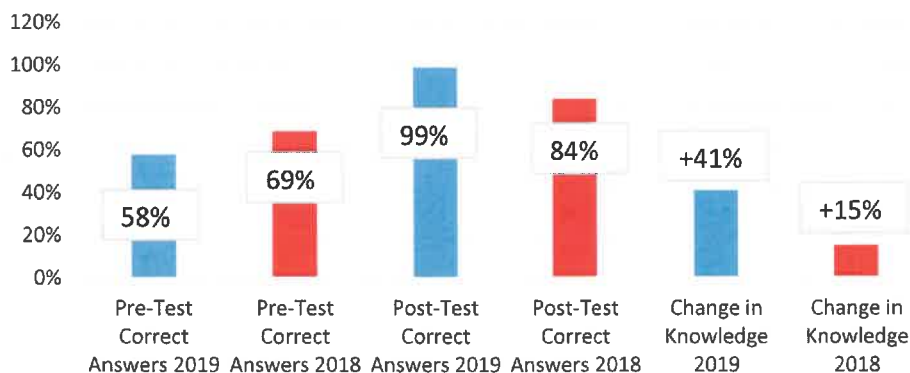
Can You Prevent Zika?



How Can You Prevent Zika?



What are the Risks for the Fetus in a Pregnant Woman Gets Zika?



As evidenced by the pre-tests during the first and second reporting periods, there was a higher number of correct pre-tests during the first reporting period (2016-18). During this time, there was substantially more information, news and discussion about Zika in the media. This may have contributed to a greater awareness and general knowledge of the virus and its consequences. In the last half of 2018 and 2019, the mentions of Zika in the media was substantially reduced as interest in the topic waned; there are corresponding diminished pre-test correct scores.

#2 Social media initiatives (Reporting metrics of various platforms)

Results:

Twitter: 540 Tweets 340 Facebook Posts 78 Instagram Posts

NJID created a #NoZika identification on Facebook, Twitter and Instagram. NJID proposed to collaborate with Middlesex County College to assist in this initiative however that engagement was not productive. NJID then established a collaboration with *Catchafire* an exceptional program which connects international pro bono professionals who wish to donate their skills to non-profits. The Robert Wood Johnson Foundation sponsors NJID's participation in Catchafire, underwriting the \$2,000 annual fee. NJID linked to five professionals who guided and mentored the creation of a social media presence. In the third year of the grant, professionals with familiarity of the South Asian Indian community were recruited to offer advice and guidance on creating appealing informational brochures.

NJID created a wide variety of social media posts focused on the Facebook platform. By utilizing graphic applications (Canva, Picmonkey) the posts are creative, fresh and attract attention, which is evident from the Social Media Impressions graph. 30% of posts were presented in Spanish language. The posts fall into four categories:

- Informative: news stories from a variety of reliable sources; CDC and WHO publications; validated research
- Shareable Quotes: quickly and easily shared information with a photo
- Pure Fun Posts: quirky images and drawings with a timely message
- Giveaway Posts: contests centered on answering Zika related questions

Posts were "boosted" to increase the number of impressions. Reviewing the most popular Facebook posts, the scope and content of the social media presence of #NoZika can be discovered:

NOZika		
Published by Brenda Crespo · November 12, 2016 ·		
Current number of #Zika cases in NJ		
NJ County	Confirmed Cases	
BERGEN		30
PASSAIC		25
ESSEX		17
HUDSON		17
UNION		11
MIDDLESEX		11
MERCER		8
OCEAN		7
MORRIS		7
CAMDEN		7
BURLINGTON		7
MONMOUTH		7
SOMERSET		4
GLOUCESTER		2
WARREN		2
ATLANTIC		2
HUNTERDON		2
CUMBERLAND		1
Grand Total		167

NOZika
Published by Brenda Crespo · April 5, 2017 ·

In light of the new macaque findings, Nielsen-Saines says she will be changing what she tells parents who ask whether they can bring a young child to an area where the disease has become endemic. "Usually we tell parents there is not much data there, but now we can say there is an animal study saying there may be neurodeficits later—so if you could not travel with your children in the first six months of life, maybe that would be a better option."

https://www.scientificamerican.com/.../zika-exposure-even-af-...

#NOZika #NOZikanj #Zika #brain #babies #baby #travel #traveling #travelers



SCIENTIFICAMERICAN.COM

Zika Exposure Even after Birth May Lead to Brain Damage

Learn More

NOZika
Published by Brenda Crespo · August 10, 2017 ·

Este video cubre todo lo que debes saber sobre #Zika! Desde la transmisión, el embarazo, la prevención y qué hacer si piensa que está infectado. ¡Echale un vistazo! #NOZika #NOZikanj

<https://www.youtube.com/watch...>

See Translation



YOUTUBE.COM

El virus del Zika en español (acento de EEUU)

El virus del Zika en español (acento de EEUU) El virus del...

Learn More

NOZika
Published by Kelly Maguire · March 12, 2017 ·

new!2 English ·

****CONTEST TIME!**** It's #MosquitoMonday and one lucky follower will win a Dunkin' Donuts gift card! Just "like" our page and share our post to enter! Winner will be announced next Monday #NOZika #Blizzardof2017 #WinterStormStella Must be 16 years or older to win. Contest is not associated with Facebook

THIS BLIZZARD WON'T BLOW ZIKA AWAY!

NOZika
Published by Kelly Maguire · April 28, 2017 ·

Traveling soon? Before you go, check out the video below to learn about Zika! Watch in HD

ZIKA TRAVELS WITH YOU

0:02 / 0:54

NOZika
Published by Brenda Crespo · September 15, 2017 ·

"In large parts of the world, the virus is now firmly entrenched. WHO and affected countries need to manage Zika not on an emergency footing, but in the same sustained way we respond to other established epidemic-prone pathogens, like dengue and chikungunya, that ebb and flow in recurring waves of infection."

-Dr Margaret Chan, Director-General of WHO

<http://www.who.int/mediac.../commentaries/.../zika-long-haul/en/>



NOZika
Published by Gianna Stonno · August 31, 2016 ·

Top 5 Zika Questions - ANSWERED!
Visit: <https://www.cdc.gov/zika/about/questions.html>
to learn more!

See More

ZIKA

QUESTIONS

answered.

Q: WHAT IS ZIKA? ZIKA VIRUS DISEASE IS CAUSED BY THE ZIKA VIRUS, WHICH IS SPREAD TO PEOPLE PRIMARILY THROUGH THE BITE OF AN INFECTED MOSQUITO. THE ILLNESS IS USUALLY MILD WITH SYMPTOMS LASTING UP TO A WEEK, AND MANY PEOPLE DO NOT HAVE SYMPTOMS OR WILL HAVE ONLY MILD SYMPTOMS.	Q: HOW IS ZIKA DIAGNOSED? TO DIAGNOSE ZIKA, YOUR DOCTOR WILL ASK YOU ABOUT RECENT TRAVEL AND SYMPTOMS YOU MAY HAVE, AND COLLECT BLOOD OR URINE TO TEST FOR ZIKA OR SIMILAR VIRUSES.	WHAT HEALTH PROBLEMS CAN RESULT FROM GETTING ZIKA? MANY PEOPLE INFECTED WITH ZIKA WILL HAVE NO SYMPTOMS OR ONLY MILD SYMPTOMS THAT LAST SEVERAL DAYS. HOWEVER, ZIKA INFECTION DURING PREGNANCY CAN CAUSE SERIOUS BIRTH DEFECTS CALLED MICROCEPHALY AND OTHER SEVERE FETAL BRAIN DEFECTS.
--	---	--

NOZika
Published by Gianna Stonno · August 17, 2016 ·

The statistic speaks for itself- protect yourself from the harmful effects of the Zika Virus!

Read this article to stay informed on all the effects of the Zika virus -
<https://www.cnn.com/.../zika-report-and-guidance-c.../index.html>



ONE IN SEVEN

"NEARLY ONE IN SEVEN BABIES BORN TO WOMEN INFECTED WITH THE ZIKA VIRUS WHILE PREGNANT HAD ONE OR MORE HEALTH PROBLEMS"

-VITAL SIGNS/CDC

#NOZIKA

NOZika
Published by Gianna Stonno · February 5 ·

When choosing a destination for your next vacation be sure to take into consideration your LOCATION!
Protect yourself and your future family!

See More



NOZika
Published by Gianna Stonno · February 27 ·

If you or your partner has recently traveled to area at risk of Zika and you are experiencing any of the following symptoms be sure to visit your Doctor! If you are diagnosed be sure to follow the treatment plan on the CDC website.

<https://www.cdc.gov/zika/symptoms/treatment.html>
<https://www.cdc.gov/zika/es/symptoms/treatment.html>

4 WAYS TO TREAT ZIKA

MEDICINE OR VACCINE FOR ZIKA VIRUS SO PREVENTION IS KEY!

Symptoms to look out for...

- FEVER
- RASH
- HEADACHE
- JOINT PAIN
- CONJUNCTIVITIS
- MUSCLE PAIN

Treatment...

- TREAT THE SYMPTOMS
- GET PLENTY OF REST
- DRINK FLUIDS TO PREVENT DEHYDRATION
- TAKE MEDICINE SUCH AS ACETAMINOPHEN TO REDUCE FEVER AND PAIN.

#3 Distribution of a wide variety of originally-created Zika awareness materials (documented number of distribution sites and events)

Results:

Reach target community

45 community events	5355 contacts
110 Faith based organizations	250 contacts
194 Nontraditional settings	3257 contacts
77 Trainings and Information sessions	2637 contacts

NJID created a variety of Zika awareness materials. Some were developed in collaboration with *Catchafire*, which matches skilled professional volunteers with nonprofits to help them increase their capacity and achieve their missions. The original thinking was that NJID would collaborate with Middlesex County College to develop collateral material however, there were obstacles with scheduling and availability of necessary skill sets to complete proposed projects. NJID then pivoted to *Catchafire* with the Robert Wood Johnson Foundation sponsoring NJID's participation in the program. *Catchafire* volunteers collaborated on 5 brochures and 3 posters. The pro-bono professionals offered valuable advice and guidance on the creation of engaging targeted communities and increasing social media presence.

Material aimed at capturing the attention of children was developed as there were many younger people attending various community events. This was very effective as an ice-breaker in speaking with parents about the Zika virus. By participating in coloring activities and answering simple quizzes, the children earned their "Superhero Zika-Fighter" badge. The NJID #NoZika publication list:

#NoZika Brochure English	#NoZika Brochure Spanish
#NoZika Brochure update English	#NoZika Brochure update Spanish
#NoZika Poster (male couple)	#NoZika Poster (hetero couple)
#NoZika Poster (female couple)	#NoZika Poster (African American)
#NoZika Summer poster	#NoZika Summer poster Spanish
Wedding checklist English	Wedding Checklist Spanish
#NoZika Brochure (children) English	#NoZika Brochure (children) Spanish
Coloring Book	Zika Fighter Masks
#NoZika also distributed logoed and generic promotional items which were enthusiastically received.	
Luggage Tags	Pens
Screen repair kits	Insect repellent wipes
Silicon cell phone card holders	

To further facilitate the distribution of material and create awareness of the Zika virus, NJID established numerous high-value collaborations:

- Robert Wood Johnson Women's Health Institute
- Rutgers School of Public Health
- St. Peter's University Hospital
- Middlesex County Health Department
- City of Perth Amboy
- Raritan Bay Medical Center (Hackensack Meridian)
- Edison Job Corps
- Shri Krishna Nidri (SKN) Foundation
- Hindu Temple & Cultural Society

The distribution of material was conducted in a variety of ways.

- Community Events –health fairs; municipal events; Planned Parenthood conferences; Hispanic Chamber of Commerce events; YMCA events; spin-the-wheel games; South Asian Indian civic groups; ethnic festivals
- Delivery to non-traditional venues: laundromats, hair/nail salons, barber shops, bodegas,
- Faith based organizations
- Middlesex County human services providers
- Middlesex County School Nurses
- High School Sports Coaches
- Travel Agencies
- Wedding-related businesses
- Perth Amboy nutrition programs
- Kiddee Keep Well Camp (County sponsored camp for at-risk youth)

Summary

The results of the final evaluation confirms that the New Jersey Institute for Disabilities (NJID) has created an innovative program of action which successfully achieved the goals and objectives as outlined in the grant application:

- Increase knowledge, identify prevention strategies; awareness of pregnancy risks
- Saturate the community with sound information on all aspects of Zika, particularly effects on pregnant women/fetuses; possibility of vaccine availability

The community trainings and dissemination of information have had a credible effect, as evidenced by the gains of knowledge from pretest to posttest.

NJID has established a social media awareness of the Zika virus and its potential effects.

Original, fresh and contemporary informational brochures and collateral material have been created and disseminated on a large scale. There is an emphasis on the sexual transmission of the Zika virus which differs from the more common mosquito vector. To best identify with the demographics of the targeted audience, the brochures and posters are diverse in race and sexual orientation. There was also consideration of the targeted audience; brochures were created to appeal to young people of different cultures.

There were several deviations from the original application which have been ameliorated with sound alternatives:

- Collaboration with Middlesex County College did not proceed as planned; NJID partnered with Catchafire to establish relationships with volunteers who are professionals in various relevant fields. Numerous high-value collaborations have contributed to the program's overall success.
- Staffing had several changes however this had no adverse effect on the overall accomplishment of goals and objectives.
- The program scope was expanded to include the South Asian Indian communities of central New Jersey. The #NoZika response was important to create awareness of the virus before travel to India.

Continuity of Project

NJID continues a modified #NoZika program under the supervision of the NJID Department of Community Relations. Support for this work is derived from Agency discretionary funds. Coordinating with the Middlesex County Department of Health (MCDOH) and the newly-established Middlesex County Healthy Communities Project, #NoZika will continue to spread awareness and information about the Zika virus.

In July, 2019, MCDOH sponsored a #NoZika education campaign in collaboration with the Middlesex County Public Libraries. In September, Zika prevention information was presented by NJID at a symposium sponsored by the Hindu Temple and Cultural Society. Future awareness activities about the Zika virus continue to be developed by NJID and MCDOH.

It is hoped that a vaccine will be developed and this will further advance the community's health. If the vaccine becomes a reality, there will be information disseminated throughout the community to encourage participation in a Zika prevention project.

Based upon this final evaluation it is obvious that NJID has not only exceeded the goals and objectives of the grant but continues the project's mission among the communities in New Jersey.



Gloria Aftanski, President
United Way of Central Jersey

October 15, 2019

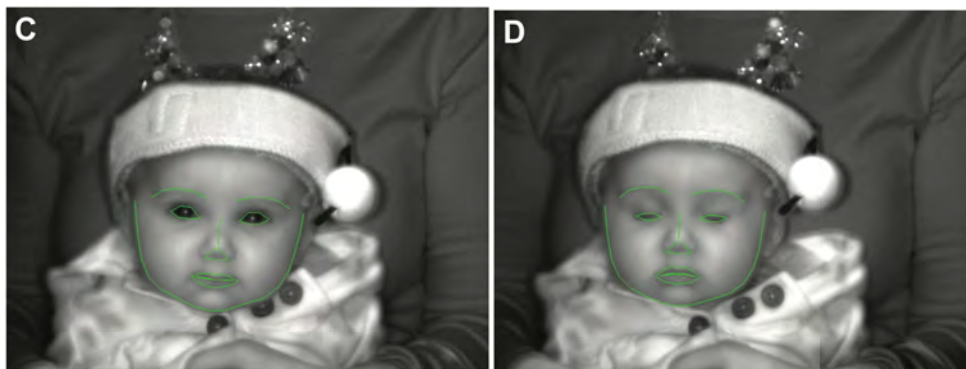
Cerebellar Dysfunction and Infant Cognition as Very Early Markers for Predicting and Preventing Developmental Disabilities

Principal Investigators

Dr. Casey Lew-Williams, Department of Psychology, Princeton University
Dr. Samuel Wang, Princeton Neuroscience Institute, Princeton University

Collaborators

Dr. Barbie Zimmerman-Bier (Bristol Myer's Squibb Children's Hospital, Rutgers)
Dr. Jeffrey Berman (Children's Hospital of Philadelphia)
Dr. Steven Buyske (Bristol Myer's Squibb Children's Hospital, Rutgers)
Dr. Eric London (NY State Institute for Basic Research in Developmental Disabilities)
Dr. Thomas Hegyi (Bristol Myer's Squibb Children's Hospital, Rutgers)



Part I

Overview of project.Page 2

Part II

Development of eyeblink conditioning task.Page 4

Part III

Development of visual prediction task.Page 12

Published article in *Cognition*Page 17

Part I

Overview of project

Our project aims to establish extremely early life markers to identify infants at risk for developmental disabilities (DDs). Specifically, we hope 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 determining which individuals would benefit from early interventions. Using a cohort of infants born prematurely with low birthweight (<1500 gm), we are examining very early development of the cerebellum, a brain region known to be critical for healthy neurodevelopment, but that is notably overlooked as a biomarker for prediction, diagnosis, and prevention of DDs.

Prematurity is a major health problem in the U.S. today. It affects nearly half a million infants yearly. In New Jersey, approximately 11% of 114,000 newborns are born preterm/low-birthweight, and are at increased risk for a wide range of DDs, including language delay; deficits in motor abilities, learning, social skills, memory, and IQ; cerebral palsy; schizophrenia; and autism spectrum disorders (ASDs). Studies have consistently shown that early intervention leads to better long-term outcomes for children with DDs. Therefore, we are examining anatomical cerebellar development and function, behavioral measures of atypical cerebellar development, and early-life markers of infant cognition. Our approach is unique because it offers an integration of medical research, neuroscience research, and psychological research, and brings together a distinctive group of principal investigators: Dr. Lew-Williams is an expert in infant development and early cognition, Dr. Wang is an expert on the development of the cerebellum, and our collaborators at Bristol Myer's Squibb Children's Hospital at Robert Wood Johnson University Hospital at Rutgers University, including Dr. Barbara Bier, are experts in the health and well-being of infants born prematurely. The significance of this research is in its ability to offer insights into the very beginnings of DD, which may have translational implications for targeted treatments for very young children with a range of DDs.

We have made significant progress on this project, including the testing of dozens of typically developing infants and approximately two-dozen children born prematurely. Entirely novel research procedures have been developed as a direct result of this funding, which will be useful not only for our own samples of participants, but for labs around the world. We have already received many inquiries from labs at other universities and in other nations who wish to adopt our techniques for understanding a range of developmental phenomena. Our ability to recruit and successfully test infants born prematurely with low birthweight has been challenging, but we are making steady progress and working within the practicalities of testing this at-risk population.

What follows is a description of our development of the eyeblink conditioning task and an infant prediction task, including one publication that appeared in a major academic journal. Once the final sample of low-birthweight infants has been tested in our suite of neural and behavioral tasks, we will analyze data and write up the results both for conference presentation and peer-reviewed publication, and we will provide you with a copy of the manuscript. At this stage, we will better understand how direct measures of cerebellar dysfunction relate to behavioral outcomes and clinical diagnosis of a range of DDs. Collectively, these measures could provide the earliest known biological and behavioral markers that – separately or in combination –

predict which infants are vs. are not at risk for developing DDs. We aim to evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening. Ultimately, we aim to increase the proportion of young children with DDs who are screened, evaluated, and enrolled in early intervention services in a timely manner.

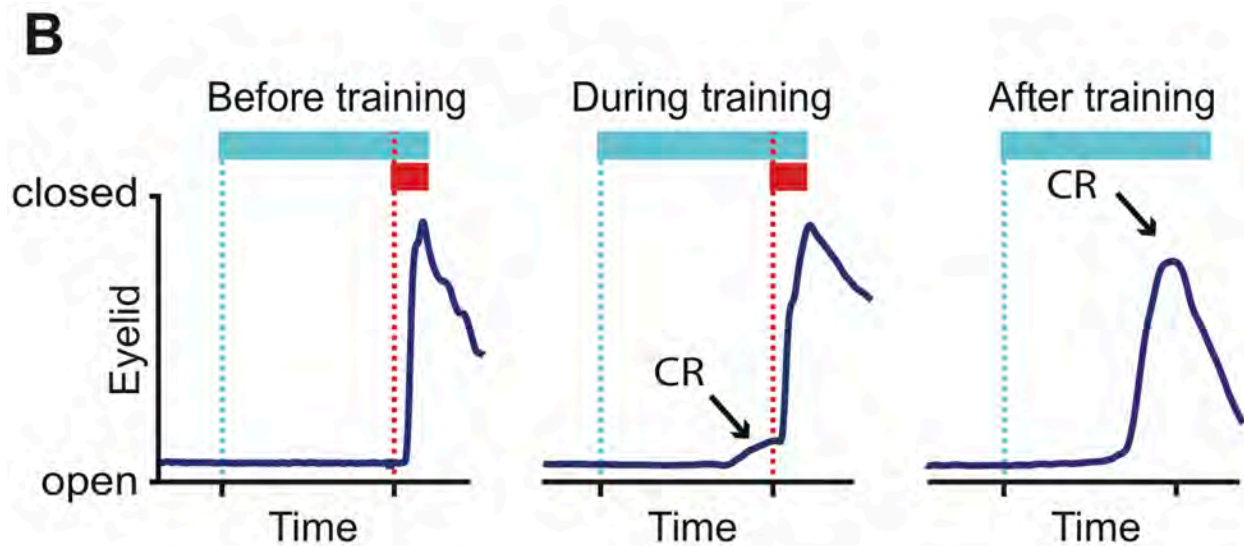
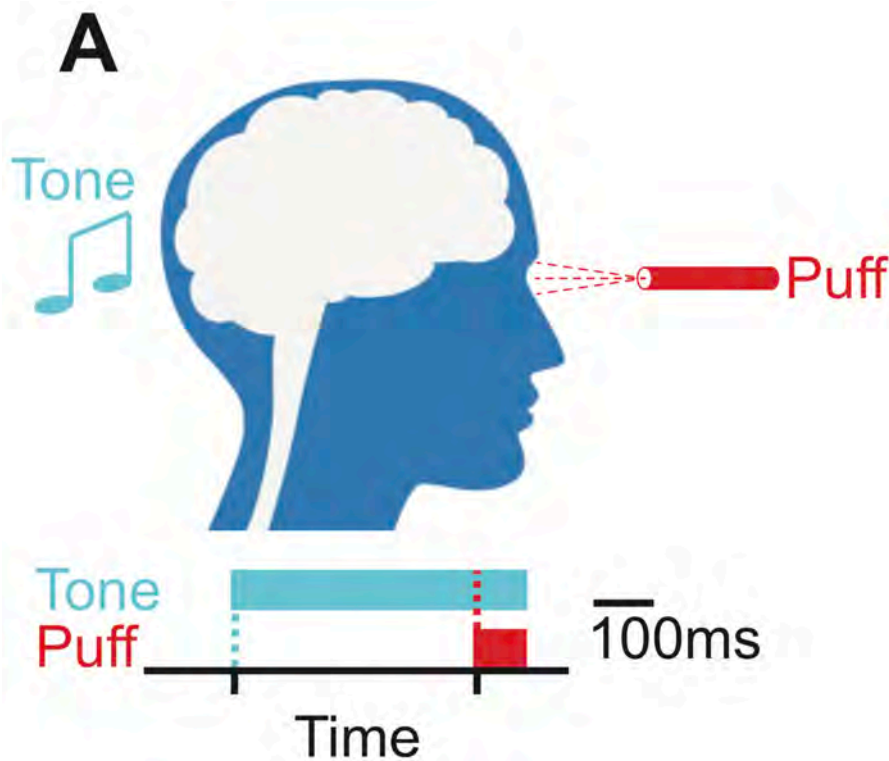
Importantly, this funding has enabled us to hire a total of 6 personnel at Rutgers and Princeton, either as half-time or full-time research staff members: Dr. Henk-Jan Boele, Eva Fourakis, Charli Ndouli, Madeline Pfeifer, Eric Preisler, and Juliana Trach.

Part II

Development of eyeblink conditioning task

Based on previous research, we have reason to believe that our eyeblink conditioning task could be used to define high risk for a range of DDs. Funding enabled us to purchase eyeblink technology from Nerasmus, Inc., located in the Netherlands, which included a week-long flyout visit from two scientists who worked with us to develop our paradigm, which is the only infant paradigm that currently exists in the world. In the task, infants are shown a visual display of brightly colored objects on a platform placed in front of them. Two small speakers direct at ear level will deliver tones (1 kHz, 80 dB). The infant is outfitted with a soft headband supporting a length of flexible tubing for delivery of a low-intensity corneal airpuff to the subject's eye. Head position is recorded by video camera and eye blinks are recorded electromyographically (EMG) using gel-pad electrodes positioned at the corner of the eye, the right temple, and the back of the neck, and processed using Stanford Instruments amplifier and National Instruments digitization board under the control of a desktop computer. As part of this funding period, we have worked with professors of psychology in South Africa to adopt an engaging, dynamic puppetshow that keeps infants entertained throughout the 15-minute task. Training sessions consist of a 750-ms long tone conditioned stimulus (CS) that end at the same time as a gentle 100-ms airpuff unconditioned stimulus (US) delivered to the eye. Conditioning consists of blocks of 10 trials in which nine trials are CS-US pairing and one trial is a CS-only stimulus to measure the full time course of the conditioned response. A maximum of 50 trials are presented for a total of up to 12 minutes, or when the infant becomes fussy – whichever comes first. Conditioned blinks are defined as anticipatory blinks occurring after presentation of the CS but before the time when the US would be delivered, and are quantified using a combination of video and EMG recording. Learning is quantified as the percentage of learned anticipatory blinks produced across six blocks. We predict that cerebellar structure and function will be related to a reduced proportion of anticipatory blinks in response to the CS in the eyeblink conditioning task. This task serves as a proxy for associative learning, with the cerebellum being central to the circuit involved (Christian & Thompson, 2003; Reeb-Sutherland & Fox, 2015). Eyeblink conditioning requires cerebellar plasticity in identified circuit substrates (Raymond et al., op. cit.) and comes online sometime between 1 and 4 months of age. This test has the potential to become a standard part of clinic/hospital-based testing for the general population (similar to brainstem-evoked potential now used with newborns).

