SPAN's dual strategy of providing Peer to Peer Support Groups to at-risk women of childbearing age and provider education during the third and fourth years of funding and expanding upon lessons learned in years five and six to educate youth through high school presentations have shown to be effective at increasing knowledge and raising awareness about FASD prevention, social determinants of health, and risks of alcohol use.

Contact Information

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Section 1: Practice Summary

PRACTICE DESCRIPTION

Since 2013 SPAN has been a recipient of OPDD funding to address and reduce the risk of preventable developmental disabilities. For the first two years, SPAN provided provider education on effective communication of prevention messages to diverse women of childbearing age and individual assistance to at-risk women. SPAN’s dual strategy of providing Peer to Peer Support Groups to at-risk women of childbearing age and provider education during the third and fourth years of funding and expanding upon lessons learned in years five and six to educate youth through high school presentations have shown to be effective at increasing knowledge and raising awareness about FASD prevention, social determinants of health, and risks of alcohol use. An evaluation of the project’s peer to peer support groups found that peer support plays 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, while at the same time, the group reinforced and validated what they already knew. Even before the OPDD funding, SPAN has had a long history of providing comprehensive information and connection to resources for families and professionals. As a Family to Family Health Information Center, SPAN shares Bright Futures information with families. Bright Futures information is preventive health