What follows is a proof-of-concept of eyeblink conditioning in infants using high-speed video recordings and automated face- and landmark-detection algorithms. This has been one of the major foci of the work completed during the funding period. In short, we have captured wide variability across typically developing infants in the ability to learn to associate a tone with a subsequently presented puff of air. We expect that this variation will be meaningfully related to cognitive and language growth trajectories in early childhood.



(A & B) During eyeblink conditioning, subjects typically hear a short beep or see a light flash (conditional stimulus, CS), followed several hundred milliseconds later by an air-puff applied to the eye (unconditional stimulus, US). As a result of repeated CS-US pairings subjects will eventually learn to close their eye in response to the CS, which is called the conditioned response (CR).

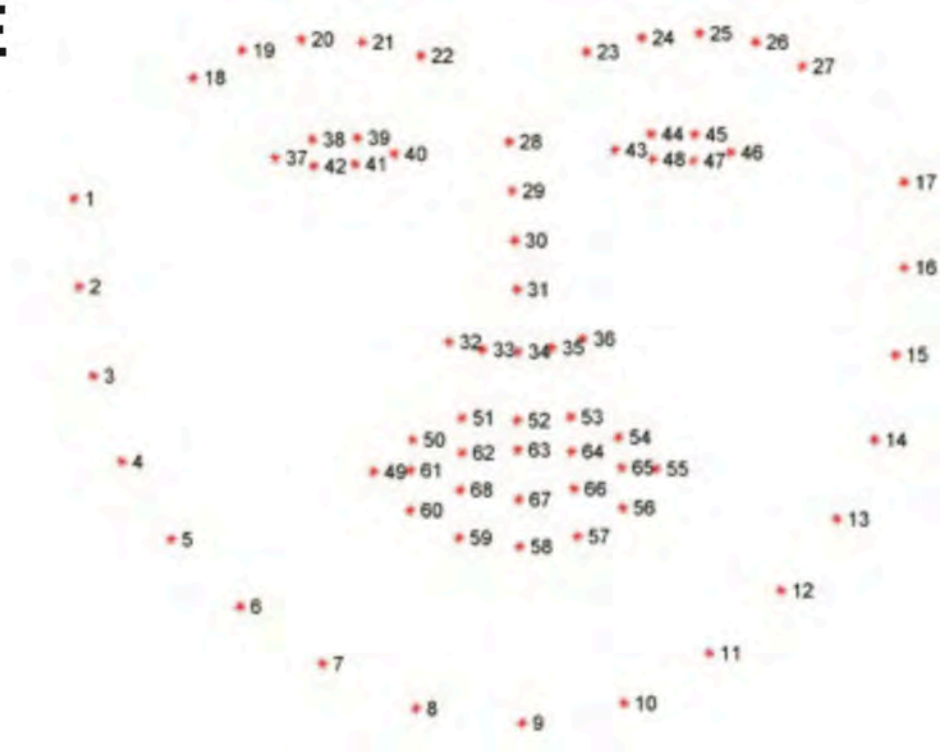


(C) Example of videoframe where eyelid is open. Green lines indicate the facial landmarks.



(D) Example of videoframe where eyelid is closed. **(E)** For each videoframe 68 landmarks are detected.

E



(E) For each videoframe, 68 landmarks are detected.

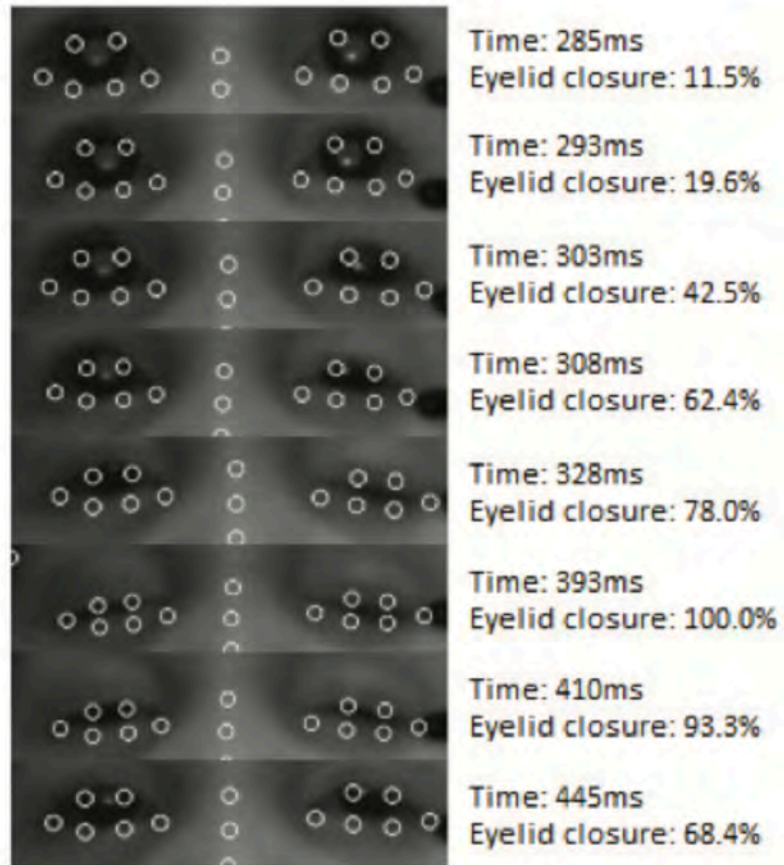
F

$$EAR = \frac{(|LM44 - LM48| + |LM45 - LM47|)}{2 * |LM43 - LM46|}$$

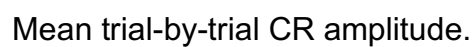
$$\text{Normalized} = 100 - (EAR - \text{MIN_EAR}) * \frac{100}{\text{MAX_EAR}}$$

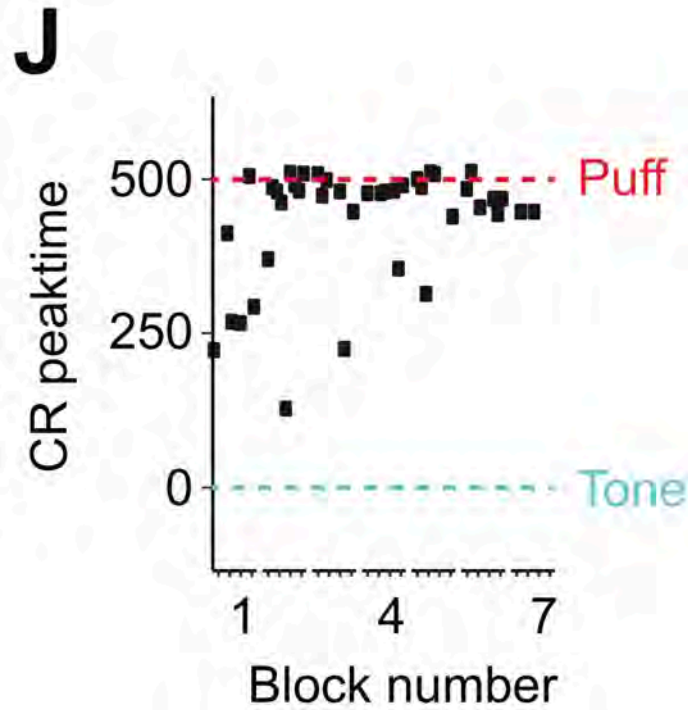
Using the eye aspect ratio (EAR), we calculate the eyelid closure.

G

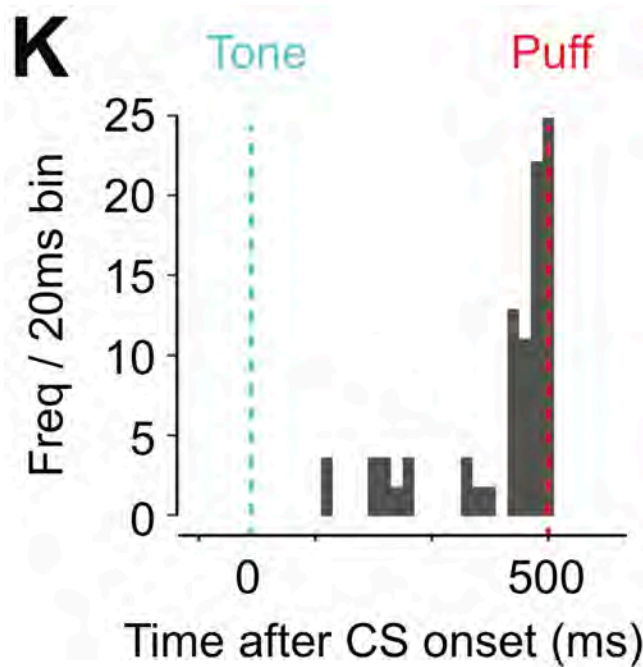


Example of eyelid closure over time; maximum closure is at time 393 ms.





Mean latency to CR peak. As training progresses, CR timing gets better, i.e. the eyelid is closed maximally at the moment that the puff will be delivered.



Peristimulus histogram showing that the vast majority of CR peaks is centered around the onset of the air puff.

Part III

Development of visual prediction task

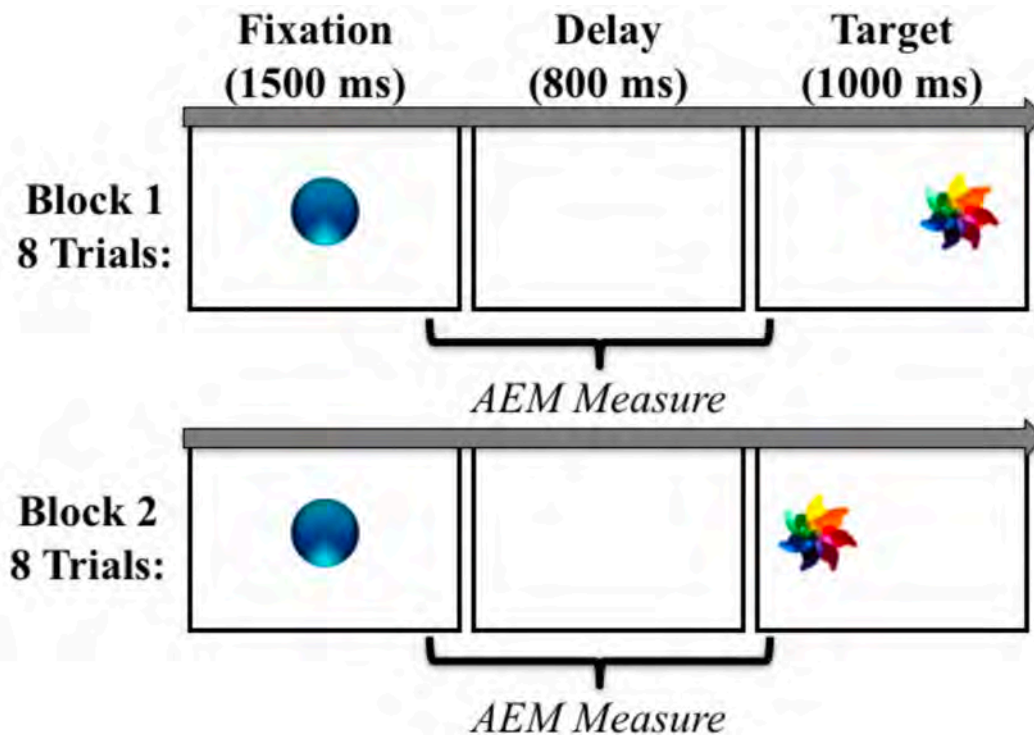
As part of this project, we developed a novel prediction task for infants, a behavior that we believe is controlled by the cerebellum. This study was published last fall in a high-impact journal in psychology, called *Cognition*. The ability to predict upcoming input has been proposed as a language learning mechanism, supported by research on individual differences in verbal prediction. Specifically, children with larger vocabularies tend to predict more and predict *flexibly* in sentence processing, quickly abandoning inaccurate predictions. One explanation for this difference is that children with larger vocabularies, by virtue of greater efficiency in language processing, can flexibly generate and update verbal predictions. Alternatively, this correlation may signal a difference in information processing, beyond the domain of language.

We investigated whether domain-general differences in information processing may lead to domain-specific differences in learning. To evaluate this possibility, we assessed infants' nonverbal prediction skills and vocabulary size. If flexibility in prediction signals a fundamental difference in information processing, we expect to find a positive correlation therein. Just as children with larger vocabularies flexibly generate *verbal* predictions, we expected infants with larger vocabularies would flexibly generate *nonverbal* predictions. We assessed nonverbal prediction in 12-24-month-old infants ($n=50$). In an eye-tracking task, infants saw a central stimulus, followed by a peripheral target, in a blocked design. Infants first saw 8 trials with a left-side target, then 8 trials with a right-side target, or vice-versa. We assessed predictions by analyzing anticipatory eye movements (AEMs) to target. We assessed flexibility in predictions by analyzing the proportion of AEMs correct (i.e., to the new target side) in Block 2.

Importantly, infants with larger vocabularies did not make more AEMs overall ($p=.39$, $r=-.12$), and in Block 1, 89% of AEMs were correct, with no vocabulary correlation ($p=.12$, $r=.24$). This suggests infants performed equally well in Block 1, and Block 2 differences are not driven by differences in Block 1. In Block 2, as expected, infants with larger vocabularies showed a larger proportion of AEMs correct ($p=.01$, $r=.39$). This finding indicates that infants with larger vocabularies flexibly updated their predictions. To control for speed of visual orienting in AEMs, we used a gap-overlap task. Infants saw a central stimulus, followed by a peripheral target, with trials quasi-randomized. Reaction time to target (RT) was faster in gap trials than in overlap trials ($p<.001$). We found no correlation between RT difference scores (overlap-gap) and vocabulary size ($p=.16$, $r=.22$), nor between RT difference scores and proportion of AEMs correct in Block 2 of the prediction task ($p=.19$, $r=.22$). Thus, individual differences in visual orienting do not account for prediction task findings.

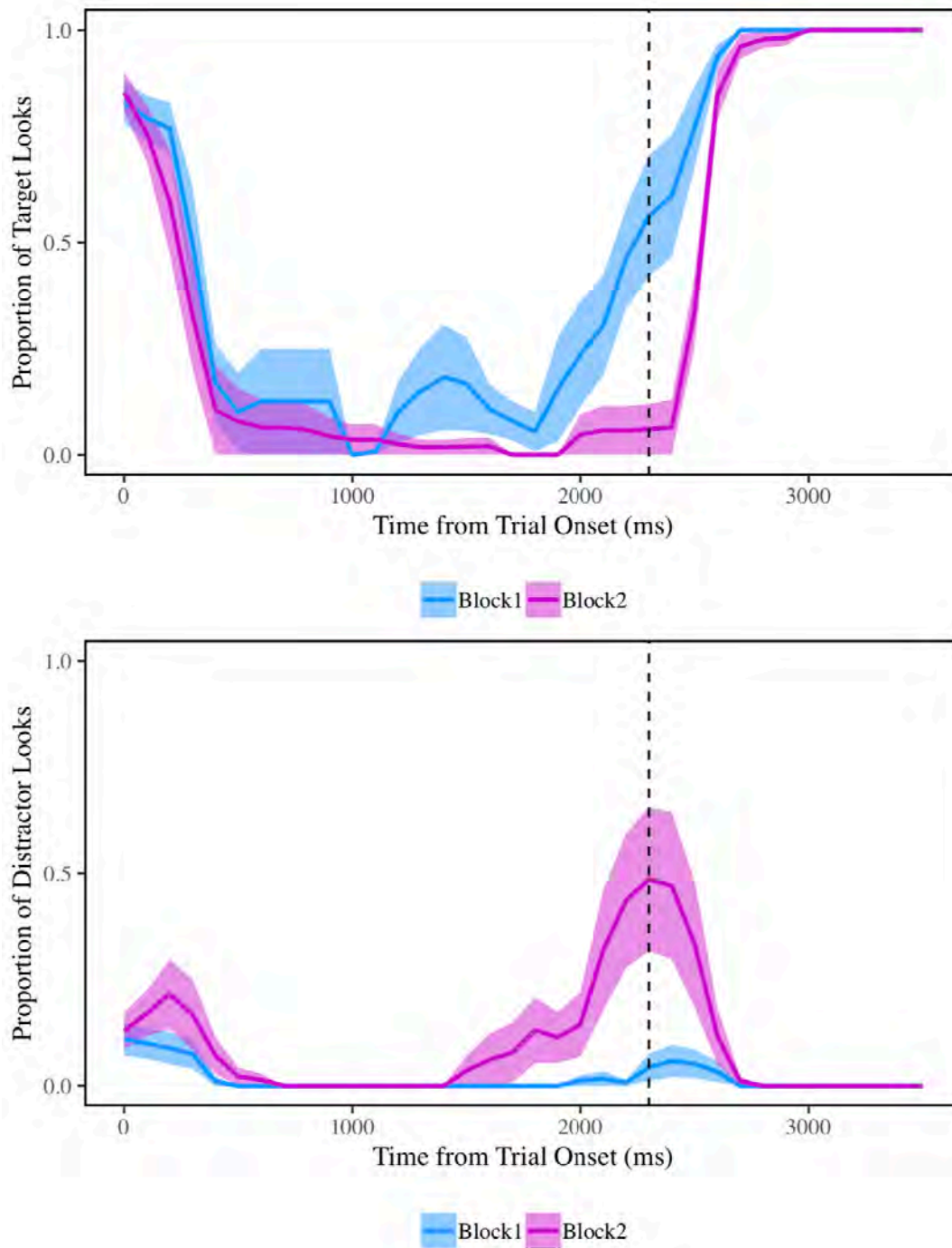
This study makes two novel contributions to our understanding of prediction and language learning. First, the link between flexibility in nonverbal prediction and vocabulary suggests that individual differences in a domain-general capacity, prediction, have implications for domain-specific learning. Second, this link is apparent even in infancy, and may underlie differences in verbal prediction years later. Given the vast opportunities to make inaccurate predictions in early language acquisition, the ability to update predictions may be crucial for learning. In our ongoing data collection with infants born prematurely with low birthweight, we are using this same task to evaluate whether the ability to predict and update predictions is (a) explained by cerebellar structure and function, and (b) able to explain variance in later diagnoses of DDs. Below, for comparison to the published study, we present data from the sample of premature infants who completed this task successfully. Then, we are attaching the published article about this paradigm in the journal *Cognition*.

(A)



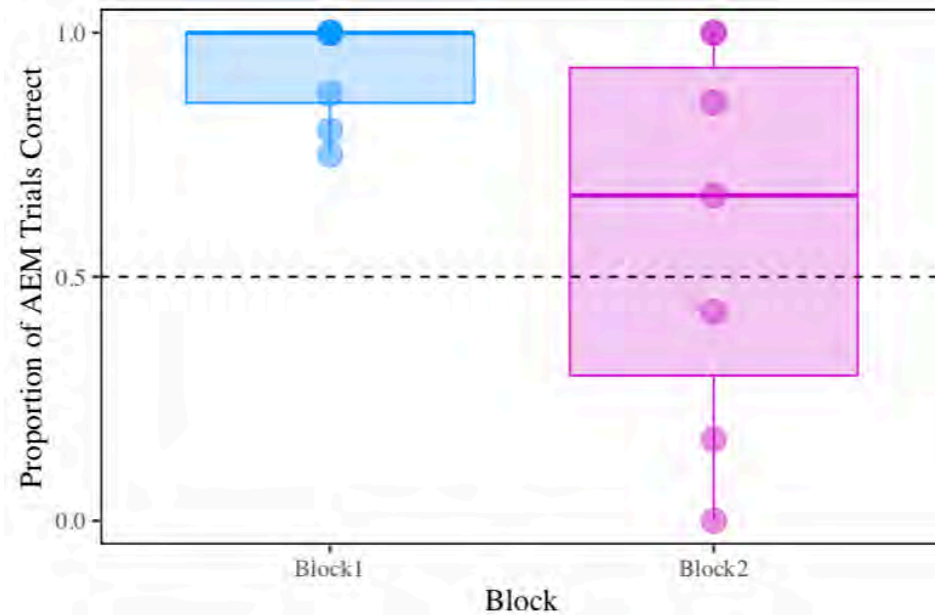
Schematic of the prediction task. Infants saw two blocks of trials. In Block 1, the target always appeared on one side (e.g., right). In Block 2, the target always appeared on the opposite side (e.g., left). On each trial, we measured infants' anticipatory eye movements (AEMs), defined as looks to either target location during a time window from 200 ms before center fixation offset until 200 ms after target onset (AEM Measure).

(B)



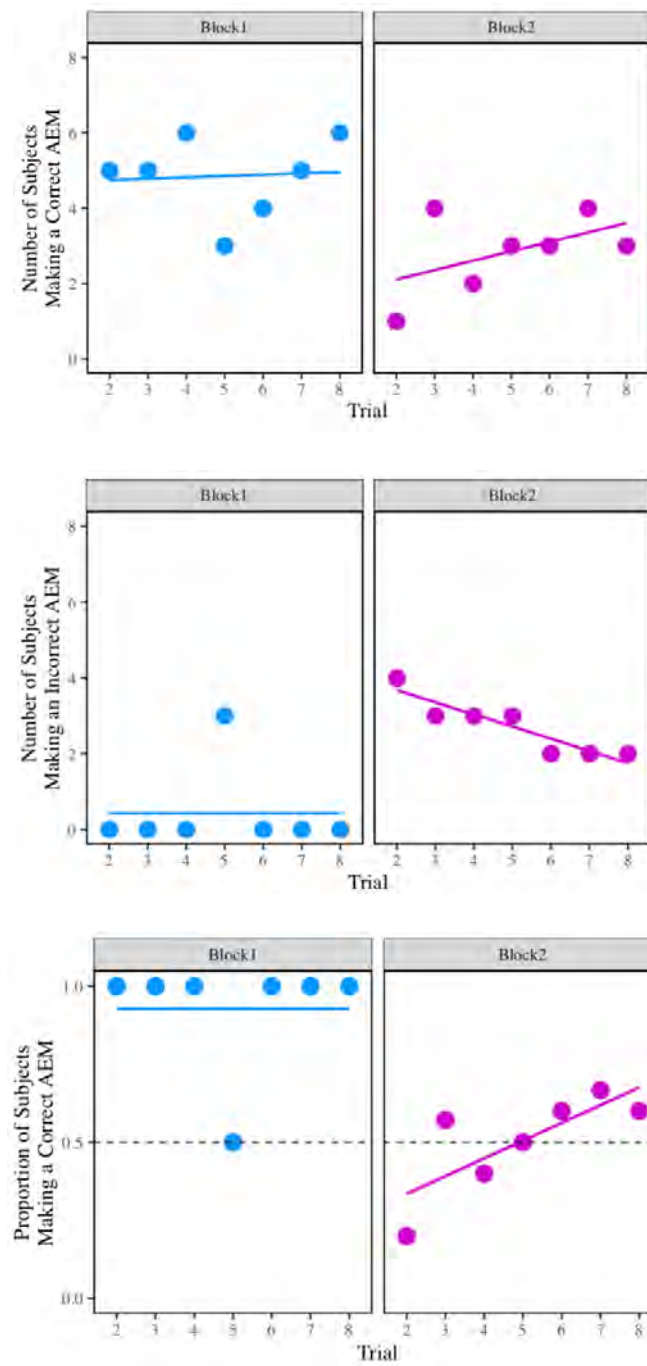
The rise in target looks before target onset (indicated by the vertical dashed line) confirms that infants generated AEMs. The greater target looks for block 1 as compared to block 2 suggests that infants generated more correct AEMs in block 1 as compared to block 2. All of this is similar to what we found in the original study.

(C)



Correct AEMs were initiated towards the target side, whereas incorrect AEMs were initiated towards the distractor side. The below plots indicate that: infants made correct AEMs in both blocks, infants made very few incorrect AEMs in block 1, and infants proportion of correct AEM trials (correct/correct+incorrect) was greater in block 1 as compared to block 2. Once again, all of these findings are similar to what we observed in the original study.

(D)



These plots indicate that infants learned the pattern very quickly in block 1 and also learned the new pattern in block 2. Infants did make some incorrect AEMs in block 1, but we did observe a few of those in the original study too. Notably, the proportion of infants making a correct AEM in block 2 looks very similar to what we found with *low-vocabulary* infants in the original study.



Brief article

Individual differences in nonverbal prediction and vocabulary size in infancy

Tracy Reuter^{a,*}, Lauren Emberson^a, Alexa Romberg^b, Casey Lew-Williams^a^a Department of Psychology, Princeton University, USA^b Department of Human Development and Quantitative Methodology, University of Maryland-College Park, USA

ARTICLE INFO

Keywords:

Prediction

Language development

Individual differences

Nonverbal

Visual

Learning

ABSTRACT

Children who generate and update verbal predictions have larger vocabularies, suggesting that prediction may be a mechanism that supports language learning. We hypothesize that this relation is not confined to the domain of language, but instead signals a broader individual difference in information processing. To investigate this possibility, we tested infants ($n = 50$) in the early stages of vocabulary development (12–24 months) on their ability to generate and update nonverbal, visual predictions. In an eye-tracking task, a central fixation reliably preceded a peripheral target. Then, halfway through the experiment, the peripheral target began appearing on the opposite side. We assessed infants' proficiency in initiating anticipatory eye movements before and after the switch, and found that infants with larger vocabularies did not generate more predictions overall, but were more efficient in updating predictions to the new target side. These findings establish a link between nonverbal prediction and vocabulary in infancy, and suggest a promising means of addressing whether or not prediction abilities are causally related to language learning.

1. Introduction

Human processing of complex information is facilitated by prediction (Bar, 2007; Summerfield & de Lange, 2014). Humans make predictions in many domains, such as vision (Rao & Ballard, 1999; den Ouden, Friston, Daw, McIntosh, & Stephan, 2009; Summerfield & de Lange, 2014), locomotion (Wolpert, Miall, & Kawato, 1998; Wolpert, Ghahramani, & Flanagan, 2001), and language (Rabagliati, Gambi, & Pickering, 2016). In language, prediction enables efficient processing among both adults and children, allowing listeners to keep pace with the rapid information flow of speech (DeLong, Urbach, & Kutas, 2005; Kutas, DeLong, & Smith, 2011; Borovsky, Elman, & Fernald, 2012; Pickering & Garrod, 2013).

In addition to its role in language processing, prediction may also be a mechanism that facilitates language learning. In error-based models of language learning, learners compare predicted input with actual input to gain information about the structure of their language (Chang, Dell, & Bock, 2006; Elman, 1990; Pickering & Garrod, 2013). For example, a child might expect to hear the word 'mouses' but instead hear 'mice,' and update future predictions accordingly (Ramscar, Dye & McCauley, 2013). There are two types of evidence that these models may be valid descriptions of learning. First, it is well-established that children generate predictions during language processing. They are

capable of drawing upon many types of linguistic information to anticipate what a speaker is likely to say next, such as phonology (Swingle, Pinto, & Fernald, 1999), semantics (Fernald, Zangl, Portillo, & Marchman, 2008; Fernald, Thorpe, & Marchman, 2010; Mani & Huettig, 2012), morphosyntax (Lew-Williams & Fernald, 2007; Borovsky et al., 2012; Lukyanenko & Fisher, 2016), and speakers' intentions (Kidd, White, & Aslin, 2011). Second, there are individual differences in the extent to which children generate verbal predictions, and these differences are related to children's language proficiency. Compared to children with smaller vocabularies, children with larger vocabularies are more likely to generate predictions in light of new linguistic information (Nation, Marshall & Altman, 2003; Borovsky et al., 2012; Mani & Huettig, 2012). Thus, in line with error-based models of learning, children who generate more verbal predictions and update those predictions efficiently have more advanced language abilities.

This research suggests that children can use multiple sources of information to anticipate downstream words and revise predictions as new linguistic information arrives. Although findings of this nature establish a link between prediction and language learning, they present an interpretational problem. There are a number of plausible explanations: One possibility is that verbal prediction is a capacity that supports vocabulary growth (see Elman, 1990). As reviewed above, prediction

* Corresponding author at: Department of Psychology, Princeton University, Princeton, NJ 08544, USA.
E-mail address: treuter@princeton.edu (T. Reuter).

errors can be used to modify the learner's representations of their language, making future predictions increasingly accurate. In contrast, a second possibility is that verbal prediction is strictly an outcome, rather than a cause, of vocabulary growth (Rabagliati et al., 2016). That is, language users may only begin to generate predictions once they have a fair amount of linguistic knowledge. Evaluating these two possibilities, as well as intermediate views, will aid in understanding the role of prediction in language processing and learning.

To further examine the relation between prediction and language learning, we used two new approaches. First, we focused on infants between 1 and 2 years of age. Previous studies showing links between prediction and vocabulary have tested children between 2 and 7 years who already comprehend and produce multiword sentences. If prediction plays a role in supporting the initial stages of language learning, then infants' prediction abilities should already be linked to their budding linguistic knowledge. Second, in the current study we evaluated whether prediction as a domain-general capacity may be related to language learning. That is, we did not aim to replicate previously established relations between verbal prediction and vocabulary. Instead, based on views of prediction as a general capacity that is present in multiple domains and possibly interacts across domains (Bar, 2007; Lupyan & Clark, 2015), we examined relations between non-verbal (i.e., visual) prediction and vocabulary size. We reasoned that differences in nonverbal prediction, as compared to verbal prediction, are less likely to be the direct result of vocabulary differences. This cross-domain approach represents a new direction for understanding the relation between prediction abilities and language proficiency.

Our investigation of how infants make and update nonverbal predictions included two main hypotheses. First, we hypothesized that the *quantity* of predictions that infants generate in a nonverbal task would be linked to vocabulary. Among older children, those with larger vocabularies, as compared to those with smaller vocabularies, are more likely to make verbal predictions (Nation, Marshall, & Altmann, 2003; Borovsky et al., 2012; Mani & Huettig, 2012). We expected that this relation would hold earlier in development and apply to the domain of nonverbal prediction. Second, we hypothesized that the *quality* of infants' nonverbal predictions would be linked to vocabulary. In error-based models, learners update predictions when they encounter incongruent information (Chang et al., 2006). Assuming these models are relevant for explaining learning toward the beginning of life, we expected that infants with larger vocabularies would be more successful in updating nonverbal predictions after observing unexpected information.

To evaluate these hypotheses, we tested 12- to 24-month-old infants in a visual prediction task, using anticipatory eye movements (AEMs) as a measure of prediction. In a second eye-tracking task, we controlled for differences in infants' speed of visual processing. We compared performance on these tasks to infants' vocabulary size (MCDI). Together, we used these measures to evaluate whether and how nonverbal prediction abilities relate to infants' early language development.

2. Method

2.1. Participants

Participants were 50 infants (26 female) from monolingual English-speaking families who ranged in age from 12 to 24 months ($M = 18$, $SD = 3.5$). Infants were full-term and had no known vision or hearing impairments. We excluded an additional 14 infants from all analyses due to parental report of developmental delay (1), bilingual language exposure (2), fussiness such that less than 50% of trials were code-able (8),¹

¹ We compared age and vocabulary measures for excluded and included infants, and found no differences in age [$t(8.58) = 0.06$, $p = 0.95$], MCDI comprehensive vocabulary size [$t(11.26) = -0.63$, $p = 0.54$], or MCDI productive vocabulary size [$t(11.71) = -0.40$, $p = 0.695$].

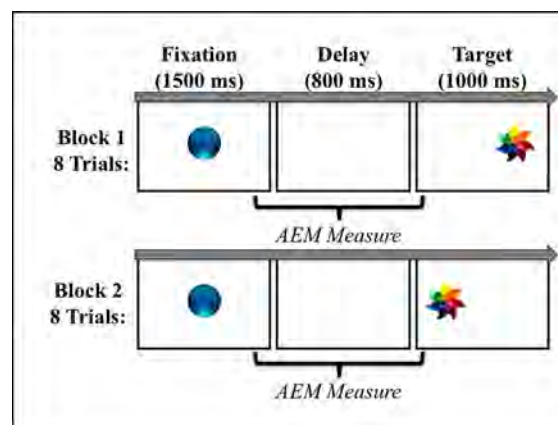


Fig. 1. Schematic of the prediction task. Infants saw two blocks of trials. In Block 1, the target always appeared on one side (e.g., right). In Block 2, the target always appeared on the opposite side (e.g., left). On each trial, we measured infants' anticipatory eye movements (AEMs), defined as looks to either target location during a time window from 200 ms before center fixation offset until 200 ms after target onset (AEM Measure).

or computer error (3). We excluded 6 of the 50 infants from visual processing task analyses due to computer error (4) or experimenter error (2). The Princeton University Institutional Review Board approved all research protocols, and a legal guardian provided informed consent for each infant.

2.2. Stimuli – Prediction task

On each trial, infants saw a central, looming fixation paired with a slide-whistle sound for 1500 ms. After an 800-ms delay, infants saw a peripheral, spinning target paired with another slide-whistle sound for 1000 ms (Fig. 1). Importantly, infants saw two blocks of trials. In the first block (trials 1–8), the target always appeared on one side, and in the second block (trials 9–16) its location switched sides. Block 1 target location was counterbalanced across infants.

On each trial, we measured infants' anticipatory eye movements (AEMs). As shown in Fig. 1, we conservatively defined AEMs as looks to either peripheral location during a time window from 200 ms before center fixation offset until 200 ms after target onset. This temporal window accounts for time needed to generate a saccade (Canfield, Smith, Brezsnayak, & Snow, 1997; Hallett, 1986; Matin, Shao, & Boff, 1993). AEMs were included in analyses regardless of infants' initial looking location.

Infants also saw a filler trial every 4 trials to maintain their attention. Fillers consisted of 5-s movies of a kaleidoscope paired with soft chimes. There was a 500-ms blank inter-trial interval.

2.3. Stimuli – Visual processing task

On each trial, infants saw a central fixation for 1000 ms, followed by a peripheral target for 1000 or 1250 ms (Fig. 2). Infants saw two types of trials. On gap trials, there was a 250-ms temporal gap between fixation offset and target onset. On overlap trials, there was a 250-ms temporal overlap between the fixation and the target. Unlike the prediction task, the target location did not follow a consistent pattern. Thus, infants were unable to accurately predict the target location. Trials appeared in one of two quasi-randomized orders, such that neither trial type (gap or overlap) nor target side (right or left) repeated for more than 3 trials sequentially. Fixation and target were stationary, and there were no auditory stimuli.

On each trial, we measured infants' reaction time (RT), defined as the time of the first target look occurring 200 ms or later after target onset (Fig. 2, "RT measure"). On overlap trials, the central stimulus

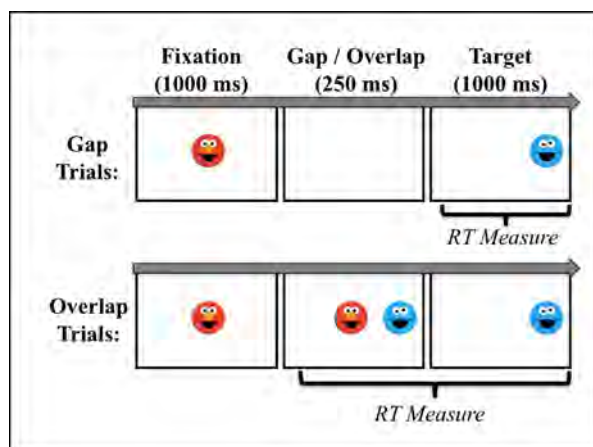


Fig. 2. Schematic of the visual processing task. Infants saw two types of trials. In gap trials, there was a 250-ms temporal gap between the fixation and the target. In overlap trials, there was a 250-ms temporal overlap between the fixation and the target. On each trial, we assessed infants' reaction time (RT), defined as the first target look during a time window from 200 ms after target onset (RT Measure).

competed for visual attention at target onset, so we expected infants' RT to be slower in overlap trials than in gap trials (Hood & Atkinson, 1993). We measured infants' visual processing speed as a difference score: overlap trials RT minus gap trials RT.

Infants also saw a filler trial every 8 trials to maintain their attention. Fillers consisted of 5-s movies of bubbles paired with child laughter. There was a 500-ms blank inter-trial interval. All stimuli are available in [supplementary materials](#).

2.4. Procedure

Before testing, caregivers completed the MacArthur-Bates Communicative Developmental Inventory (MCDI). We administered the MCDI Words and Gestures for infants 12–15 months old, and MCDI Words and Sentences for infants 16–24 months old, and standardized infants' scores in accordance with the MCDI technical manual (Fenson et al., 2007). During testing, each infant completed the prediction task, and then immediately completed the visual processing speed task. Infants sat on their caregiver's lap, and caregivers wore occluded glasses to avoid influencing the infants' behavior. Infants were approximately 70 cm from a large, flat-screen television monitor (68 × 122 cm). The experimenter recorded infants' eye movements via a video camera below the screen. After testing, a research assistant coded videos of infants' eye movements, indicating the direction of looks as: left, center, right, away, or shifting. Another research assistant also coded 25% of the videos. Inter-coder reliability was 98%.

3. Results

We hypothesized that infants with larger vocabularies would make more predictions and would update predictions more readily than infants with smaller vocabularies. To evaluate these hypotheses, we correlated infants' productive vocabulary percentile (MCDI) and anticipatory eye movements (AEMs) during the prediction task. We excluded trial 1 from all analyses, as there was no basis for infants to generate predictions therein. We also compared high-vocabulary and low-vocabulary groups, based on a median split in MCDI scaled scores. Finally, we analyzed visual processing speed to evaluate alternative explanations for individual variability in infants' performance on the prediction task.

3.1. Prediction task

To evaluate whether infants with larger vocabularies generated more predictions overall (regardless of accuracy), we first correlated infants' vocabulary size with their proportion of total trials with an AEM to either location. There was striking variation in both vocabulary size (MCDI percentile range = 5–99, $M = 42$, $SD = 28$) and proportion of trials with an AEM (range = 0–100, $M = 55$, $SD = 29$). Including all infants, regardless of how many AEMs they generated, we found no correlation between infants' vocabulary size and overall proportion of trials with an AEM [$r(48) = -0.12$, $p = 0.39$]. Examining each Block separately, there was no correlation in Block 1 [$r(48) = -0.03$, $p = 0.82$] nor in Block 2 [$r(47) = -0.17$, $p = 0.23$]. Thus, contrary to our first hypothesis, infants with relatively larger vocabularies were not more likely to anticipate the target's appearance.

To test our second hypothesis, that infants with larger vocabularies would update predictions more readily, we classified AEMs in Block 2 as directed toward the *novel* location (i.e., the Block 2 target location) or the *familiar* location (i.e., the Block 1 target location). Trial 9 was excluded from this analysis, because this was the first trial in which the target appeared in the novel location. Thus, infants had no basis for directing an AEM to the novel target location on this trial. Infants who did not make any AEMs in Block 2 ($n = 8$) or who did not have any code-able trials ($n = 1$) were not included in this analysis. For each infant, we calculated the proportion of their AEMs that were to the novel location (i.e., novel AEMs divided by total AEMs).

We found a significant correlation between infants' vocabulary size and the proportion of their AEMs to the novel location [$r(39) = 0.34$, $p = 0.028$]. Consistent with our second hypothesis, when making an AEM in Block 2, infants with larger vocabularies were more likely to make an AEM to the novel target location than infants with smaller vocabularies (Fig. 3). By comparison, in Block 1, 98% of infants' AEMs were directed to the correct peripheral target location, and there was no correlation between correct AEMs in Block 1 and vocabulary size [$r(42) = 0.24$, $p = 0.12$].

To examine the time-course of prediction updating, we analyzed AEMs trial by trial in Block 2. We divided infants into high-vocabulary and low-vocabulary groups based on a median split in MCDI percentile scores (high vocabulary: $n = 22$, $M = 64$, $SD = 19$; low vocabulary: $n = 19$, $M = 17$, $SD = 9$). Then, on each trial we calculated the proportion of AEMs to the novel location as the number of infants who made an AEM to the novel location divided by the number of infants who made AEMs to either location (Fig. 4). A binomial test was used to test this proportion against a chance value of 0.5. The low-vocabulary group only performed above chance on trial 16 ($p = 0.039$), making significantly more AEMs to the novel than the familiar location. The high-vocabulary group was marginally above chance in trial 13

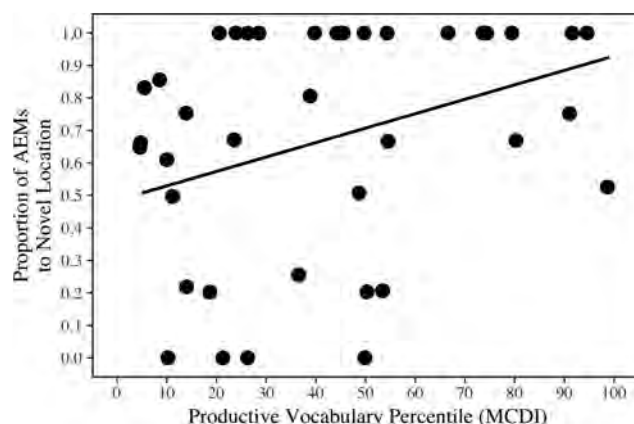


Fig. 3. Proportion of AEMs to the novel target location in Block 2. Line indicates linear regression and points represent individual subjects ($n = 41$).

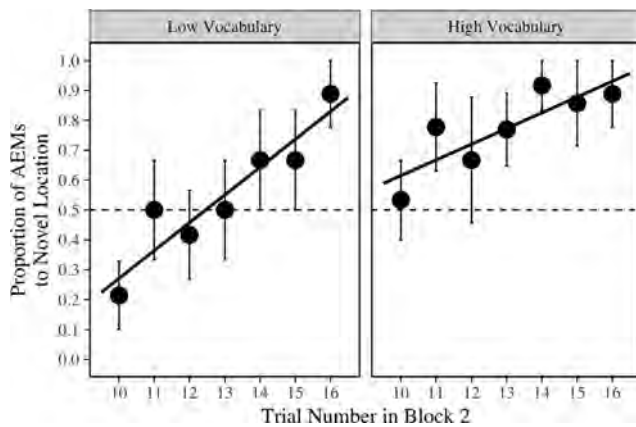


Fig. 4. Proportion of AEMs to the novel target location, by trial in Block 2, for high vocabulary infants ($n = 22$) and low vocabulary infants ($n = 19$). Lines indicate linear regression and bars represent standard error of the mean.

($p = 0.092$), above chance in trial 14 ($p = 0.006$), and above chance in trial 16 ($p = 0.039$).

To assess whether nonverbal prediction varied as a function of age, we repeated the above correlations with infants' age in months as a factor. We found no correlation between infants' age and overall proportion of trials with an AEM [$r(48) = -0.25$, $p = 0.08$]. There was no correlation in Block 1 [$r(48) = -0.23$, $p = 0.11$] or in Block 2 [$r(47) = -0.22$, $p = 0.13$]. Finally, there was no correlation between infants' age and the proportion of their AEMs to the novel location in Block 2 [$r(39) = 0.10$, $p = 0.52$].

3.2. Visual processing task

The gap-overlap task allowed us to examine whether individual differences in AEMs were due to differences in visual processing speed. First, we confirmed that infants were slower to shift their eyes to the target on overlap trials when there was a competing stimulus than on gap trials when there was no competing stimulus [gap trials: $M = 408$ ms, $SD = 31$; overlap trials: $M = 509$ ms, $SD = 74$; two-tailed $t(42) = -10.4$, $p < .001$]. Next, we computed RT difference scores for each infant (i.e., overlap trials minus gap trials) and used this difference score as the measure of visual processing speed independent of prediction. We found no correlation between infants' RT difference scores and their proportion of AEMs overall [$r(40) = -0.09$, $p = 0.56$] and no correlation between infants' RT difference scores and their proportion of AEMs to the novel target location in Block 2 of the prediction task [$r(33) = 0.18$, $p = 0.29$]. Together, these findings suggest that infants' performance on the prediction task was not related to variation in orienting to the dynamics of visual events.

4. Discussion

A growing body of research demonstrates a link between verbal prediction and language learning (Nation et al., 2003; Borovsky et al., 2012; Mani & Huettig, 2012), but the nature of this relation remains uncertain (Rabagliati et al., 2016). Specifically, is prediction a cause or a consequence of language learning? While the present study does not license causal inferences, our approach represents one step toward addressing this directionality puzzle by investigating nonverbal, visual prediction in infancy.

In particular, the present findings make two novel contributions to the current understanding of prediction and language learning. First, we demonstrate a link between infants' nonverbal prediction and vocabulary. Nonverbal prediction, as compared to verbal prediction, is less likely to be the direct result of language learning. Thus, our findings suggest that language learning may be supported in part by domain-

general prediction abilities (see Bar, 2007; Summerfield & de Lange, 2014). Second, we show that the ability to update predictions in infancy – and to not perseverate with previously learned predictions – may be particularly important for learning. Infants with larger vocabularies did not generate more predictions overall, but they updated predictions quickly in light of new information. Together, these findings suggest that prediction capacities beyond the domain of language are relevant for understanding early vocabulary growth, and that the quality of predictions (i.e., updating) rather than quantity of predictions (i.e., overall tendency to predict) might support vocabulary growth.

How might infants' abilities to flexibly update predictions support language learning? Updating predictions to adapt to changes in the environment is a central feature of error-based learning models (e.g., Rescorla & Wagner, 1972). In such models, predictions are not static. Rather, predictions are continuously updated in light of new information, so that the learner can generate more accurate predictions in the future. Updating predictions may enable infants to better represent the shifting statistics of the input, incrementally generating more precise predictions as they gain more information. In contrast, maintaining the same predictions throughout learning may block infants from processing and encoding novel information. Individual differences in infants' abilities to update predictions may operate from early in infancy and contribute to gains in a variety of domains, including language.

However, it is not clear what causes early differences in prediction abilities. One possibility is that learning from more variable input encourages infants to update predictions more frequently. Dynamic, rich experience with objects, people, and language could reinforce the benefits of attending to and learning from new information. Supporting this view in a laboratory context, Romberg and Saffran (2013) found that infants who received variable input in an audio-visual learning task updated predictions more readily than those who received deterministic input. Similarly, Kovács and Mehler (2009) found that bilingual infants, as compared to monolinguals, rapidly updated predictions in a nonverbal task. In both experiments, there was variation in prediction updating, much like the present findings; some infants never updated predictions despite the fact that their predictions were consistently incorrect. Thus, learning from more variable input may encourage prediction updating. Another possibility is that the relation between prediction and language learning is mediated by related cognitive capacities, such as executive function (Kovács & Mehler, 2009) or working memory (Mani & Huettig, 2013; Huettig & Janse, 2016). Further experiments are needed to fully characterize the connections between prediction and language learning, by taking into account both linguistic and nonlinguistic factors and by considering plausible third variables. Here, we suggest that a more general framework of predictive information processing, especially one that captures how learners update predictions, will be fruitful in understanding how infants begin learning patterns in the world, including language.

Acknowledgements

This research was funded by grants from the National Institute of Child Health and Human Development to Casey Lew-Williams (R03HD079779) and to Lauren Emberson (R00HD076166-02). We thank the participating families and members of the Princeton Baby Lab. We are especially grateful to Jean Bellamy and Fernanda Fernandez for coding.

Appendix A. Supplementary material

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.cognition.2018.03.006>.

Stimuli, data, and R code are available on Dataverse (doi: <http://dx.doi.org/10.7910/DVN/GFVHHS>).

References

- Bar, M. (2007). The pro-active brain: Using analogies and associations to generate predictions. *Trends in Cognitive Sciences*, 11, 280–289.
- Borovsky, A., Elman, J. L., & Fernald, A. (2012). Knowing a lot for one's age: Vocabulary skill and not age is associated with anticipatory incremental sentence interpretation in children and adults. *Journal of Experimental Child Psychology*, 112(4), 417–436.
- Canfield, R. L., Smith, E. G., Brezsnayak, M. P., & Snow, K. L. (1997). Information processing through the first year of life: A longitudinal study using the visual expectation paradigm. *Monographs of the Society for Research in Child Development*, 62, 1–45.
- Chang, F., Dell, G. S., & Bock, K. (2006). Becoming syntactic. *Psychological Review*, 113(2), 234.
- DeLong, K. A., Urbach, T. P., & Kutas, M. (2005). Probabilistic word pre-activation during language comprehension inferred from electrical brain activity. *Nature Neuroscience*, 8(8), 1117–1121.
- den Ouden, H. E. M., Friston, K. J., Daw, N. D., McIntosh, A. R., & Stephan, K. E. (2009). A dual role for prediction error in associative learning. *Cerebral Cortex*, 19(5), 1175–1185.
- Elman, J. L. (1990). Finding structure in time. *Cognitive Science*, 14(2), 179–211.
- Fenson, L., Marchman, V. A., Thal, D. J., Dale, P. S., Reznick, J. S., & Bates, E. (2007). *Macarthur-bates communicative development inventories: User's guide and technical manual* (2nd ed.). Baltimore, MD, USA: Brookes.
- Fernald, A., Thorpe, K., & Marchman, V. A. (2010). Blue car, red car: Developing efficiency in online interpretation of adjective-noun phrases. *Cognitive Psychology*, 60, 190–217.
- Fernald, A., Zangl, R., Portillo, A. L., & Marchman, V. A. (2008). Looking while listening: Using eye movements to monitor spoken language comprehension by infants and young children. In I. A. Sekerina, E. M. Fernandez, & H. Clahsen (Eds.). *Developmental psycholinguistics: Online methods in children's language processing*. Amsterdam, Netherlands: John Benjamins Publishing Company.
- Hallett, P. E. (1986). Eye movements. In K. R. Boff, L. Kaufman, & J. P. Thomas (Eds.). *Handbook of perception and human performance*. New York, NY, USA: Wiley.
- Hood, B. M., & Atkinson, J. (1993). Disengaging visual attention in the infant and adult. *Infant Behavior and Development*, 16(4), 405–422.
- Huetting, F., & Janse, E. (2016). Individual differences in working memory and processing speed predict anticipatory spoken language processing in the visual world. *Language, Cognition and Neuroscience*, 31(1), 80–93.
- Kidd, C., White, K. S., & Aslin, R. N. (2011). Toddlers use speech disfluencies to predict speakers' referential intentions. *Developmental Science*, 14(4), 925–934.
- Kovács, A. M., & Mehler, J. (2009). Cognitive gains in 7-month-old bilingual infants. *Proceedings of the National Academy of Sciences*, 106(16), 6556–6560.
- Kutas, M., DeLong, K. A., & Smith, N. J. (2011). A look around at what lies ahead: Prediction and predictability in language processing. In M. Bar (Ed.). *Predictions in the brain: Using our past to generate a future*. Oxford: Oxford University Press.
- Lew-Williams, C., & Fernald, A. (2007). Young children learning Spanish make rapid use of grammatical gender in spoken word recognition. *Psychological Science*, 18(3), 193–198.
- Lukyanenko, C., & Fisher, C. (2016). Where are the cookies? Two- and three-year-olds use number-marked verbs to anticipate upcoming nouns. *Cognition*, 146, 349–370.
- Lupyan, G., & Clark, A. (2015). Words and the world: Predictive coding and the language-perception-cognition interface. *Current Directions in Psychological Science*, 24(4), 279–284.
- Mani, N., & Huettig, F. (2012). Prediction during language processing is a piece of cake—But only for skilled producers. *Journal of Experimental Psychology: Human Perception and Performance*, 38, 843–847.
- Mani, N., & Huettig, F. (2013). Towards a complete multiple-mechanism account of predictive language processing. *The Behavioral and Brain Sciences*, 36(4), 365–366.
- Martin, E., Shao, K. C., & Boff, K. R. (1993). Saccadic overhead: Information-processing time with and without saccades. *Perception & Psychophysics*, 53, 372–380.
- Nation, K., Marshall, C. M., & Altmann, G. (2003). Investigating individual differences in children's real-time sentence comprehension using language-mediated eye movements. *Journal of Experimental Child Psychology*, 86, 314–329.
- Pickering, M. J., & Garrod, S. (2013). An integrated theory of language production and comprehension. *The Behavioral and Brain Sciences*, 36(4), 329–347.
- Rabagliati, H., Gambi, C., & Pickering, M. J. (2016). Learning to predict or predicting to learn? *Language, Cognition and Neuroscience*, 31, 94–105.
- Rao, R. P., & Ballard, D. H. (1999). Predictive coding in the visual cortex: a functional interpretation of some extra-classical receptive-field effects. *Nature Neuroscience*, 2(1), 79–87.
- Ramscar, M., Dye, M., & McCauley, S. M. (2013). Error and expectation in language learning: The curious absence of mouses in adult speech. *Language*, 89(4), 760–793.
- Rescorla, R. A., & Wagner, A. R. (1972). A theory of Pavlovian conditioning: Variations in the effectiveness of reinforcement and non-reinforcement. In A. H. Black, & W. F. Prokasy (Eds.). *Classical conditioning II: Current research and theory*. Appleton Century Crofts: New York, NY, USA.
- Romberg, A. R., & Saffran, J. R. (2013). Expectancy learning from probabilistic input by infants. *Frontiers in Psychology*, 3(JAN), 1–16.
- Summerfield, C., & de Lange, F. P. (2014). Expectation in perceptual decision making: neural and computational mechanisms. *Nature Reviews Neuroscience*, (October), 1–12.
- Swingle, D., Pinto, J. P., & Fernald, A. (1999). Continuous processing in word recognition at 24 months. *Cognition*, 71, 73–108.
- Wolpert, D. M., Ghahramani, Z., & Flanagan, J. R. (2001). Perspectives and problems in motor learning. *Trends in Cognitive Sciences*, 5(11), 487–494.
- Wolpert, D. M., Miall, R. C., & Kawato, M. (1998). Internal models in the cerebellum. *Trends in Cognitive Sciences*, 2(9), 338–347.

**Partnership for Maternal and Child Health of Northern New Jersey
Perinatal Addictions Prevention Project
Division on Developmental Disabilities Grant**

***Fetal Alcohol Spectrum Disorders (FASD) and
Screening, Brief Intervention, Referral to Treatment (SBIRT) Training
Year Two Evaluation Report***

Pam Kelley, Ph.D.
Kelley Analytics, LLC
July 1, 2019

Contents

	Page
Executive Summary	iii
I. Introduction	1
Background	1
Program Overview	1
Evaluation Purpose	2
Logic Model	2
Key Evaluation Questions	4
II. Methods.....	5
III. Results	5
A. Staff Training.....	5
B. Client Outcomes	12
IV. Discussion and Recommendations	20
Appendices.....	22
Appendix A. Training Evaluation Form	23
Appendix B. Client Pre- and Posttest	26
Appendix C. Supplemental Tables	28

**Partnership for Maternal and Child Health of Northern New Jersey
Perinatal Addictions Prevention Project
Division on Developmental Disabilities Grant
Fetal Alcohol Spectrum Disorders (FASD) and
Screening, Brief Intervention, Referral to Treatment (SBIRT) Training**

Year Two Evaluation Report: Summary of Key Findings

Pam Kelley, Ph.D.

Kelley Analytics, LLC

July 2019

Introduction and Methods

This document presents a summary of key evaluation findings from Year Two of a program developed by the Partnership for Maternal and Child Health of Northern New Jersey designed to train home visitors and community health workers in the Screening, Brief Intervention, and Referral to Treatment (SBIRT) approach to educate pregnant women and new mothers about FASD and the importance of abstaining from alcohol use during pregnancy. Funded through a grant from the New Jersey Office for the Prevention of Developmental Disabilities, the overarching goal of the program was to utilize the expertise and trusting relationships developed by home visitors and community health workers with their clients to provide risk-appropriate, one-on-one education to pregnant women and new mothers to reduce the incidence of mental and developmental disabilities caused by maternal alcohol consumption during pregnancy. The program aimed to achieve the following four objectives:

1. To increase home visitors' /community health workers' comfort level with the SBIRT method;
2. To increase home visitors'/community health workers' intent to utilize the SBIRT method during client interactions;
3. To increase client knowledge about the links between FASD and developmental disabilities; and
4. To increase client intent to abstain from alcohol consumption during pregnancy.

To assess the extent to which the program achieved these objectives, the evaluation employed a mixed methods design that included the following components:

Staff Training Evaluation Form: A 32-item instrument that utilized a retrospective pretest design to measure training participants' levels of knowledge, competence, and confidence, related to FASD and the SBIRT method, before and after the training. The tool also included open-questions designed to collect qualitative information on participants' satisfaction with the training and suggestions for improvement. The tool was administered to training participants via paper and pen immediately following each training event.

Client Pre-Posttest: A four-item questionnaire for home visitors/community health workers to administer verbally to clients at the beginning and end of their home visits. The questionnaire was designed to assess change in client knowledge regarding the risks and consequences of alcohol consumption during pregnancy. The posttest included two multiple choice questions designed to assess clients' self-reported increase in knowledge of the links between FASD and developmental disabilities and intentions to abstain from alcohol consumption during pregnancy (Please refer to full report for more details on the evaluation methods).

Key Findings

Home Visitors and Community Health Workers

- A total of **42** home visitors and community health workers attended the program trainings.
- For home visitors/community health workers who attended the training, **a statistically significant increase was found in all four of the program's key competency areas**, including: 1) overall knowledge of the SBIRT method; 2) comfort level with asking clients about their substance use;

3) comfort level in beginning the conversation about substance use; and 4) level of preparation to use the SBIRT technique with clients.

- **95%** reported an increase in their comfort level with using the SBIRT method with clients.
- **100%** reported being either *very likely* or *moderately likely* to use the SBIRT method with their clients.
- According to qualitative data, training participants were **highly satisfied with the training, experienced it as very valuable, and planned to integrate what they learned into their professional practice**, particularly with regard to improving communication with, and understanding their clients.

Program Clients

- Home visitors and community health workers distributed the program Toolkits and education to **561** clients.
- Clients' **overall knowledge of FASD increased significantly**, from an average score of 87 prior to receiving the program education to **97** afterwards (out of 100 possible points).
- **90%** of participating clients reported an **increase in their knowledge about the links between FASD and developmental disabilities**.
- After receiving the program education, a majority of **84%** of participating clients reported their **plans to abstain from alcohol during pregnancy had increased**.

Discussion

Based on these evaluation findings, Year Two of the FASD and SBIRT training program was successful in preparing home visitors and community health workers in using the SBIRT approach to educate pregnant women and new mothers about FASD and the importance of abstaining from alcohol use during pregnancy.

According to pre-post results, average scores for training attendees increased significantly in all four of the program's key competency areas, including: 1) overall knowledge of the SBIRT method; 2) comfort level with asking clients about their substance use; 3) comfort level in beginning the conversation about substance use; and 4) level of preparation to use the SBIRT technique with clients. In addition, 95% of training attendees reported an increase in their comfort level with using the SBIRT method with clients and 100% reported being either *very likely* or *moderately likely* to use the SBIRT method with their clients. Thus, the program was successful in meeting (and exceeding) its target benchmark of 85.0% for these training objectives. Qualitative data obtained from the training attendees supported these results, with common themes that suggested participants were highly satisfied with the training, experienced it as valuable, and planned to integrate what they learned into their professional practice, particularly with regard to improving communication with, and understanding their clients.

Pre-posttest results from program clients showed their overall knowledge of FASD increased significantly, from an average score of 87 prior to receiving the program education to 97 afterwards. In addition, 90% reported an increase in knowledge about the links between FASD and developmental disabilities and a majority of 84% reported their plans to abstain from alcohol during pregnancy had increased.

Taken together, these positive results provide preliminary evidence for the program's effectiveness in achieving its short- and medium-term outcomes. Program leaders may wish to consider a future evaluation to assess the program's longer-term outcomes, such as client behavior change and birth outcomes. As with all projects, the evaluation had some limitations, including the use of small convenience samples and self-reported information, which may not be generalizable to larger populations and thus, care should be taken in extrapolating the results to the broader group of program participants. However, the use of a mixed methods approach with multiple sources of quantitative and qualitative data may have mitigated these biases to some extent. Finally, these findings, as a summary of the participants' experiences and perspectives, may provide program leaders with important information to assist with planning and implementing similar programs in the future.

I. Introduction

Background

This report presents Year Two findings from an evaluation of a program developed by the Partnership for Maternal and Child Health of Northern New Jersey (the Partnership) designed to train home visitors and community health workers in the Screening, Brief Intervention, and Referral to Treatment (SBIRT) approach to educate pregnant women and new mothers about FASD and the importance of abstaining from alcohol use during pregnancy.

SBIRT¹ is an evidence-based practice used to identify, reduce, and prevent problematic alcohol and substance use, abuse and dependence. SBIRT consists of three major components: *screening*, in which the client is assessed for risky substance use behaviors using standardized screening tools;² *brief intervention*, in which the client is engaged in a short conversation that provides feedback and advice; and *referral to treatment*, in which the professional provides a referral to therapy/treatment for clients in need.

Program Overview

Funded through a grant from the New Jersey Office for the Prevention of Developmental Disabilities, the overarching goal of the program was to utilize the expertise and trusting relationships developed by home visitors and community health workers with their clients to provide risk-appropriate, one-on-one education to pregnant women and new mothers in order to reduce the incidence of mental and developmental disabilities caused by maternal alcohol consumption during pregnancy. The program aimed to achieve the following four objectives:

1. To increase home visitors'/community health workers' comfort level with the SBIRT method;
2. To increase home visitors'/community health workers' intent to utilize the SBIRT method during client interactions;
3. To increase client knowledge about the links between FASD and developmental disabilities; and
4. To increase client intent to abstain from alcohol consumption during pregnancy.

The key program activities included the development and implementation of a training curriculum targeted to home visitors and community health workers with focus on the SBIRT method and education related to alcohol use during pregnancy and the risk of developmental disabilities associated with FASD. Trained home visitors and community health workers were encouraged to apply their new knowledge and skills in their interactions with clients. In accordance with the SBIRT method, clients whose screening results indicate they are at risk for alcohol use during pregnancy would receive a brief intervention and referral to treatment from their home visitor/community health worker. The ongoing relationship between the home visitor/community health worker and the client would then allow for follow-up to ensure that the client was actually connected to care and assessed and treated by appropriate clinical

¹ See the SAMHSA-NRSA Center for Integrated Health Solutions website: <https://www.integration.samhsa.gov/clinical-practice/sbirt>

² New Jersey utilizes the PRA (Prenatal Risk Assessment) which includes the 4-P's Plus (parents' use, partners use, past use and present use).

professionals. The key program activities also included the development of an FASD Toolkit containing relevant educational materials and resources for home visitors and community health workers to share with their clients.

Evaluation Purpose

During an initial evaluation planning meeting, the evaluation consultant and program leadership met as a team to discuss the purpose and informational priorities for the evaluation. The discussion was guided by evaluation best practices, particularly the evaluation standards set forth by the Centers for Disease Control and Prevention (CDC)³ of utility (i.e., who will be the primary users of the evaluation results and what results will be most useful to them); and feasibility (i.e., is there sufficient time and are there sufficient resources available to implement the desired evaluation). The team agreed that the primary purpose of the evaluation would be twofold: a) to assess the extent to which the program achieved its stated objectives and b) to identify potential areas of improvement for future implementation.

Logic Model

The CDC standards also recommend that a program *logic model* be developed to set the stage for determining the focus of the evaluation.⁴ A logic model is a visual representation of the relationships between a program's planned work and its intended results.^{5,6} Logic models are read left to right and identify a program's available resources (inputs), what the program does or the services it provides (activities), the program's reach and direct products of its activities (outputs) and what the program expects to achieve (outcomes). In addition to providing program stakeholders with a shared frame of reference about how the program is expected to work, the logic model serves as a conceptual model for the evaluation and thus guides what will be measured and how the relationships between program components will be analytically tested in the evaluation.

The evaluation consultant and program leadership worked collaboratively to develop the program logic model presented in Figure 1:

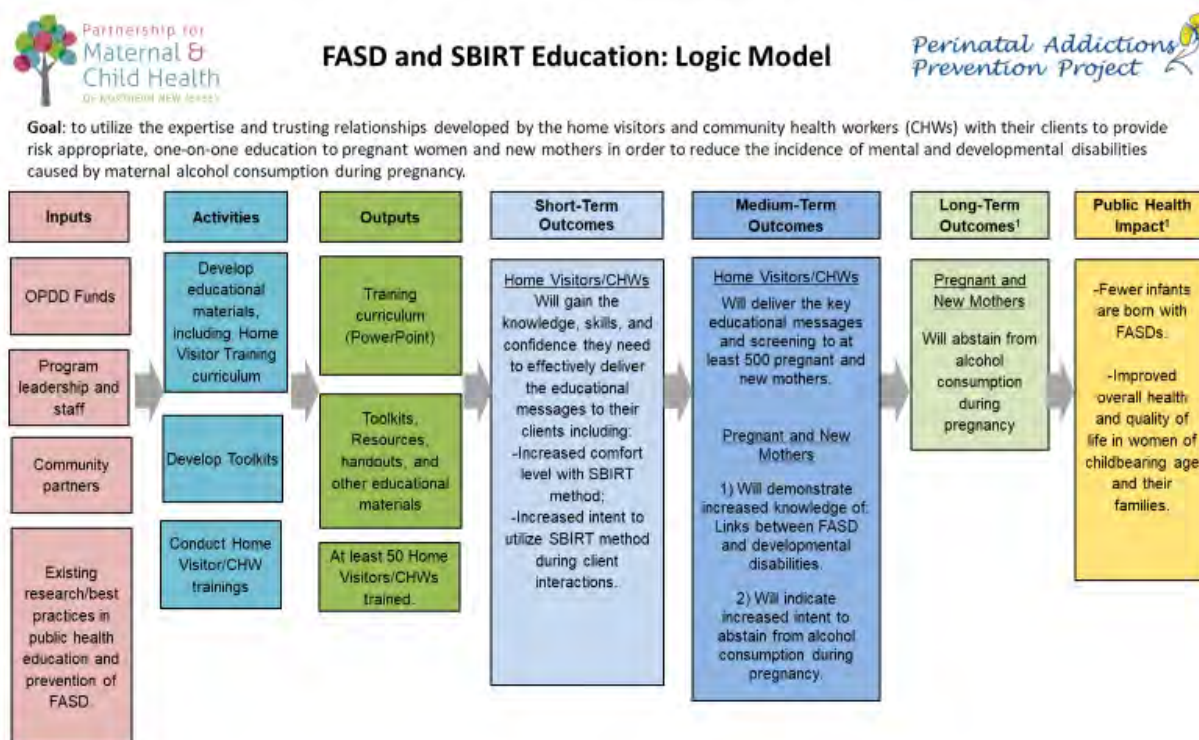
³ For a good description of the evaluation standards, see the CDC's *Introduction to program evaluation for public health programs*. Available at <http://www.cdc.gov/evalguide/step3/index.htm>

⁴ See <http://www.cdc.gov/evalguide/step3/index.htm>

⁵ See W.K. Kellogg Foundation (2001). *The logic model development guide*. Battle Creek, MI: available from <http://www.smart4vers.org/uploads/logicmodelguide.pdf>

⁶ A logic model is one of several tools that are commonly used in evaluation planning to describe a program, others include driver diagrams, etc.

Figure 1. Logic Model



¹ These long term outcomes and public health impact will not be evaluated in the current project but are included in the logic model for completeness.

As shown in Figure 1, **Inputs** (first column), are defined as the various resources that a program has available to direct towards doing its work. In addition to the grant funding, the FASD and SBIRT Training program inputs include the program leadership and staff, community partners, and the Partnership's existing knowledge and resources regarding the latest research and best practices in public health education and prevention of FASD.

Activities: (second column) describe the processes, services, interventions, tools, events, technology, and actions that are intentional components of implementing the program and that are used to bring about the program's intended changes or results. The key activities of the FASD and SBIRT Training program include developing and implementing the home visitor/community health worker training curriculum, developing/identifying other relevant educational materials and resources, and the development of a program Toolkit with information and resources for clients.

Outputs (third column) are the direct products obtained or produced as a result of the program activities and may include types, levels, and targets of its services and products. Most outputs are quantifiable, including tallies/counts of the number of the number of program participants, characteristics of participants, education/trainings conducted, and number/type of resources distributed. The key outputs include the training curriculum PowerPoint presentation, program Toolkits, and other informational resources and handouts, and the training of at least 50 home visitors/community health workers.

Outcomes are the changes, impacts, or results of program implementation (activities and outputs). The program outcomes are grouped into short-, medium-, and long-term, according to when they are expected to occur in relation to the intervention:

Short-term Outcomes (fourth column) are expected to occur shortly (i.e. usually within approximately six months) from the time participants access the program services and/or interventions and usually describe changes in knowledge, skills, and attitudes. For the FASD and SBIRT Training program, this includes increased knowledge, skills, and confidence among home visitors and community health workers to effectively deliver the program's educational messages to their clients, with special focus on increased comfort level with using the SBIRT method and increased intent to use SBIRT method during client interactions.

Medium-term outcomes (fifth column) are expected to occur following the achievement of the short-term outcomes and generally describe applying the new knowledge, skills, and capacity. For home visitors and community health workers, this includes using the SBIRT method with their clients and delivering the program key educational messages to their clients. For the clients, this includes increased knowledge of the links between FASD and developmental disabilities, and increased intent to abstain from alcohol consumption during pregnancy.

Long-term outcomes are expected to occur after achievement of the short- and medium-term outcomes and generally describe the positive results, such as changes in behaviors or level of functioning, that are intended to occur as a result of the program intervention. Meanwhile, **public health impact** refers to the system or community level changes expected to result from the program, such as improved conditions for a community or population. Evaluation of long-term outcomes and public health impact of the Partnership's FASD and SBIRT Training program were determined to be beyond the scope of the current evaluation; however, they were included in the logic model for completeness.

Key Evaluation Questions

Guided by the program logic model and the informational priorities described in the previous section, the evaluation consultant and program leadership designed the evaluation to answer the following key questions:

1. To what extent was the program successful in reaching its intended targets for training 50 home visitors/community health workers and providing the program's education and resources to 500 of their clients?
2. To what extent did home visitors/community health workers who participated in the training report increased comfort level with the SBIRT method? To what extent did the program achieve its intended target benchmark of at least 85.0% for this objective?
3. To what extent did home visitors/community health workers who participated in the training report increased intent to use the SBIRT method during client interactions? To what extent did the program achieve its intended target benchmark of at least 85.0% for this objective?
4. What did home visitors/community health workers find most valuable about the training?

5. What suggestions do home visitors/community health workers have for improving the training?
6. To what extent did clients' knowledge about the link between FASD and developmental disabilities and clients' intent to abstain from alcohol during pregnancy increase as a result of receiving the program education/information? To what extent did the program achieve its target benchmark of 85.0% for these objectives?

II. Methods

To answer the evaluation questions, the evaluation consultant worked collaboratively with the program leaders to design a mixed methods evaluation that included the following components:

Staff Training Evaluation Form (Appendix A): A 32-item instrument developed by the evaluation consultant and program leaders that utilized a retrospective pretest design to measure training participants' levels of knowledge, competence, and confidence, related to FASD and the SBIRT method, before and after the training. In addition, the tool included questions designed to collect qualitative and quantitative data on participants' satisfaction with the training, achievement of learning objectives, most valuable lessons learned, and how participants plan to integrate what they learned in their professional practice. The tool was administered to training participants via paper and pen immediately following each training event.

Client Pre-Posttest (Appendix B): To measure change in client knowledge about FASD and intention to abstain from alcohol use during pregnancy, the evaluation consultant worked with the program leaders to develop a brief questionnaire for home visitors/community health workers to administer verbally to clients at the beginning and end of their home visits. The questionnaire consisted of four true or false questions designed to assess change in client knowledge regarding the risks and consequences of alcohol consumption during pregnancy. In addition, the posttest included two multiple choice questions designed to assess clients' self-reported increase in knowledge of the links between FASD and developmental disabilities and intentions to abstain from alcohol consumption during pregnancy.

For all analyses, missing data were excluded.

The following section will present the evaluation results.

III. Results

A. Staff Training

Evaluation Response

Eight training events were attended by a total of 42 home visitors and community health workers; all of whom completed evaluation forms, for a response rate of 100.0% (Table 1):

Table 1. Training Evaluation Response by Event

	Number in Attendance	Evaluation Forms Submitted	Response
Training Event and Date	N	n	%
Phillipsburg (9/12/18)	5	5	100.0
Irvington (9/17/18)	8	8	100.0
YCS PAT Hudson (10/1/18)	3	3	100.0
Care Plus Healthy Families: TIP Bergen & Hudson (10/19/18)	9	9	100.0
Healthy Women Healthy Families, Paterson (10/24/18)	4	4	100.0

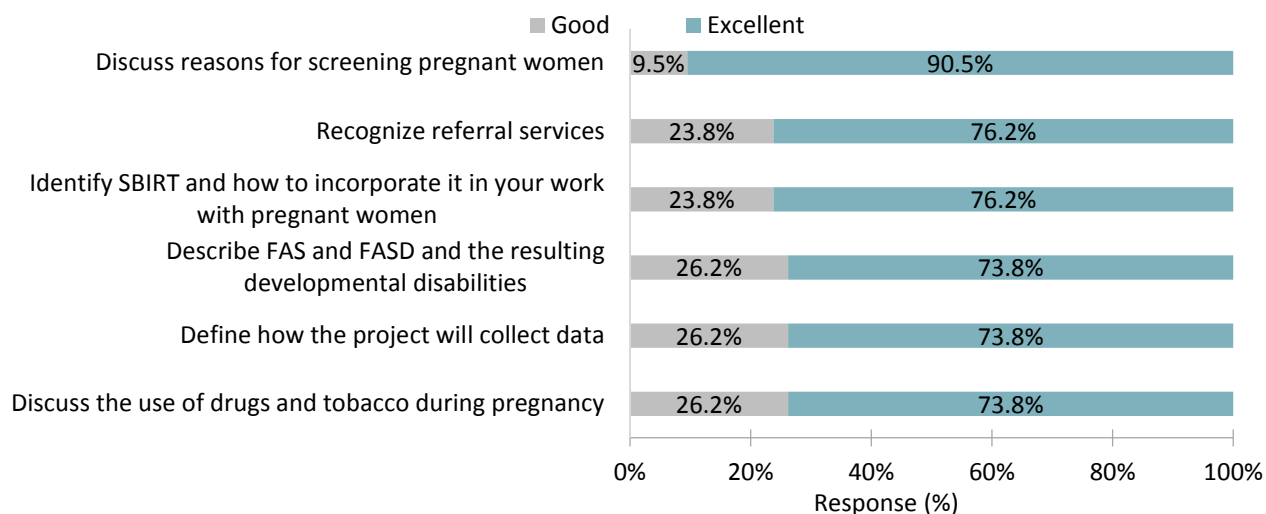
YCS NFP Morris County (11/5/18)	3	3	100.0
Project Self Sufficiency, Newton (11/20/18)	7	7	100.0
Partnership for MCH - Paterson (2/4/19)	3	3	100.0
Total	42	42	100.0

Learning Objectives

Participant Abilities

A series of questions on the evaluation tool asked training participants to rate their abilities on six key learning objectives, with response choices of *excellent*, *good*, *fair*, *poor*, or *not applicable*. Based on data from 42 participants, **100.0% rated their abilities as either excellent or good on all six learning objectives.** (None of the participants selected *fair*, *poor*, or *not applicable*). See Figure 1.

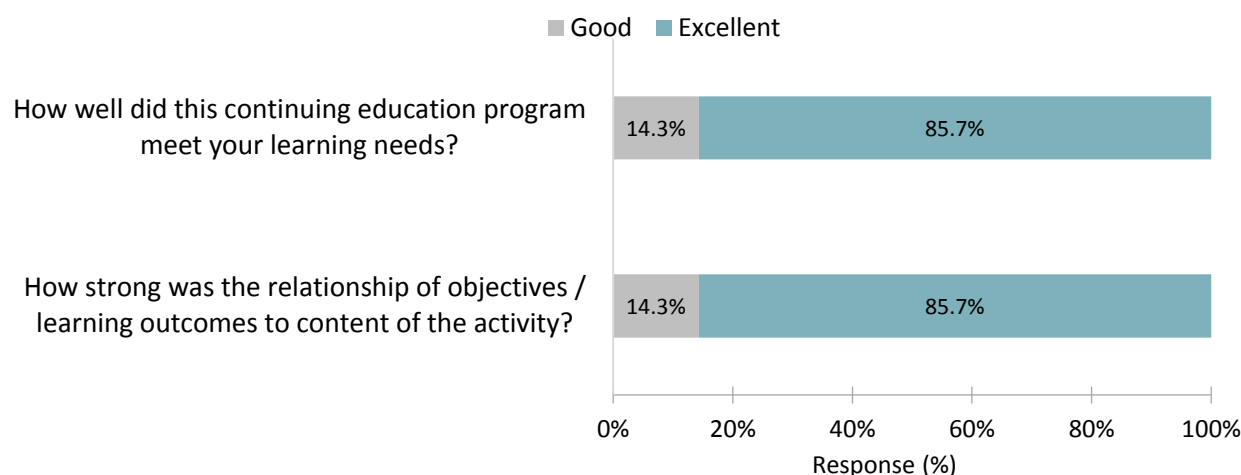
Figure 1. Participants' Ability Self-Ratings
Percentage of Excellent and Good Responses (N=42)
 (Response Choices: *Excellent*, *Good*, *Fair*, *Poor*, *Not Applicable*)



Learning Needs and Objectives

Of 42 participants, **100.0% rated the training as either excellent or good in meeting their learning needs and in the strength of the relationship between the learning objectives and training content** (none of the participants selected *fair*, *poor*, or *not applicable*). See Figure 2.

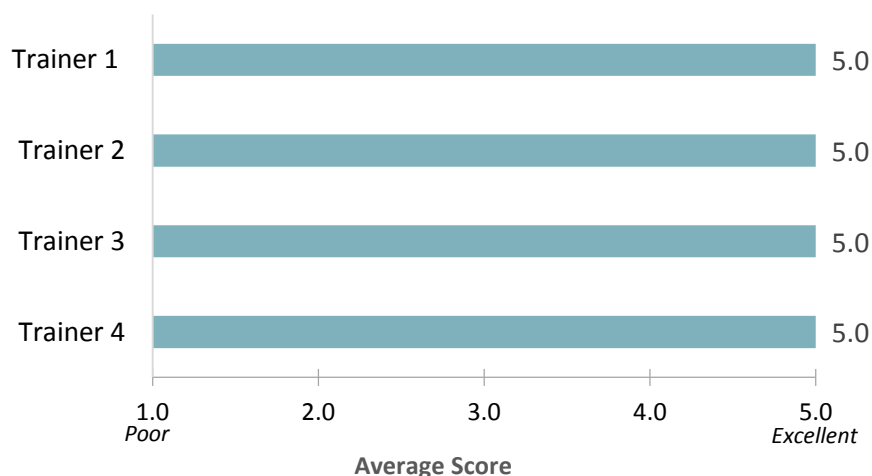
Figure 2. Participants' Training Experience Ratings
Percentage of *Excellent* or *Good* Responses (N=42)
 (Response Choices: *Excellent*, *Good*, *Fair*, *Poor*, *Not Applicable*)



Trainer Ratings

Training participants rated the trainers very highly on indicators of trainer knowledge, presentation skills, and effective use of slides and handouts. When these indicators were averaged to create an overall Trainer Effectiveness Index, all four trainers received average ratings of 5.0 (the highest possible rating) on a scale of 1 to 5 (Figure 3).

Figure 3. Average Trainer Effectiveness Index Scores (N=42)
 (Scale: 1=lowest possible score, 5=highest possible score)



Training Participants' Competencies Before and After Training

Using a five-point rating scale (1=low, 5=high), training participants were asked to assess their competencies before and after the training in four key areas using a retrospective pretest that included the following: 1) overall knowledge of the SBIRT method; 2) comfort level regarding asking clients about their substance use; 3) comfort level in beginning the conversation about

substance use; and 4) level of preparation to use the SBIRT technique with clients. The results are presented below:

Overall knowledge of the SBIRT method

On average, participants reported overall knowledge of the SBIRT method increased from 2.3 before the training to 4.6 after the training, an increase of 2.3 scale points. This translates to an average increase of 100.0% in overall knowledge of the SBIRT method.

Results of a paired samples t-test indicated a statistically significant difference in mean participant ratings after the training ($M=4.6$, $SD=0.6$) compared to before ($M=2.3$, $SD=1.2$); $t(42) = 12.2$, $p<.001$. These findings suggest that the training resulted in a statistically significant increase in overall knowledge of the SBIRT method among the participants.

Comfort level regarding asking clients about their substance use

On average, participants reported comfort level with asking clients about their substance use increased from 3.1 before the training to 4.7 after the training, an increase of 1.6 scale points. This translates to an average increase of 51.6% in participants' comfort level with asking clients about their substance use.

Results of a paired samples t-test indicated a statistically significant difference in mean participant ratings after the training ($M=4.7$, $SD=0.46$) compared to before ($M=3.1$, $SD=1.3$); $t(41) = 9.6$, $p<.001$. These findings suggest that the training resulted in a statistically significant increase in participants' comfort level regarding asking clients about their substance use.

Comfort level in beginning the conversation about substance use

On average, participants reported comfort level in beginning the conversation about substance use increased from 3.2 before the training to 4.7 after the training, an increase of 1.5 scale points. This translates to an average increase of 46.9% in participants' comfort level with beginning the conversation about substance use.

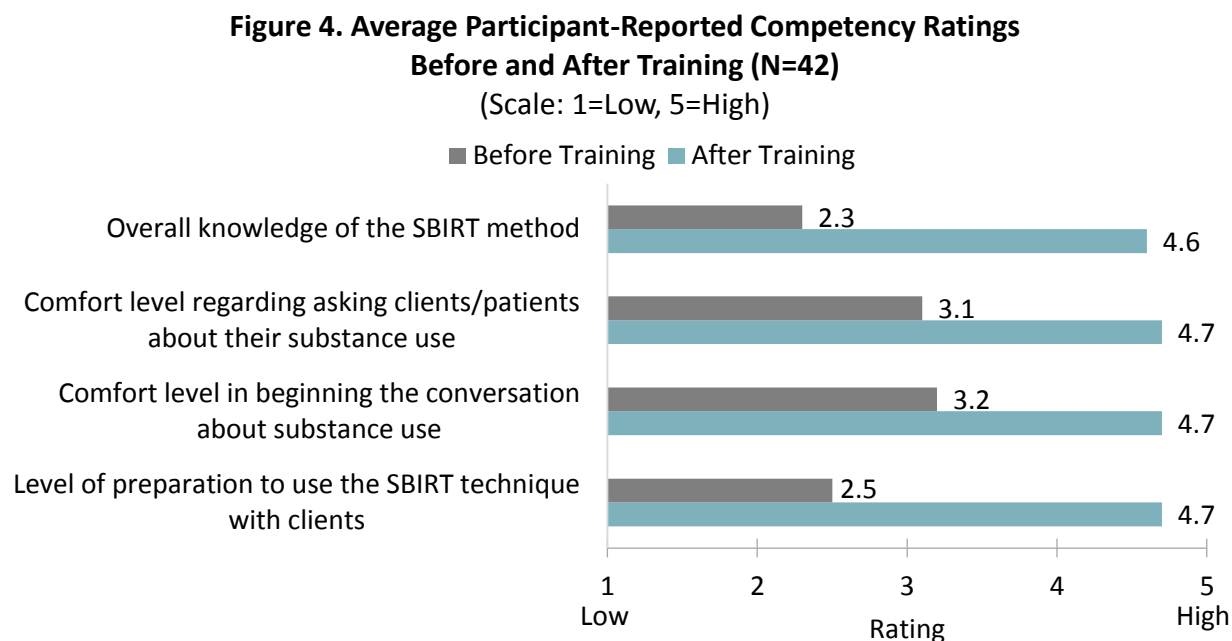
Results of a paired samples t-test indicated a statistically significant difference in mean participant ratings after the training ($M=4.7$, $SD=0.5$) compared to before ($M=3.2$, $SD=1.3$); $t(41) = 9.3$, $p<.001$. These findings suggest that the training resulted in a statistically significant increase in participants' comfort level in beginning the conversation about substance use.

Level of preparation to use the SBIRT technique with clients

On average, participants reported level of preparation to use the SBIRT technique with clients increased from 2.5 before the training to 4.7 after the training, an increase of 2.2 scale points. This translates to an average increase of 88.0% in participants' level of preparation to use the SBIRT technique with clients.

Results of a paired samples t-test indicated a statistically significant difference in mean participant ratings after the training ($M=4.7$, $SD=0.5$) compared to before ($M=2.5$, $SD=1.4$); $t(41) = 10.8$, $p<.001$. These findings suggest that the training resulted in a statistically significant increase in participants' level of preparation to use the SBIRT technique with their clients.

Figure 4 presents the results for the four key areas (see Appendix C1 for tabular presentation):



Comfort Level with Using the SBIRT Method

Outcome Target: At least 85% of home visitors will report increased comfort level with using the SBIRT method.

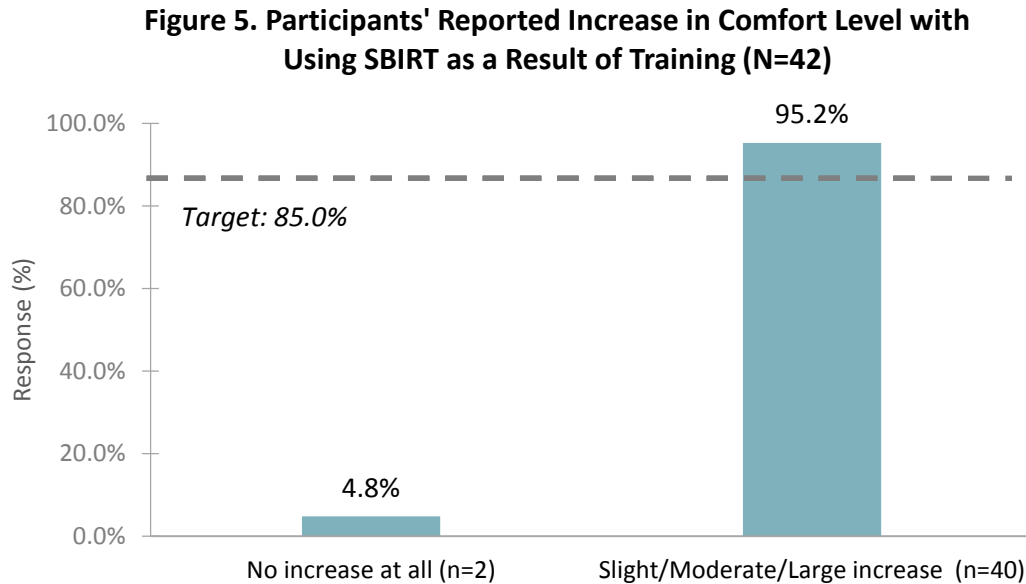
To assess home visitors' and community health workers' comfort level with using the SBIRT method, the evaluation instrument included a question that asked, "As a result of this training, how much would you say your comfort level has increased with using the SBIRT method with your clients?" with answer choices of no increase at all; slight increase; moderate increase; and large increase.

Of 42 respondents, half (50.0%) reported a large increase; 33.3% reported a moderate increase; and 11.9% reported a slight increase. Meanwhile, only two respondents (4.8%) reported no increase at all (Table 2).

	n	%
Large increase	21	50.0
Moderate increase	14	33.3
Slight increase	5	11.9
No increase at all	2	4.8
Total	42	100.0

Based on the results presented in Table 2, a combined percentage of 95.2% of respondents reported an increase of any magnitude (i.e., slight, moderate, or large) in their comfort level with

using the SBIRT method with clients as a result of the training. Thus, the target of 85.0% for this outcome was met and exceeded (Figure 5):



Intentions to Utilize the SBIRT Method During Client Interactions

Outcome Target: At least 85% of home visitors will report intentions to utilize the SBIRT method during client interactions.

To assess home visitors' and community health workers' intent to use SBIRT method, the evaluation instrument included a question that asked, "As a result of this training, how likely are you to use the SBIRT method with your clients?" with answer choices of *not at all likely*; *slightly likely*; *moderately likely*; and *highly likely*.

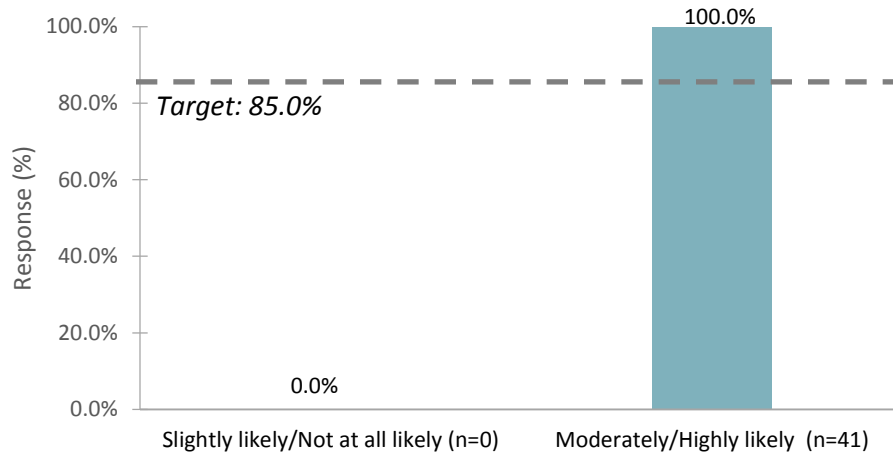
Of 41 respondents (one respondent skipped this question), 80.5% reported *very likely* and 19.5% reported *moderately likely*. No participants reported *slightly likely* or *not at all likely* (Table 3):

Table 3. Training Participants' Reported Intentions to Use the SBIRT Method During Client Interactions (N=41)		
	n	%
Very likely	33	80.5
Moderately likely	8	19.5
Slightly likely	0	0.0
Not at all likely	0	0.0
Total	41	100.0

Note: One missing response.

Based on the results presented in Table 3, a combined percentage of 100.0% of participants reported they were either *moderately likely* or *very likely* to use the SBIRT method with their clients as a result of the training. Thus, the target objective of 85% for this outcome was met and exceeded (Figure 6):

Figure 6. Participants' Reported Likelihood to Use SBIRT with Clients as a Result of Training (N=41)



Most Valuable Lesson Learned

The evaluation tool included an open-ended question that asked participants, "what was the most valuable thing you learned from this training?" Of the 42 participants, 38 responded to this question. Based on the responses, the following common themes were identified:

- Knowledge and information about substance use (mentioned by 17);
- Learning about SBIRT (mentioned by 14);
- Signs and symptoms of FAS/FASD (mentioned by 9);
- Client resources (mentioned by 5); and
- Other positive comments (mentioned by 3).

Integrating Knowledge in Professional Practice

The evaluation tool included an open-ended question that asked participants to describe how they will integrate what they learned into their professional practice. Of the 42 participants, 35 responded to this question. Based on the responses, the following common themes were identified:

- General integration of what was learned during home visits (mentioned by 11);
- Improve communication with, and understanding clients (mentioned by 10);
- Screening and using SBIRT effectively (mentioned by 8);
- Educating clients about substance use (mentioned by 7);
- Providing clients with referrals and resources (mentioned by 5); and
- Providing staff with SBIRT-related supervision and procedures/policies (mentioned by 3).

Overall Satisfaction

Of the 42 training participants, 100.0% reported that they would recommend the training to a colleague, which suggests a very high level of overall satisfaction with the training.

Suggestions for Improvement

The evaluation tool included an open-ended question that asked participants for suggestions to improve the training. Of 42 participants, 25 responded to this question. Of these, most (n=17) reported "None" or "Not applicable, (N/A)." Of the nine respondents who provided valid suggestions, the identified themes included the following:

- More role play/video vignettes and examples (n=4);
- More "visual information" for clients (n=2); and
- Other specific requests (n=3) including one request for the slide handouts and "additional info on what parts of the brain are specifically being damaged."

B. Client Outcomes

Evaluation Response

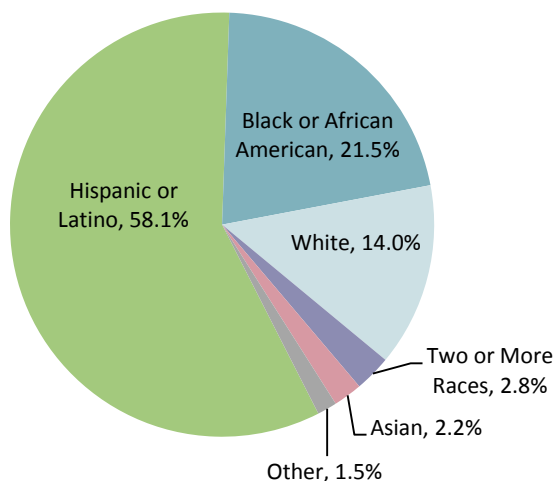
A total of 561 client pre-post questionnaires were submitted by the trained home visitors/community health workers. Of these, six were excluded for missing pretest data, which left a total of 555 for the analyses presented in this section.

Client Demographics

Race and Ethnic Background

Of the 544 questionnaires with complete race and ethnic background data, 58.1% reported clients of Hispanic or Latino backgrounds, 21.5% reported Black or African American, 14.0% reported White, 2.2% reported Asian, 2.8% reported two or more racial and ethnic backgrounds, and 1.5% reported other racial and ethnic backgrounds. Those who specified other backgrounds (n=8) reported Arabic, Middle Eastern, and Pakistan/Asian (Figure 7):

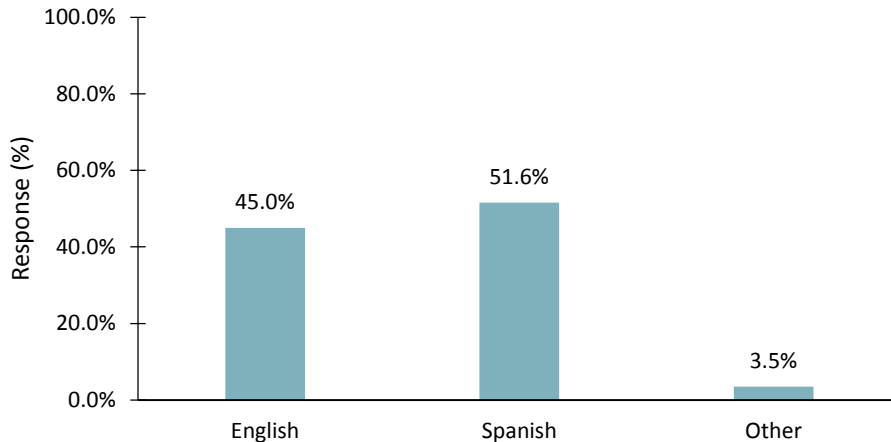
Figure 7. Race and Ethnicity of Clients Served (N=544)



Primary Language

Of 545 questionnaires with complete language data, slightly more than half (51.6%) reported Spanish as the primary language spoken in the client's home; slightly less than half (45.0%) reported English; and 3.5% reported other languages. Those who specified other languages reported Arabic, Bengali, Greek, Haitian-Creole, Portuguese, Telugu, Urdu, and Yoruba (Figure 8):

Figure 8. Clients' Primary Language Spoken at Home (N=545)



Client Knowledge About the Risks and Consequences of Alcohol Use During Pregnancy

Client Pre-Posttest Item Analysis

Pre-Post Question #1: Alcohol use during pregnancy can cause lifelong effects for the child. (Correct Answer: True)

Prior to receiving the program education, 93.9% of participating clients answered this question correctly (i.e. true). This suggests that the vast majority of clients knew of the negative consequences of alcohol use during pregnancy prior to receiving the program education. After receiving the program education, the percentage increased to 99.8%. Thus, the percentage of clients who answered correctly increased from 93.9% before the program education to 99.8% afterwards (Figure 9; Table 4):

Figure 9. Q1. Alcohol use during pregnancy can cause lifelong effects for the child (N=555)

Correct Answer: True

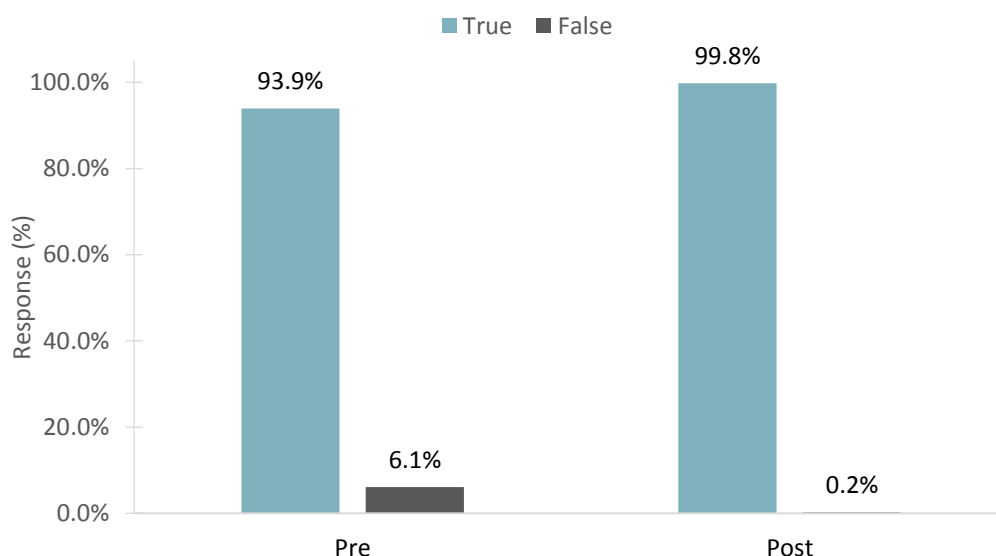


Table 4. Alcohol use during pregnancy can cause lifelong effects for the child (N=555)				
	Pre		Post	
	n	%		
True	521	93.9	554	99.8
False	34	6.1	1	0.2
Total	555	100.0	555	100.0

Pre-Post Question #2. Beer, wine, and wine coolers are safe to drink occasionally during pregnancy. (Correct Answer: False)

Prior to receiving the program education, 75.5% of participating clients answered this question correctly (i.e. false). After receiving the program education, the percentage increased to 92.1%. Thus, the percentage of clients who answered correctly increased from 75.5% before the program education to 92.1% afterwards (Figure 10; Table 5).

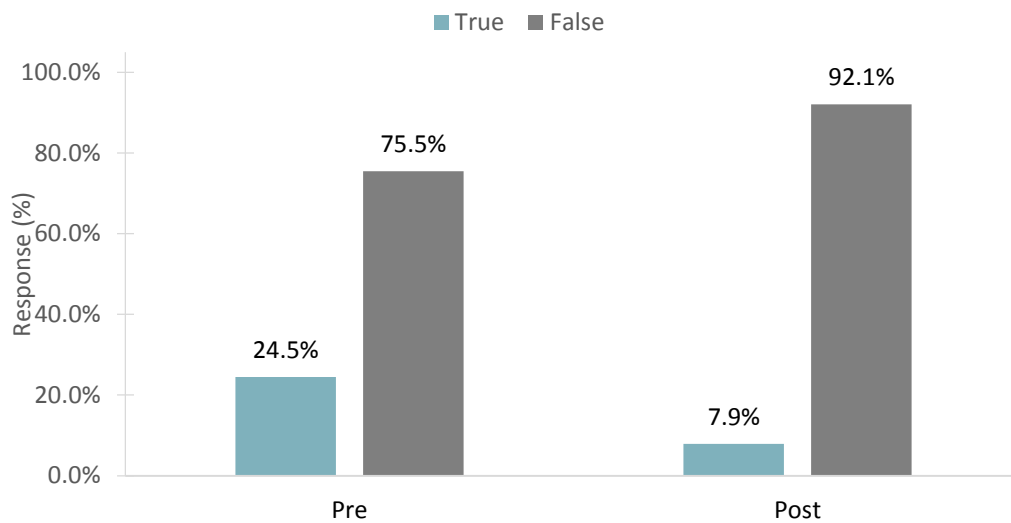
Figure 10. Q2. Beer, wine, and wine coolers are safe to drink occasionally during pregnancy (N=555)

Table 5. Beer, wine, and wine coolers are safe to drink occasionally during pregnancy. (N=555)				
	Pre		Post	
	n	%		
True	419	75.5	511	92.1
False	136	24.5	44	7.9
Total	555	100.0	555	100.0

Pre-Post Question #3. If a woman is trying to get pregnant she should stop drinking alcohol. (Correct Answer: True)

Prior to receiving the program education, 90.1% of participating clients answered this question correctly (i.e. true). After receiving the program education, the percentage increased to 98.6%. Thus, the percentage of clients who answered correctly increased from 90.1% before the program education to 98.6% afterwards (Figure 11; Table 6):

Figure 11. Q3. If a woman is trying to get pregnant she should stop drinking alcohol (N=555)
Correct Answer: True

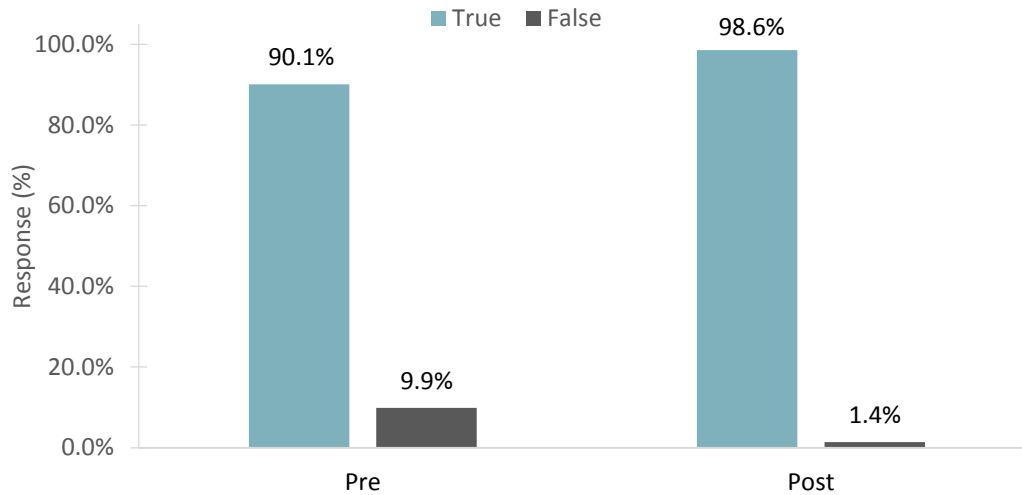


Table 6. If a woman is trying to get pregnant she should stop drinking alcohol. (N=555)				
	Pre		Post	
	n	%		
True	500	90.1	547	98.6
False	55	9.9	8	1.4
Total	555	100.0	555	100.0

Pre-Post Question #4. No amount of alcohol is safe to drink during pregnancy.
(Correct Answer: True)

Prior to receiving the program education 87.9% of participating clients answered this question correctly (i.e. true). After receiving the program education, the percentage increased to 96.0%. Thus, the percentage of clients who answered correctly increased from 87.9% before the program education to 96.0% afterwards (Figure 12; Table 7):

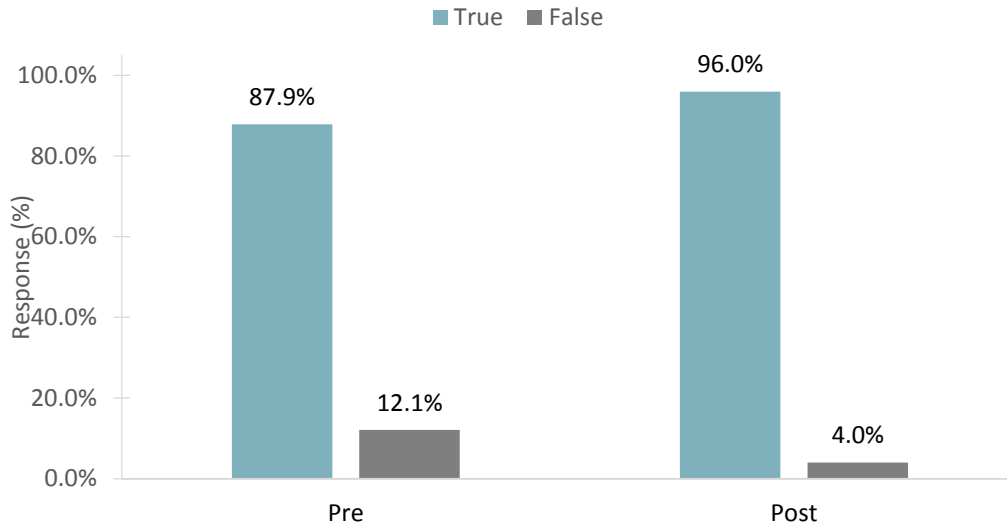
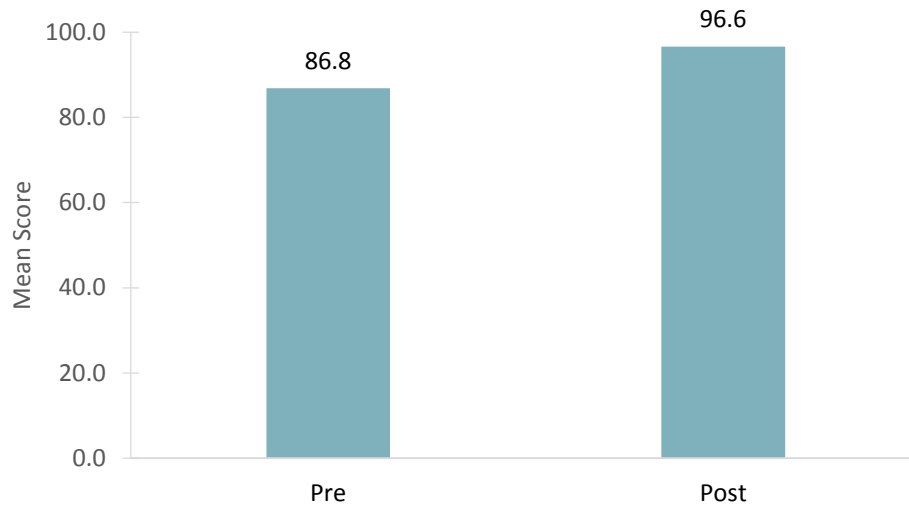
Figure 12. Q4. No amount of alcohol is safe to drink during pregnancy. (N=555)*Correct Answer: True*

Table 7. No amount of alcohol is safe to drink during pregnancy. (N=555)				
	Pre		Post	
	n	%		
True	488	87.9	533	96.0
False	67	12.1	22	4.0
Total	555	100.0	555	100.0

Client Pre-Posttest Total Score

A total score representing clients' overall FASD knowledge was created by summing the number of correct responses to the four pre-post questions and dividing by the total number of pre-post items (4). For the 555 clients, the mean total score increased from 86.8 (SD=22.0) on the pretest, to 96.6 (SD=8.8) on the posttest, an increase of 9.8 points. This translates to an average increase of 11.3% in overall knowledge of FASD (Figure 13; Table 8):

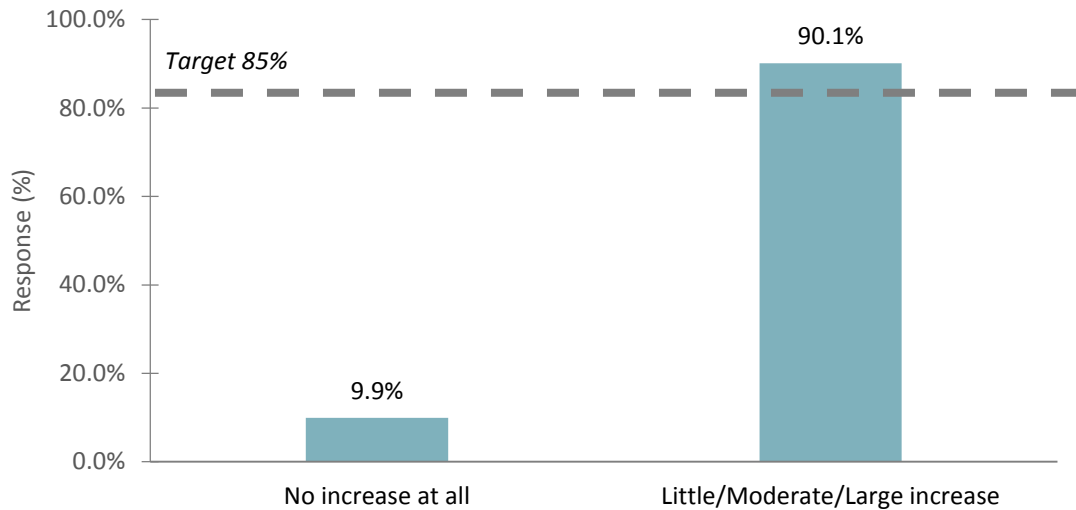
Figure 13. Client Knowledge of FASD: Total Mean Score (N=555)**Table 8. Knowledge of FASD: Total Mean Score**

	N	Mean Score	Standard Deviation	Lowest Score	Highest Score
Pre	555	86.8	22.0	0.0	100.0
Post	555	96.6	8.8	50.0	100.0

Client Knowledge of the Links Between FASD and Developmental Disabilities

A posttest-only question asked clients to indicate how much their knowledge of the links between FASD and developmental disabilities had increased as a result of the program education, with answer choices of a large increase; a moderate increase; a little increase or no increase at all. A combined percentage of 90.1% of participating clients reported an increase of any amount in their knowledge (51.4% reported a large increase; 18.0% reported a moderate increase; and 20.7% reported a little increase). Meanwhile, 9.9% reported no increase at all. Thus, the program's target benchmark of 85.0% of clients with increased knowledge of the links between FASD and developmental disabilities was met. These results are shown in Figure 14 (see Appendix C2 for tabular presentation).

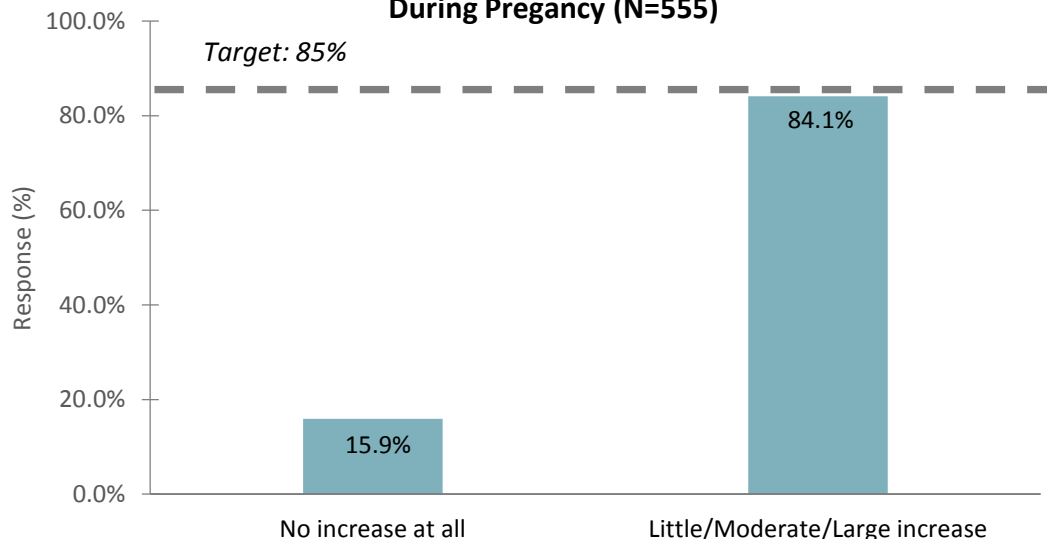
Figure 14. Clients' Self-Reported Increase in Knowledge About the Links between FASD and Developmental Disabilities (N=555)



Client Plans to Abstain from Alcohol

A posttest-only question asked clients to indicate how much their plans to abstain from alcohol consumption during pregnancy had increased as a result of the program education, with answer choices of a large increase; a moderate increase; a little increase or no increase at all. A combined percentage of 84.1% of participating clients reported their plans to abstain had increased (64.0% reported a large increase; 8.1% reported a moderate increase; and 11.9% reported a little increase). Meanwhile, 15.9% reported no increase at all. Thus, the percentage of clients with increased plans to abstain from alcohol during pregnancy was very close, but slightly below (nine-tenths of a percentage point), the target benchmark of 85.0%. These results are shown in Figure 15 (see Appendix C3 for tabular presentation).

Figure 15. Clients' Reported Plans to Abstain from Alcohol During Pregnancy (N=555)



IV. Discussion and Recommendations

Based on the evaluation findings presented in this report, Year Two of the Partnership for Maternal and Child Health of Northern New Jersey's FASD and SBIRT training program was successful in preparing home visitors and community health workers in using the SBIRT approach to educate pregnant women and new mothers about FASD and the importance of abstaining from alcohol use during pregnancy. According to results from a pre-posttest measuring changes in knowledge, average scores for training attendees increased significantly in all four of the program's key competency areas, including: 1) overall knowledge of the SBIRT method; 2) comfort level with asking clients about their substance use; 3) comfort level in beginning the conversation about substance use; and 4) level of preparation to use the SBIRT technique with clients.

In addition, 95.2% of home visitors and community health workers reported an increase in their comfort level with using the SBIRT method with clients and 100.0% reported being either *very likely* or *moderately likely* to use the SBIRT method with their clients. Thus, the program was successful in meeting (and exceeding) its target benchmark of 85.0% for these training objectives.

Qualitative feedback obtained from the training attendees supported these results, with common themes that suggested home visitors and community health workers were highly satisfied with the training, experienced it as valuable, and planned to integrate what they learned into their professional practice, particularly with regard to improving communication with, and understanding their clients.

Pre-posttest results from 555 clients of the trained home visitors and community health workers showed that clients' overall knowledge of FASD increased significantly, from an average score of 86.8 prior to receiving the program education to 96.6 afterwards. In addition, over 90% reported an increase in knowledge about the links between FASD and developmental disabilities, thus meeting and exceeding the target benchmark of 85% for this objective. A majority of 84.1% of clients reported their plans to abstain from alcohol during pregnancy had increased as a result of the program education. This large majority was just nine-tenths of a point below the 85.0% target benchmark.

Taken together, these positive results provide preliminary evidence for the program's effectiveness in achieving its short- and medium-term outcomes. Because an evaluation of the program's long-term outcomes, including actual behavior change and birth outcomes, was beyond the timeframe and scope of the current project, the extended impact of the program remains unknown at this time. To further support the program's success in the future, program leaders may also wish to consider the following recommendations:

- Due to the high average baseline knowledge about FASD observed among clients (the average score was 86.8 out of 100.0 possible points on the pretest), program leaders may wish to consider piloting new and/or more in-depth content in the future to enhance clients' learning experiences.
- For future implementation, program leaders may wish to consider allocating additional evaluation resources to allow for the inclusion of a comparison group. This would allow for more rigorous evaluation designs that compare outcomes for clients who received the program intervention with outcomes for a similar group who did not, thereby providing stronger evidence for the program's effects.

As with all projects, the evaluation had some limitations, including the use of small convenience samples which may not be generalizable to larger populations. In addition, the project relied primarily on self-reported information, which may have resulted in a subjectivity bias. Thus, care should be taken in extrapolating the results to the broader group of program participants. However, the use of a mixed methods approach that included multiple sources of quantitative and qualitative data may have mitigated this bias to some extent. Finally, these findings, as a summary of the participants' experiences and perspectives, may provide program leaders with important information to assist with planning and implementing similar programs in the future.

APPENDICES

Appendix A. Training Evaluation Form

Partnership for Maternal and Child Health of Northern New Jersey Evaluation Form

Program: FASD, Screening and S-BIRT**At:****Date:****Number of attendees:****Number of evaluations:****Evaluation Code:** A = Excellent, B = Good, C = Fair, D = Poor, E = Not applicable**ACHIEVEMENT OF OBJECTIVES**

How were the following learning objectives met? After attending this program are you able to:	A	B	C	D	E
Describe FAS and FASD and the resulting developmental disabilities					
Discuss the use of drugs and tobacco during pregnancy					
Identify SBIRT and how to incorporate it in your work with pregnant women					
Discuss reasons for screening pregnant women					
Recognize referral services					
Define how the project will collect data					
How strong was the relationship of objectives / learning outcomes to content of the activity?					
How well did this continuing education program meet your learning needs?					

SPEAKERS

<i>Judith King, MSW, LCSW, LCADC, CPAS</i>	A	B	C	D	E
Knowledge of subject					
Presentation orderly and understandable					
Effective use of slides and handouts					

<i>Yisel Alaoui, MA LCADC, ICADC, FASD and TIPS® Certified</i>	A	B	C	D	E
Knowledge of subject					
Presentation orderly and understandable					
Effective use of slides and handouts					

<i>Rachel Ugrinovsky, BA CADAC, FASD Educator</i>	A	B	C	D	E
Knowledge of subject					
Presentation orderly and understandable					
Effective use of slides and handouts					

<i>Melissa Boucaud, BS</i>	A	B	C	D	E
Knowledge of subject					
Presentation orderly and understandable					
Effective use of slides and handouts					

Please rate yourself on the following competencies, now, AFTER you have finished the training, compared to how you felt BEFORE the training, by checking a number for each. using a scale from 1 to 5 with 1 being lowest (no/low competence) and 5 being the highest (high competence). If you think there was no change, check the same number for both:

Low ← → High						Low ← → High				
AFTER TRAINING						BEFORE TRAINING				
1	2	3	4	5		1	2	3	4	5
					Overall knowledge of the SBIRT method					
					Comfort level regarding asking clients/patients about their substance use					
					Comfort level in beginning the conversation about substance use					
					Level of preparation to use the SBIRT technique with clients					

As a result of this training, how much would you say your **comfort-level** has increased with using the SBIRT method with your clients?

- No increase at all
- Slight increase
- Moderate increase
- Large increase

As a result of this training, how **likely** are you to use the SBIRT method with your clients?

- Not at all likely
- Slightly likely
- Moderately likely
- Highly likely

What was the most valuable thing you learned from this training?

How will you integrate what you learned into your professional practice?

Would you recommend this program to a colleague? Yes ___No ___Unsure ___

Do you have any suggestions for how we can improve this training?

We welcome your general comments:

Appendix B. Client Pre and Posttest

Date: _____

Client ID: _____

CLIENT PRETEST (BEFORE)

1. Alcohol use during pregnancy can cause lifelong effects for the child.

☐ True

☐ False

2. Beer, wine, and wine coolers are safe to drink occasionally during pregnancy.

☐ True

☐ False

3. If a woman is trying to get pregnant she should stop drinking alcohol.

☐ True

☐ False

4. No amount of alcohol is safe to drink during pregnancy.

☐ True

☐ False

5. Which of the following best describes your race/ethnicity?

☐ White

☐ Black or African American

☐ Hispanic or Latino

☐ Asian

☐ Two or more races

☐ Other (specify) _____

6. What is the primary language spoken at home? (Check one)

☐ English

☐ Korean

☐ Spanish

☐ Russian

☐ Haitian Creole

☐ Hindi or Gujarati

☐ Chinese or Mandarin

☐ Other (specify) _____

CLIENT POSTTEST (AFTER)

- 1. Alcohol use during pregnancy can cause lifelong effects for the child.**
 - ☐ **True**
 - ☐ **False**

- 2. Beer, wine, and wine coolers are safe to drink occasionally during pregnancy.**
 - ☐ **True**
 - ☐ **False**

- 3. If a woman is trying to get pregnant she should stop drinking alcohol.**
 - ☐ **True**
 - ☐ **False**

- 4. No amount of alcohol is safe to drink during pregnancy.**
 - ☐ **True**
 - ☐ **False**

- 5. Now that we have had our talk, how much would you say your knowledge about the links between FASD and developmental disabilities has increased?**
 - ☐ **No increase at all**
 - ☐ **A little increase**
 - ☐ **A moderate increase**
 - ☐ **A large increase**

- 6. Now that we have had our talk, how much would you say your plans to abstain from alcohol consumption during pregnancy have increased?**
 - ☐ **No increase at all**
 - ☐ **A little increase**
 - ☐ **A moderate increase**
 - ☐ **A large increase**

Appendix C. Supplemental Tables

Table C1. Training Participant Reported Competency Ratings Before and After Training (N=42)						
	N	Before Training		After Training		t
		Mean	SD	Mean	SD	
Overall knowledge of the SBIRT method	41	2.29	1.24	4.57	.59	12.19***
Comfort level regarding asking clients about their substance use	41	3.14	1.26	4.71	.46	9.59***
Comfort level in beginning the conversation about substance use	41	3.19	1.25	4.69	.52	9.33***
Level of preparation to use the SBIRT technique with clients	41	2.48	1.37	4.74	.50	10.76***

*** Significant at $p < 0.001$ (alpha level adjusted for multiple testing).

Table C2. Clients' Self-Reported Increase in Knowledge About the Links between FASD and Developmental Disabilities. (N=555)		
	n	%
A large increase	285	51.4
A moderate increase	100	18.0
A little increase	115	20.7
No increase at all	55	9.9
Total	555	100.0

Table C3. Clients' Self-Reported Increase in Plans to Abstain from Alcohol Consumption During Pregnancy. (N=553)		
	n	%
A large increase	354	64.0
A moderate increase	45	8.1
A little increase	66	11.9
No increase at all	88	15.9
Total	553	100.0

Note: Does not include missing data (n=2).

Spina Bifida Resource Network
HEALTHY *NOW*, HEALTHY *LATER*
Optimizing Preconceptual Health

Year Two Final Evaluation Report

Pam Kelley, Ph.D.
Kelley Analytics, LLC
July 8, 2019

Contents

	Page
I. Introduction	1
Background and Program Overview	1
Key Goals and Objectives.....	1
II. Evaluation Methods.....	2
III. Results	2
A. Train the Trainer Pre-Posttest	2
B. Form H	9
IV. Discussion and Recommendations	12

I. Introduction

Background and Program Overview

This report presents Year Two evaluation findings from *Healthy NOW, Healthy Later* (NNHL), (aka *Optimizing Preconceptual Health*), a program developed by the Spina Bifida Resource Network (SBRN) and funded through a grant from the New Jersey Office for the Prevention of Developmental Disabilities that was designed to raise awareness among college-age young adults (18 to 24 years) about the benefits of better health before becoming pregnant to improve their own health in the present and reduce the chances of having children with disabilities in the future.

To achieve these goals, the NNHL program used a "train the trainer" approach, in which SBRN staff provided training and support to college students to help them become peer spokespersons about the importance of preconceptual health. In addition to learning the NNHL program core content, the student training curriculum included designated time for discussion and a question-answer period. After completing the training, students were expected to conduct educational presentations among their peers at their respective college campuses.

Key Goals and Objectives

The NNHL program aimed to achieve three main goals and objectives, listed below:

Goal 1: Train college students to become spokespersons about preconceptual health, including the benefits of healthy diets, behaviors, and weight, in improving overall health and reducing the risk for birth defects and developmental disabilities.

Objective 1a: At least 30 individuals will receive the in-depth program training and will demonstrate competency with the material via scores on a pre-posttest.

Objective 1b: Trained participants will deliver presentations to their college peers.

Goal 2: Increase awareness among young women and men, through presentations by trained participants, about the need for healthy diets and behaviors before becoming pregnant to improve their health and reduce the risks of having babies with disabilities.

Objective 2a: 90% of participants will demonstrate understanding that nutritious diets, including specific vitamins and minerals and healthy weight, can help prevent birth defects, other disabilities and diseases, and that healthy behaviors should begin before becoming pregnant to reduce the risks.

Objective 2b: 90% of participants will be able to identify foods that are high in folate and other vitamins/nutrients and will recognize healthy versus bad diets.

Objective 2c: 90% of participants will identify risks involved with drinking and smoking including how it affects health and pregnancies.

Goal 3 (Long Term): Increase healthy preconceptual diets and behaviors among young women and men, including college students.

Objective 3: 75% of participants will report intentions to make at least one change in their preconceptual diets and behaviors to improve health, after receiving the program education.

II. Evaluation Methods

To assess the extent to which the NNHL training was successful in achieving its goals and objectives, the evaluation used a mixed methods approach with the following components:

Train the Trainer Pre-Posttest: A 10-item pre-posttest questionnaire was developed through a collaborative process by the SBRN project team and the evaluation consultant. The questionnaire included specific content designed to assess training participants' understanding of the key program content, including the role of specific nutrients such as calcium, iron, and folic acid in having a healthy pregnancy and preventing birth defects; identifying foods high in these nutrients; the importance of a healthy diet and healthy behaviors prior to becoming pregnant; and risks associated with binge drinking. Participants were asked to complete the questionnaire immediately prior to, and immediately following the training presentation. The posttest included one additional item designed to assess participants' level of confidence to conduct trainings with their peers. *Plan of Analysis:* To assess participants' overall knowledge of the program content and objectives, a total score was calculated for each respondent by dividing the total number of correct responses by the total number of pre-post questionnaire items.

Form N (Peer Presentation Assessment): To assess the effectiveness of the NNHL program and its train the trainer model at raising awareness about the need for healthy diets and behaviors before becoming pregnant to improve their health and reduce the risks of having babies with disabilities, a brief, seven-item questionnaire was developed by the SBRN with input from the evaluation consultant. The questionnaire was designed to assess presentation attendees' knowledge about the importance of a healthy diet and healthy behaviors prior to becoming pregnant; identifying foods high in nutrients, such as calcium, iron, and folic acid, that help prevent birth defects; risks associated with binge drinking; and any planned healthy behaviors resulting from what they learned from the presentation. Form N also included a retrospective pretest item designed to assess change in participants' overall knowledge of how healthy diets and behaviors can help prevent birth defects. The questionnaire was administered to presentation attendees immediately following the presentation/discussion. *Plan of Analysis:* Response frequencies and percentages were calculated for each item on the questionnaire.

III. Results

A. Train the Trainer Pre-Posttest

A total of 92 training attendees submitted partially or fully completed pre-posttests from six train the trainer events held at Rowan College at Burlington County, Monmouth University, Raritan Valley Community College, and Bergen Community College.

Of the 92 returned pre-posttest instruments, two were excluded from the analyses due to missing data (the pretest was missing), leaving an analysis sample size of N=90. Pre-post items with skipped responses or with more than one answer choice selected were coded as incorrect. The data collected from the training events were pooled for the analyses presented in this report.

Item Analysis

Q1. Insufficient calcium now can negatively affect future pregnancy by:

Of 90 participants, the percentage that chose the correct answer, (a) *affecting fetal skeletal development*, increased slightly from 96.7% before the training to 98.9% after the training (Table 2):

Table 2. Insufficient calcium now can negatively affect future pregnancy by: (N=90)				
	Pre		Post	
	n	%	n	%
a. affecting fetal skeletal development.	87	96.7	89	98.9
b. increasing the risk of maternal depression.	1	1.1	0	0.0
c. increasing the risk of Down Syndrome.	2	2.2	1	1.1
d. by making it harder to lose weight after pregnancy.	0	0.0	0	0.0
Total	90	100.0	90	100.0

Q2. Lack of iron before and during pregnancy can lead to:

Of 90 participants, the percentage that correctly selected answer choice, (b) *anemia, which increases the risk for preterm or low-birth-weight babies*, increased from 92.2% before the training to 97.8% after the training (Table 3):

Table 3. Lack of iron before and during pregnancy can lead to: (N=90)				
	Pre		Post	
	n	%	n	%
a. maternal diabetes, which increases the risk for fetal growth problems.	5	5.6	1	1.1
b. anemia, which increases the risk for preterm or low-birth-weight babies.	83	92.2	88	97.8
c. dramatic weight gain, which can increase the risk of obesity in children.	1	1.1	1	1.1
d. all of the above	1	1.1	0	0.0
Total	90	100.0	90	100.0

Q3. When is the best time to begin taking folic acid to help prevent birth defects?

Of 90 participants, the percentage that chose the correct answer, (a) *Before becoming pregnant (because damage to the spine occurs in the first few weeks after conception before women even know they are pregnant)*, increased from 52.2% before the training to 97.8% after the training (Table 4).

Table 4. When is the best time to begin taking folic acid to help prevent birth defects? (N=90)				
	Pre		Post	
	n	%	n	%
a. Before becoming pregnant (because damage to the spine occurs in the first few weeks after conception before women even know they are pregnant)	47	52.2	88	97.8
b. As soon as you know you are pregnant (to protect the fetus from spinal cord damage in the 2nd and 3rd trimester)	36	40.0	1	1.1
c. During the third trimester (because that is the time of the most rapid growth of the spine and brain)	4	4.4	0	0.0
d. None of the above	3	3.3	1	1.1
Total	90	100.0	90	100.0

Q4. Which of these foods is a good source of calcium, iron AND folic acid?

Of 90 participants, the percentage that correctly answered (c) *spinach and beans*, increased from 53.3% before the training to 92.2% after the training (Table 5).

Table 5. Which of these foods is a good source of calcium, iron AND folic acid? (N=90)				
	Pre		Post	
	n	%	n	%
a. Apples and bananas	9	10.0	0	0.0
b. Beef and chicken	4	4.4	1	1.1
c. Spinach and beans	48	53.3	83	92.2
d. Milk and cheese	29	32.2	6	6.7
Total	90	100.0	90	100.0

Q5. Spina bifida is a birth defect where the spinal cord does not form correctly during the first weeks of pregnancy.

Of 90 participants, the percentage that correctly answered *true* increased from 92.2% before the training to 98.9% after the training (Table 6):

Table 6. Spina bifida is a birth defect where the spinal cord does not form correctly during the first weeks of pregnancy (N=90)				
	Pre		Post	
	n	%	n	%
True	83	92.2	89	98.9
False	7	7.8	1	1.1
Total	90	100.0	90	100.0

Q6. Maintaining a healthy weight now may help reduce the risks for pregnancy complications and birth defects later.

Of 90 participants, the percentage that correctly answered *true* increased from 96.7% before the training to 100.0% after the training (Table 7):

Table 7. Maintaining a healthy weight now may help reduce the risks for pregnancy complications and birth defects later. (N=90)				
	Pre		Post	
	n	%	n	%
True	87	96.7	90	100.0
False	3	3.3	0	0.0
Total	90	100.0	90	100.0

Q7. Which type of diet will likely be highest in important nutrients?

Of 90 participants, the percentage that correctly answered, (c) *One that emphasizes smaller portions of a variety of healthy foods*, increased from 82.2% before the training to 95.6% after the training (Table 8):

Table 8. Which type of diet will likely be highest in important nutrients? (N=90)				
	Pre		Post	
	n	%	n	%
a. One that focuses primarily on high protein	13	14.4	3	3.3
b. One that focuses on reducing carbs	2	2.2	1	1.1
c. One that emphasizes smaller portions of a variety of healthy foods	74	82.2	86	95.6
d. One that emphasizes juice cleanses	1	1.1	0	0.0
Total	90	100.0	93	100.0

Q8. How does drinking alcohol and binge-drinking increase the risk of birth defects?

Of 90 participants, the percentage that chose the correct answer, (d) *all of the above*, increased from 70.0% before the training to 93.3% after the training (Table 9):

Table 9. How does drinking alcohol and binge-drinking increase the risk of birth defects? (N=90)				
	Pre		Post	
	N	%	n	%
a. May increase the chance of having unprotected sex.	2	2.2	1	1.1
b. Exposes the fetus to alcohol.	21	23.3	4	4.4
c. Interferes with the bodies' ability to metabolize folic acid.	4	4.4	1	1.1
d. All of the above.	63	70.0	84	93.3
Total	90	100.0	90	100.0

Q9. How do men's health habits affect the risk of birth defects?

Of 90 participants, the percentage that chose the correct answer, (d) *all of the above*, increased from 60.0% before the training to 95.6% after the training (Table 10):

Table 10. How do men's health habits affect the risk of birth defects? (N=90)				
	Pre		Post	
	n	%	n	%
a. Obese men are more likely to have obese children.	1	1.1	1	1.1
b. A lack of folic acid in men can increase the risk of chromosomal defects in their sperm cells, which could result in disorders such as Down syndrome.	32	35.6	3	3.3
c. Ongoing alcohol use by men can negatively affect fetal development.	3	3.3	0	0.0
d. All of the above.	54	60.0	86	95.6
Total	90	100.0	90	100.0

Q10. What is the main message of the Healthy Now, Healthy Later program?

Of 90 participants, the percentage that chose the correct answer, (b) *Even if you're not thinking of getting pregnant now, it's important to develop healthy habits now to reduce the risk of possible birth defects later*, increased from 86.7% before the training to 97.8% after the training (Table 11):

Table 11. What is the main message of the Healthy Now, Healthy Later program? (N=90/ 89*)				
	Pre		Post	
	n	%	n	%
a. Fad diets are the healthiest for losing weight, even if they don't include important nutrients.	3	3.3	0	0.0
b. Even if you're not thinking of getting pregnant now, it's important to develop healthy habits now to reduce the risk of possible birth defects later.	78	86.7	87	97.8
c. Vitamins and minerals such as calcium, iron and folic acid are only important if you are planning to get pregnant.	9	10.0	2	2.2
Total	90	100.0	89	100.0

*One respondent was excluded at post-test because they were accidentally given an older version of the post-test with different response choices.

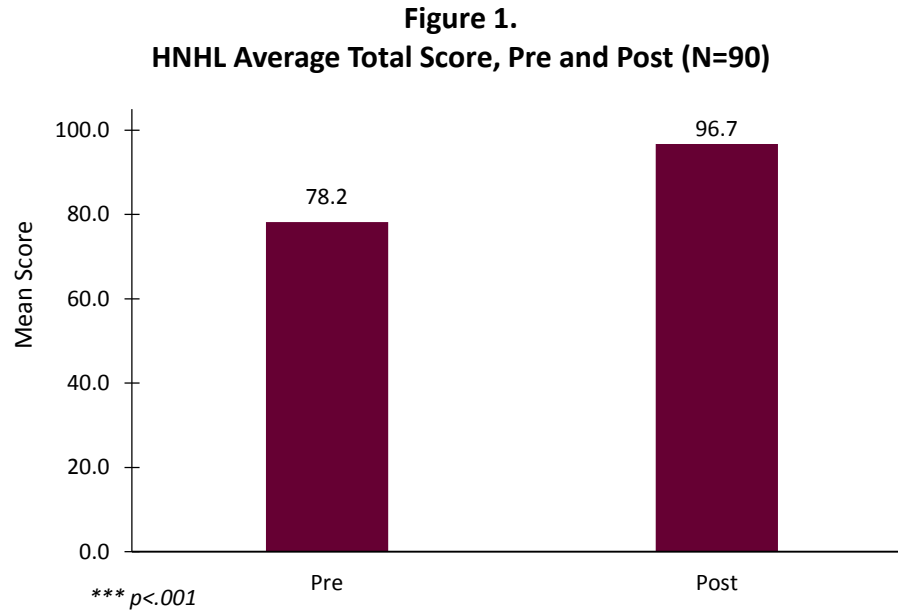
Q11. Now that you have completed this training, how confident do you feel to teach others? (Post-test only).

Of 90 participants, a combined percentage of 100.0% reported feeling either *very confident* (72.2%) or *somewhat confident* (27.8%) in their ability to teach others. No participants reported *not at all* or *not very confident* (Table 12):

Table 12. Now that you have completed this training, how confident do you feel to teach others? (N=90)		
	n	%
a. not at all confident	0	0.0
b. not very confident	0	0.0
c. somewhat confident	25	27.8
d. very confident.	65	72.2
Total	90	100.0

Total Score: Overall Knowledge

To assess overall knowledge of the NNHL training content, a total score was calculated for each of the 90 respondents by dividing the number of correct responses by the total number of questionnaire items (i.e. the percentage of correct responses) for the pre-posttest items (10). On average, participants' overall knowledge scores increased from 78.2% before the training to 96.7% afterwards, an increase of 18.5 points. This translates to a 23.7% average increase in overall knowledge (Figure 1, Table 13).



	Mean Score	SD	Lowest Score	Highest Score
Pre	78.2	16.3	40.0	100.0
Post	96.7	6.2	80.0	100.0

Results of a paired samples t-test indicated a statistically significant increase in mean scores after the training ($M=96.7$, $SD=6.2$) compared to before ($M=78.2$, $SD=16.3$); $t(89) = 11.506$, $p < .001$. These findings suggest that the training resulted in a statistically significant increase in overall knowledge of the NNHL key content among the training participants.

B. Form H

This section presents findings from the educational presentations delivered by the college trainers to their peers at Rowan College at Burlington County, Raritan Valley Community College, Bergen Community College and Monmouth University. A total of 651 Form H questionnaires were returned, of which 643 contained valid data.

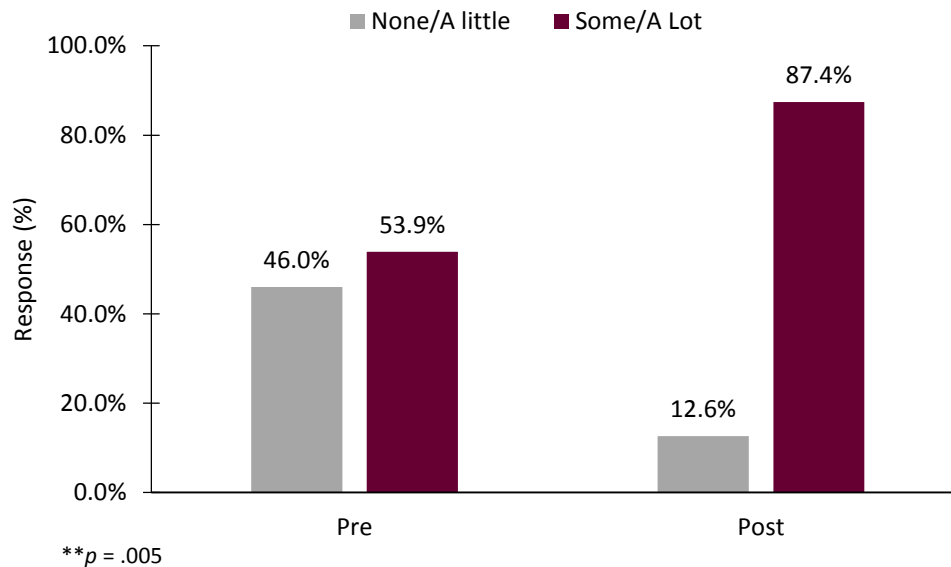
Item Analysis

Q1. NOW that you've heard the information about healthy living, how would you describe your knowledge of how healthy diets and behaviors can help prevent birth defects?

Q2. Think back to BEFORE you heard the information today and describe your knowledge of how healthy diets and behaviors can help prevent birth defects.

Of 643 respondents who answered this question, the combined percentage of those who reported knowing *some* or *a lot* increased from 53.9% before the training (*some*: 29.5%; *a lot*: 24.4%) to 87.4% after the training (*some*: 30.5%; *a lot*: 56.9%). Meanwhile, those who reported knowing either *none* or *a little* decreased from 46.0% before the training (*none*: 14.3%; *a little*: 31.7%) to 12.6% after the training (*none*: 1.6%; *a little*: 11.0%). These results are presented in Figure 2:

Figure 2. HNHL Participants' Self-Reported Knowledge of How Healthy Diets and Behaviors Can Help Prevent Birth Defects (N=643)



A chi-square test of independence was conducted to compare participant knowledge before and after attending the HNHL presentation. A significant relationship was found $\chi^2(1, 643) = 7.8$, $p = .005$, indicating that participants' knowledge was greater following the training compared to before.

Q3. When should you begin getting enough folic acid, calcium and iron to help prevent birth defects?

Of 649 respondents, 77.3% correctly answered that you should begin getting enough folic acid, calcium and iron to help prevent birth defects *before becoming pregnant*, while 11.6% incorrectly answered *as soon as you know you are pregnant*; 2.6% answered *during the third trimester*; and 8.5% answered *I don't know* (Table 14).

Table 14. When should you begin getting enough folic acid, calcium and iron to help prevent birth defects? (N=649)		
	n	%
a. Before becoming pregnant	502	77.3
b. As soon as you know you are pregnant	75	11.6
c. During the third trimester	17	2.6
d. I don't know	55	8.5
Total	649	100.0

Q4. Which of these foods is a good source of calcium, iron AND folic acid?

Of 649 respondents, 75.3% correctly identified *spinach and beans* as a good source of calcium, iron, and folic acid. Meanwhile, 12.6% chose *milk and cheese*; 8.2% chose *apples and bananas* and 3.9% chose *beef and chicken* (Table 15).

Table 15. Which of these foods is a good source of calcium, iron AND folic acid? (N=649)		
	N	%
a. Apples and bananas	53	8.2
b. Beef and chicken	25	3.9
c. Spinach and beans	489	75.3
d. Milk and cheese	82	12.6
Total	649	100.0

Q5. Maintaining a healthy weight through a healthy, balanced diet may help reduce the risks for pregnancy complications and birth defects later.

Of 649 respondents, 96.0% correctly answered *true*, while only 4.0% chose *false* (Table 16).

Table 16. Maintaining a healthy weight through a healthy, balanced diet may help reduce the risks for pregnancy complications and birth defects later (N=649)		
	n	%
True	623	96.0
False	26	4.0
Total	649	100.0

Q6. How does drinking alcohol and binge-drinking increase the risk of birth defects?

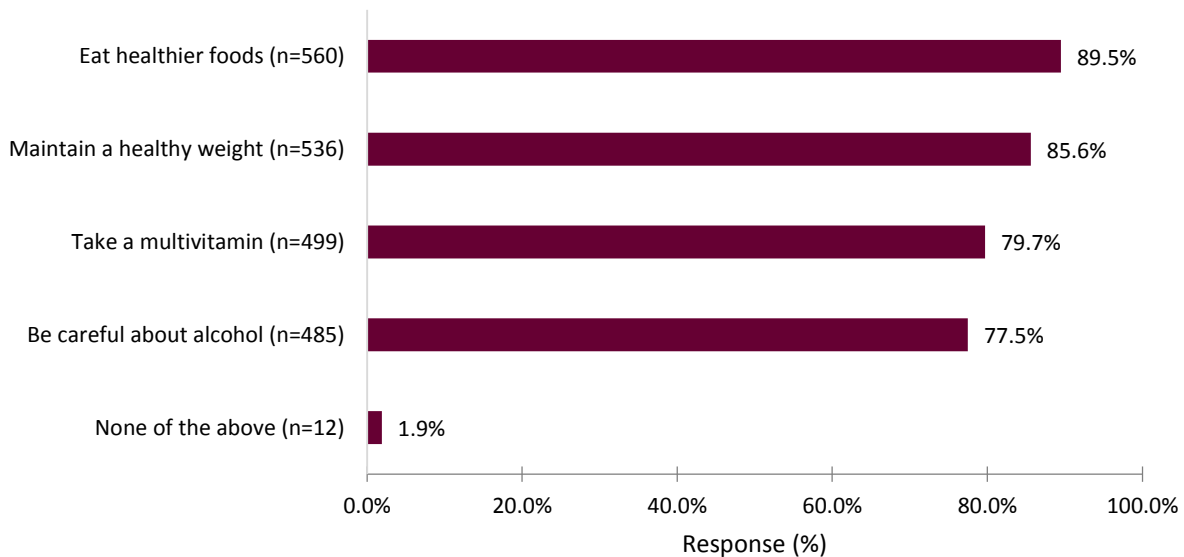
Of 649 respondents, 85.5% correctly answered (d) *all of the above*. Meanwhile, 2.0% chose (b) *exposes the fetus to alcohol*; 7.9% chose (c) *interferes with the bodies' ability to metabolize folic acid*; and 4.6% chose (a) *increases the chance of having unprotected sex* (Table 17):

Table 17. How does drinking alcohol and binge-drinking increase the risk of birth defects? (N=649)		
	n	%
a. Increases the chance of having unprotected sex.	13	2.0
b. Exposes the fetus to alcohol.	51	7.9
c. Interferes with the bodies' ability to metabolize folic acid.	30	4.6
d. All of the above.	555	85.5
Total	649	100.0

Q7. Now that you've learned about "Healthy Now, Healthy Later," which of the following do you think you will do (check all that apply):

Of 627 respondents,¹ 99.4% reported that they think they will do at least one healthy behavior from a list of four. The most commonly reported healthy behavior was: *eat healthier foods* (89.5%); followed by *maintain a healthy weight* (85.6%); *take a multivitamin* (79.7%); and *be careful about alcohol* (77.5%). Meanwhile, only 1.9% reported that they will do none of the four healthy behaviors (Figure 3):

Figure 3.
HNHL Participants' Planned Healthy Behaviors (N=627)



Note: Respondents could select more than one answer, therefore percentages may sum to more than 100%.

Respondents who selected *none of the above* and one or more healthy behavior choices (n=22) were excluded from the analysis.

¹ There were 22 respondents who selected *none of the above* and one or more of the four healthy behavior choices; these cases were excluded from the analysis.

An additional analysis showed that the majority of respondents (63.1%) reported that they think they will do all four healthy behaviors, 17.7% reported they think they will do three healthy behaviors, 9.4% reported two healthy behaviors, and 7.8% reported one healthy behavior (only 1.9% reported none of the above).

Put another way, after participating in the NNHL educational presentation, nearly all respondents (about 98.1%) reported that they think they will do at least one of the four recommended healthy behaviors after receiving the program education from their college peers.

IV. Discussion and Recommendations

Based on the findings presented in this report, the SBRN's NNHL program successfully achieved its three main goals to (a) prepare college students to serve as spokespeople on the importance of preconceptional health and reducing the risks for birth defects/developmental disabilities; (b) increase awareness among their college peers about the need for healthy diets and behaviors before becoming pregnant to improve their health and reduce the risks of having babies with disabilities; and (c) increase healthy preconceptional diets and behaviors among young adults.

Based on pre-posttest results, college students who participated in the NNHL train the trainer training successfully demonstrated increased knowledge and either met and/or exceeded the program's target benchmark of 90% in all key content areas, including the benefits of healthy diets, healthy behaviors, and maintaining healthy weight for improving overall health and reducing the risk for birth defects and developmental disabilities. More specifically, the pre-posttest results showed that students' overall knowledge of the program's key content increased by an average of 18.5 points, from 78.2 before the training to 96.7 after the training (out of 100.0 possible points). This translates to an average increase in knowledge of 24%. In addition, after participating in the training, 100.0% of the students reported that they felt either somewhat or very confident in their ability to teach others.

These findings were supported by equally positive results from a test of knowledge administered to students who attended presentations given by their trained peers, in which the majority successfully demonstrated knowledge of the program's key content areas, including the following: the importance of getting enough folate acid, calcium, and iron before getting pregnant (77.3%); identifying foods that are high in calcium, iron, and folate acid (75.3%); maintaining a healthy weight (96.0%); and the risks of binge drinking (85.5%). While as a group, these students scored slightly below the 90.0% target in some areas, the percentage of students who reported knowing either some or a lot about how healthy diets and behaviors can help prevent birth defects increased significantly from 53.9% before the presentation to 87.4% afterwards. In addition, following the presentation, nearly 100% reported that they thought they would practice one or more healthy behaviors, including eat healthier foods, maintain a healthy weight, be careful about alcohol and/or take a multivitamin. Taken together, these positive results provide preliminary evidence for the success of NNHL as a promising practice in empowering college students to educate and inform their peers about the importance of healthy behaviors before becoming pregnant to improve their health and to reduce the risks of having babies with disabilities in the future. However, because an evaluation of the program's long-term outcomes, including actual behavior change and future birth outcomes was beyond the timeframe and scope of the current project, the extended impact of the program remains unknown at this time. To further support the success of NNHL and similar programs in the future, program

decision-makers may wish to consider allocating resources for an investigation of these long-term program outcomes.

As with all projects, this evaluation had some limitations, including the use of small convenience samples and reliance on self-reported information, which may result in a subjectivity bias. Therefore, care should be taken in extrapolating these findings to a broader population. However, the use of a mixed methods design that included multiple sources of quantitative and qualitative data may have mitigated this bias to some extent.

Finally, these findings, as a summary of the NNHL participants' experiences and perspectives, may provide program leaders with useful information to assist with planning and implementing similar programs in the future.

SPAN Parent Advocacy Network
New Jersey Office for the Prevention of Developmental Disabilities
Fetal Alcohol Spectrum Disorders (FASD) Grant Project Evaluation: Year Two
Final Report

Pam Kelley, Ph.D.
Kelley Analytics, LLC
July 8, 2019

Contents

Page	
I. Introduction	1
Background	1
Project Overview.....	1
Purpose of the Evaluation.....	1
Evaluation Questions	2
II. Methods.....	2
III. Results	3
A. Peer Support Focus Groups	3
B. High School FASD Educational Presentations.....	7
IV. Discussion and Recommendations	9
Appendices.....	11
Appendix A. Peer Support Group Feedback Form.....	12
Appendix B. High School Youth Presentation Staff Feedback Form.....	14

I. Introduction

Background

This report presents the final evaluation results from Year Two of the SPAN Parent Advocacy Network (SPAN) Fetal Alcohol Spectrum Disorders (FASD) project, funded through the New Jersey Office for the Prevention of Developmental Disabilities (OPDD). This report represents the final deliverable in a contract between SPAN and Kelley Analytics for Kelley Analytics to provide evaluation consulting services for the SPAN OPDD FASD project from July 1, 2018 to June 30, 2019.

Project Overview

The primary goals of the SPAN OPDD FASD project included the following:

- Increase the knowledge of youth ages 14-21 on FASD prevention and the social determinants of health that impact alcohol use by implementing an educational presentation targeting high school youth.
- Improve access to culturally, linguistically, and socio-economically relevant peer support for women at risk of alcohol use/abuse and of having a child with FASD by collaborating with community organizations to provide enhanced peer-to-peer support groups targeting women of childbearing age to raise awareness on the social determinants of health; to learn prevention strategies to reduce the risk of FASD; and to link participants to available community resources and supports.

Purpose of the Evaluation

During an initial evaluation planning meeting, the evaluation consultant and program leadership met as a team to discuss the purpose of the evaluation and the program's informational priorities. The discussion was guided by evaluation best practices, particularly the evaluation standards set forth by the Centers for Disease Control and Prevention (CDC) of *utility* (i.e., who will be the primary users of the evaluation results and what results will be most useful to them); and *feasibility* (i.e. is there sufficient time and are there sufficient resources available to implement the desired evaluation).¹

The team agreed that the goals of the evaluation were to:

1. Gain understanding and insight into the experiences of women who participated in the program's peer to peer support groups, including participants' satisfaction with the groups; perceptions on the groups' effectiveness; and suggestions for improvement.
2. Assess the effectiveness of the educational presentation at increasing high school youths' knowledge about the social determinants of health; the impact of alcohol use on health; and FASD prevention.

The information gained from the evaluation will be used by SPAN to make improvements to the program and to inform future efforts to prevent intellectual and developmental disabilities by

¹ For more information on the CDC's evaluation standards, see the CDC program evaluation webpage: <https://www.cdc.gov/eval/standards/index.htm>

raising awareness and providing support to women of childbearing age and youth, particularly those who may be negatively affected by the social determinants of health.

Evaluation Questions

During the evaluation planning meeting, the team developed a set of broad questions that the evaluation would be designed to answer, as follows:

A. Peer Support Groups

1. What were the experiences of women who participated in the peer support groups?
Sub questions include:
 - a. To what extent did participants find the support groups helpful in increasing their knowledge about the risks of alcohol use during pregnancy?
 - b. Did participants find the groups helpful in learning about overall health?
 - c. What aspects of the group did participants find most valuable?
 - d. What suggestions do participants have for improving the groups in the future?

B. Youth FASD Educational Presentations

1. To what extent was the educational presentation successful in increasing knowledge among high school youth on FASD prevention and the risks involved in using alcohol and drugs?

II. Methods

To answer the evaluation questions, the evaluation consultant worked with the program leadership to design a mixed methods evaluation consisting of the following components:

- A. *Peer-to-Peer Support Group Participant Questionnaire* (Appendix A): To assess the effectiveness of the peer support groups, the evaluation consultant and project leadership developed a brief, anonymous, questionnaire for support group participants to complete at the end of each meeting. The questionnaire used a multiple-choice format to assess the extent participants' perceptions about the extent to which participating in the peer support group helped them learn about the risks of alcohol use during pregnancy and about general health. The questionnaire also asked participants to rate a series of five indicator statements to assess their satisfaction and experiences with the group, including their perceptions of the group's usefulness and effectiveness. In addition, open-ended questions ask participants to describe what they liked best and suggestions for how to improve the support groups. English and Spanish versions of the questionnaire were made available to support group participants.
- B. *High School Educational Presentation Feedback Form* (Appendix B): To assess the effectiveness of the high school presentations, the evaluation consultant and project leadership developed a form for presentation facilitators to record notes on the main themes from their guided discussion with students during the presentation. The form included sections on students' feedback on what they learned from the presentation; in

what ways the presentation may have changed their views; and usefulness of the information. The facilitators' notes were then summarized by the evaluator to identify key themes and relevant content across the school groups.

III. Results

A. Peer Support Groups

Evaluation Response

As shown in Table 1, A total of 43 evaluation tools were submitted by participants from 10 peer support groups conducted in the northern, central, and southern regions of New Jersey. Of groups with data on the total number of attendees, 100% of the attendees completed the evaluation tool (data on the total number of attendees was not collected prior to 1/24/19). Evaluation tools were submitted by 37 individual participants who attended one group only, and four individuals who attended two or three groups (attended two groups: n=2; attended three groups: n=2).

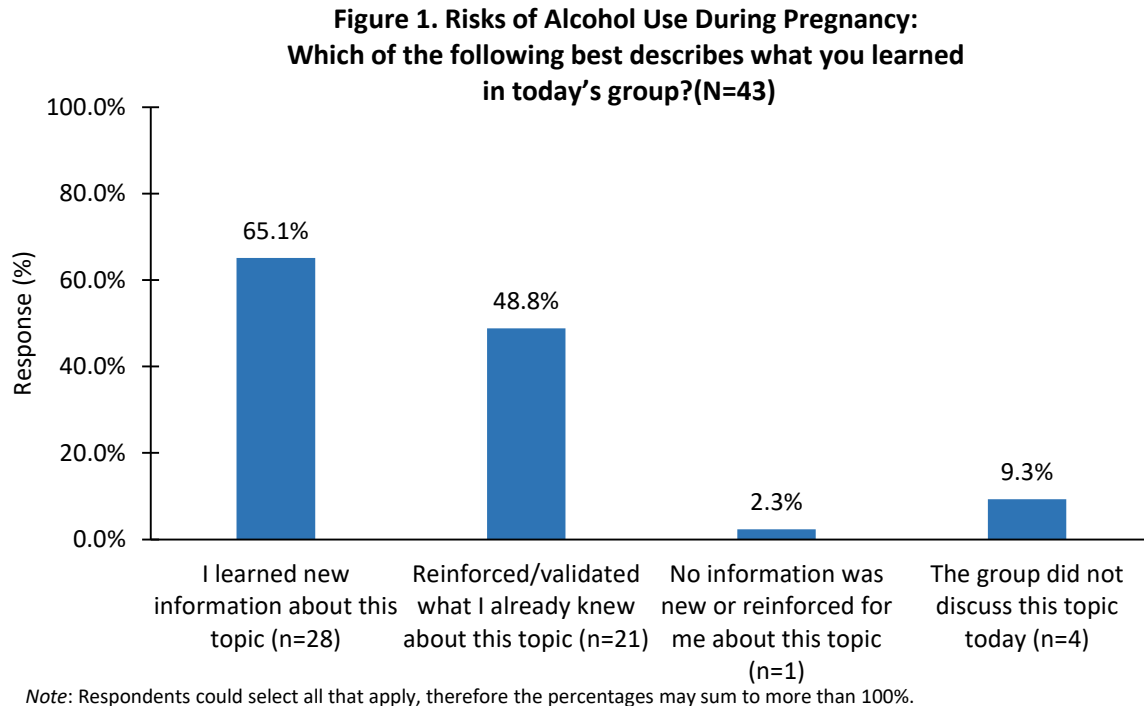
Peer Group	Peer Group Date	County	Completed Evaluation Tools	Total in Attendance	Response Rate
Unidos Para Las Familias	10/25/18	Cumberland	3	-	-
MeTime	10/25/18	Middlesex	10	-	-
NORWESCAP	1/24/19	Morris	3	3	100%
Unidos Para Las Familias	1/24/19	Cumberland	4	4	100%
Denville NORWESCAP	4/17/19	Morris	1	Missing Data	
Atlantic Cape Family Support Organization	4/25/19	Atlantic	5	5	100%
Atlantic Cape Family Support Organization	5/1/2019	Atlantic	5	5	100%
First Presbyterian Church	5/22/2019	Morris	2	Missing Data	
Family Center Cape May Court House	6/13/19	Cape May	5	5	100%
Atlantic Cape Family Support Organization	6/19/19	Atlantic	5	5	100%
Total			43	-	-

Risks of Alcohol Use During Pregnancy

The peer support group questionnaire included a question that asked, "Which of the following best describes what you learned in today's group about the risks of alcohol use during pregnancy?" with answer choices that included the following: (a) I learned new information about this topic; (b) Reinforced/validated what I already knew about this topic; (c) No

information was new or reinforced for me about this topic; and (d) The group did not discuss this topic today. Respondents could select all that apply.

Of 43 responses, 65% reported that they learned new information about the risks of alcohol use during pregnancy, and 49% reported the group reinforced or validated what they already knew. Meanwhile, only one respondent (2.3%) reported no information was learned or reinforced and four (9.3%) reported that the group did not discuss the risks of alcohol use on that day (Figure 1).

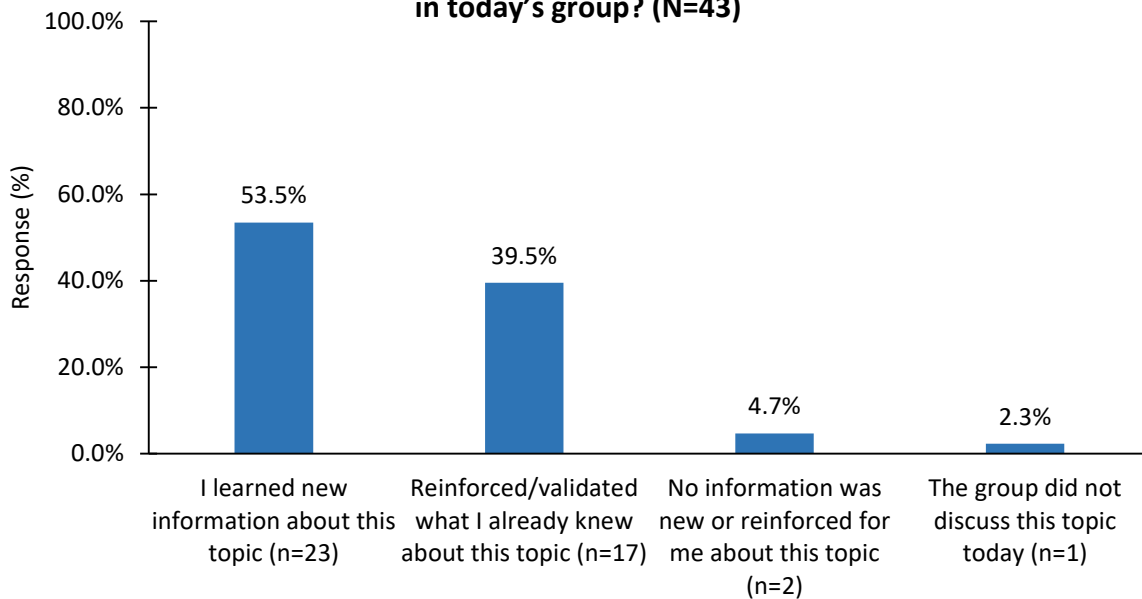


General Health

The peer support group questionnaire included a question that asked, "Which of the following best describes what you learned in today's group about general health?" with answer choices that included the following: (a) I learned new information about this topic; (b) Reinforced/validated what I already knew about this topic; (c) No information was new or reinforced for me about this topic; and (d) The group did not discuss this topic today. Respondents could select all that apply.

Of 43 responses, 54% reported that they learned new information about general health and 40% reported the group reinforced or validated what they already knew. Meanwhile, only two respondents (4.7%) reported no information was learned or reinforced and one (2.3%) reported that the group did not discuss general health on that day (Figure 2).

Figure 2. General Health:
Which of the following best describes what you learned
in today's group? (N=43)

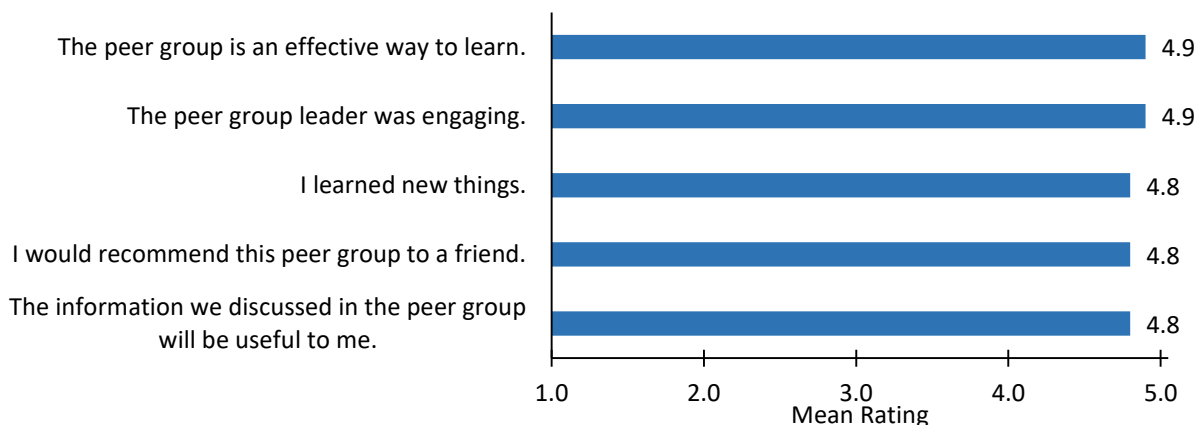


Note: Respondents could select all that apply, therefore the percentages may sum to more than 100%.

Satisfaction with the Peer Support Groups

To assess participant satisfaction with the peer support group, the questionnaire asked participants to rate their agreement with five indicator statements using a scale from 1 (strongly disagree) to 5 (strongly agree). Based on the average responses from the group (n=43), participants were highly satisfied with the peer support groups, with an average agreement rating of 4.8 or higher on all five of the support group satisfaction indicators (Figure 3).

Figure 3. Peer Group Satisfaction: Average Participant Ratings (N=43)
Rating Scale: 1 (Strongly disagree) to 5 (Strongly Agree)



What Participants Liked Best

The questionnaire included an open-ended question that asked participants what they liked best about today's discussion. Of the 32 responses, the following themes were identified:

- Support, sharing, openness (40.6%)
- Learning about specific topics, including FASD (40.6%)
- Clear explanations, general learning (21.9%)
- Group interaction (12.5%)
- Family-centered; helps with family (12.5%)
- Other (3.1%)

Notable Quotes:

- » Loved the interchange of ideas and information.
- » I learned being open and honest has its benefits and can help others who may be going through the same situation.
- » Everything we talked about was important to help us. Alcohol in the young was an important issue.
- » Being able to have questions answered; facilitator was excellent.
- » Felt much needed support.
- » It feels nice to hear other moms have the same issues.
- » Sharing our individual stories.
- » The topic is constructive and helps to be objective as I help my family.
- » The facilitator explained this topic very well; I learned very much. Thank you for the support.
- » [Learning] about fetal alcohol spectrum disorder.
- » Open forum, easy to follow information being presented.
- » I enjoyed how the session was led. It was very effective.

Participants' Suggestions for Improvement

The questionnaire included an open-ended question that asked participants for suggestions to improve the peer support groups. Only ten participants reported valid suggestions for improvement, including the following:

- » Keep the group discussion and the exercises.
- » More time for discussing the information; more time.
- » Learn more about understanding my child.
- » I'd like to bring some people to the class so we can have a great discussion.
- » Get-togethers on various topics.
- » Discuss topics such as - strategies about how to deal with others who are not aware of our children's disabilities and make fun of them.
- » Make sure kids are out before the person starts talking with parents.

- » [Offer more groups in] Bridgeton/Cumberland County.
- » More [participants] would come if a gift card was offered.

B. High School FASD Educational Presentations

Educational presentations were conducted at six high schools in four counties located in the northern, central, and southern regions of New Jersey. The number of students that attended each presentation ranged from between 1-10 and 11-20 students per group (Table 2).

Date	School	County	Number in Attendance (Range)
2/25/2019	Vineland Senior High School	Cumberland	1 - 10
4/30/2019	Dover High School	Morris	1 - 10
5/2/2019	Dover High School	Morris	1 - 10
5/22/2019	Atlantic County High School Students	Atlantic	11 - 20
5/30/2019	9th Grade Academy - Trenton	Mercer	11 - 20
6/6/2019	Dover High School	Morris	1 - 10

Learning Key Content

The discussion themes identified in the presenter's notes suggest that students from all six schools successfully learned the program's key content, focusing on FAS/FASD, risks of alcohol and drug use, and other related topics. The student discussion themes included the following:

- **Risks of alcohol use** was discussed with students in all six schools.
- **Risks of drug use** was discussed with students in all six schools. Students expressed a lot of interest in learning about the risks of drug use. In some groups, the discussion focused on risks related to using **over-the-counter medications** and **marijuana use**. Some students shared their experiences with seeing other students being arrested at school for drugs.
- **FAS/FASD** was discussed with students from five schools (data was missing from one school so it is unknown whether FASD was actually discussed).
- **Risks of abusing household products** was discussed with students from four schools. At one school, the discussion was prompted after one of the participants shared that they knew a young person who drank rubbing alcohol.
- **Risks of vaping** was a topic of interest at some schools with many participants who shared similar experiences around seeing a lot of students vaping.
- **Risks of smoking** was discussed with students at one school.
- The topic of **abusive relationships** was discussed with students at one school with some students sharing how their lives have been impacted by abusive relationships.
- **Maternal health** was discussed with students at one school. Some participants, who were young mothers, shared similar experiences with mild episodes of "baby blues."

Changing Student Perspectives About Risky Behaviors

At four of the six schools, the presentation included a guided group discussion about how the presentation may have changed the students' views. According to the presenter notes, many students reported their views had changed with regard to the program's key messages of risk prevention and healthy behaviors, including the following themes:

- **Importance of not drinking alcohol;** some students mentioned having a better understanding of the effects of alcohol abuse. In the words of one student, "[It] made me realize how bad it is for you."
- **Importance of not doing drugs;** at one school, deeper discussion was generated by a student who shared that a friend had overdosed. At another school, students discussed having changed their views about marijuana use. In the words of one student, "[There is] less chance that I will waste money on weed."
- **Importance of good nutrition;** at one school, discussed was generated with some students who shared similar experiences around not having enough money for food.
- **Importance of health in general;** at one school, deeper discussion was prompted by a student who shared that their family does not have health insurance. In the student's words, "It's hard when we get sick."
- **Importance of the social determinants of health;** some students shared that their community has a lot of liquor stores; many students shared their individual experiences related to social determinants of health, and discussion followed about where to go for help, if needed.

Student Perspectives on Usefulness of Presentation

Following each presentation, students were asked to discuss how the presentation might be useful to them. The group discussion themes suggest that students found the presentation useful in identifying and dealing with risk behaviors and pressure to drink alcohol and do drugs; encouragement of healthy behaviors and getting help when needed; sharing what they learned with others and making a difference in the community. More specifically, the identified discussion themes included the following:

- Pressure to drink and do drugs use is a form of abuse
- Warning signs and red flags of risky behaviors
- How to get help and not be afraid
- What to look for in a healthy relationship
- I learned that I can try to make a difference in my community
- I will tell my friends about the risks of drinking at parties and driving home
- We see our parents stress over money and it makes us scared
- I understand better now what could happen
- I will share what I learned with others

Imagining the Future . . .

The presentations included a guided group discussion in which the presenters asked students, "Imagine that it is 25 years from now and you have a son or daughter exactly the same age as you are now. What might you say to him or her about drinking and drugs?" The identified discussion themes suggest that students perceive communication and role models to be important protective factors in preventing alcohol and drug use among youth and, at the same time, suggest optimism with plans to communicate more and to be positive role models in the future for their own children. More specifically, the discussion themes included the following:

- Some students expressed that that they would talk to their children about how drugs and alcohol can have effects on your body.
- Many students mentioned that they would talk to their children more about everything. Some students discussed how saying "Don't do what I did" may be effective.
- Some students discussed advising their children to walk away immediately from abuse; to watch out for signs of abuse; and to speak up!
- *I would say it's easy to get addicted so don't start.*
- *I would say it's a waste of money.*
- *I would say you will hurt your health.*
- *I would say it will be harder to get a good job.*
- *I would tell them not to drive if drinking and that I would come get them.*

IV. Discussion and Recommendations

The findings presented in this report provide qualitative evidence that suggests the SPAN Parent Advocacy Network's program was successful in achieving its dual goals of improving access to peer-to-peer support for women at risk of alcohol use/abuse and of having a child with FASD; and increasing knowledge among youth on FASD prevention and general health.

Based on the data collected directly from 43 peer support group participants, the groups appear to play an important role in the learning process about FASD: most participants reported that through participating in the group, they learned new information about the risks of alcohol use during pregnancy (65.1%) while nearly half reported that the group reinforced and validated what they already knew about these risks (48.8%). Similar results were found for learning the program's key content around general health, with slightly more than half who reported they learned new information about health (53.5%) and nearly 40% who reported the group reinforced or validated what they already knew. In addition to these positive learning experiences, participants rated the support group very highly on average (4.8 or higher on a scale from 1 to 5) on five indicators, including learning new things, the group leader's level of engagement, usefulness of information, and whether they would recommend it to a friend.

The high school presentations yielded similar positive, qualitative findings, with group discussion themes that suggested students learned the curriculum's key content including FAS/FASD; and risks associated with alcohol use; drug use; vaping; and smoking. Students reported that participating in the presentation changed their views about risk prevention and healthy behaviors, with discussion themes that included the importance of not drinking alcohol or doing drugs, as well as the importance of good nutrition, general health, and the social determinants of health. The findings also suggest that students found the presentations useful with regard to the following: identifying and dealing with risk behaviors and pressure to drink alcohol and do drugs; encouragement of healthy behaviors and getting help when needed; sharing what they learned with others and making a difference in the community. In addition, when students were asked to imagine what they might say 25 years from now to their future children about the risks of alcohol and drugs, the discussion themes suggested that students perceive communication and role models to be important protective factors in preventing alcohol and drug use among youth and, at the same time, suggested a sense of optimism about the future that includes plans to communicate more and to be positive role models for their own children.

While these positive findings suggest the program was successful in meeting its intended goals, program leaders and other stakeholders should keep in mind that the type of qualitative methods used for this evaluation are generally considered limited in their ability to determine a program's actual effectiveness, from a scientific or evidence-based perspective. For this reason, program leaders may wish to consult with the evaluator about options for using more rigorous designs in the future in order to provide more definitive evidence of the program's impact. Other limitations experienced by this project included issues with maintaining data consistency and data quality, and, therefore, the results presented in this report should be interpreted with caution. For future projects, it is strongly recommended that program leaders work with the evaluation consultant to identify data collection strategies that will be less burdensome for program staff and that will yield higher quality data. In spite of these limitations, these findings, as a summary of the program participants' experiences and perspectives, provide important information and insight that may assist program leaders with making improvements when implementing similar programs in the future.

APPENDICES

Appendix A.

Today's Date: _____

Group Location/Organization: _____

County: _____

SPAN Staff Name: _____

SPAN PEER GROUP FEEDBACK FORM

Instructions: Please help us improve our program by completing this anonymous questionnaire about the group you attended today.

1. Please provide the following information so that we can create a unique code for your questionnaire.

- a. What is the first letter of your first name? _____
- b. What is the first letter of your **mother's** first name? _____
- c. What is the first letter of the city or town where you were born? _____
- d. On what **day** of the month were you born? (enter a number **from 01 to 31**)

2. Which of the following best describes what you learned in today's group about the **risks of alcohol use during pregnancy**? (Circle all that apply)

- a. I learned new information about this topic.
- b. Reinforced/validated what I already knew about this topic.
- c. No information was new or reinforced for me about this topic.
- d. The group did not discuss this topic today.

3. Which of the following best describes what you learned today about **general health**? (Circle all that apply)

- a. I learned new information about this topic.
- b. Reinforced/validated what I already knew about this topic.
- c. No information was new or reinforced for me about this topic.
- d. The group did not discuss this topic today.

4. For each statement, please tell us how much you agree or disagree by circling your answer:

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
The information we discussed in the peer group will be useful to me.	5	4	3	2	1
The peer group leader was engaging.	5	4	3	2	1
The peer group is an effective way to learn.	5	4	3	2	1
I would recommend this peer group to a friend.	5	4	3	2	1
I learned new things.	5	4	3	2	1

5. What did you like best about today's discussion?

6. Please tell us how we can improve the peer group in the future or any other comments you would like us to know:

Thank you for your time!

Appendix B.

SPAN OPDD/FASD High School Educational Presentation SPAN Staff Feedback Form (to be completed by SPAN Staff)

Instructions for the SPAN Staff: Please complete this form yourself after each presentation you give. If you give more than one presentation at a single school, complete one form for each presentation. It is important that you complete the form **immediately after** each presentation. When you are finished, please email your completed form/s to: Pam Kelley at pkelley@kelleyanalytics.com

I. General Information

Date of presentation					
Time of Presentation	AM / PM				
Number of student attendees (circle one):	1-10	11-20	21-30	31-50	More than 50
School Name					
School County					

II. Student's Feedback

Instructions: For each discussion question below, please indicate whether or not you discussed it with the students who attended your presentation today by circling Yes or No and answer the remaining questions.

- Did you discuss the following question with students today during your presentation: **What did you learn today that you didn't know before?**
 - Yes
 - No (skip to question #3)
- If you circled Yes**, please circle any topics that were mentioned during the discussion from the list in column (a) and circle how many students mentioned the topic (b) using the following guidelines: Few = 1 or 2; Some=more than two but less than half; Many=approximately half; Most=more than half.

(a) Circle any topics that were discussed	(b) How many students mentioned this topic? (Circle one)				(optional) Specific comments made by students and/or SPAN staff observations:
a. Risks of alcohol usage	Few	Some	Many	Most	
b. Risks of drug usage	Few	Some	Many	Most	
c. FAS/FASD related	Few	Some	Many	Most	

d. Maternal health related	Few	Some	Many	Most	
e. Risks of household products usage	Few	Some	Many	Most	
f. Other:	Few	Some	Many	Most	
g. Other:	Few	Some	Many	Most	

3. Did you discuss the following question with students today during your presentation: **Did today's presentation change your views? If so, how?**

- a. Yes
- b. No (skip to question #5)

4. **If you circled Yes**, please circle any topics that were mentioned during the discussion from the list in column (a) and circle how many students mentioned the topic (b) using the following guidelines: Few = 1 or 2; Some=more than two but less than half; Many=approximately half; Most=more than half.

(a) Circle any topics that were discussed	(b) How many students mentioned this topic? (Circle one)	(optional) Specific comments made by students and/or SPAN staff observations:
a. Importance of health in general	Few Some Many Most	
b. Importance of not drinking	Few Some Many Most	
c. Importance of not doing drugs	Few Some Many Most	
d. Importance of good nutrition	Few Some Many Most	
e. Importance of the social determinants of health	Few Some Many Most	
f. Other:	Few Some Many Most	
g. Other:	Few Some Many Most	

5. Did you discuss the following question with students today during your presentation: **How might the information in this presentation be useful to you?** (circle one)

- a. Yes
- b. No (skip to question #7)

6. **If you circled Yes**, please list the students' suggestions

Suggestions (list)
1.
2.
3.
4.
5.

7. Did you discuss the following question with students today during your presentation: **Imagine that it is 25 years from now and you have a son or daughter exactly the same age as you are now. What might you say to him or her about drinking and drugs?** (circle one)

- a. Yes
- b. No

8. **If you circled Yes**, please list what students would tell their sons or daughters 25 years from now:

Suggestions (list)
1.
2.
3.
4.
5.

Please email your completed form/s to: Pam Kelley at pkelley@kelleyanalytics.com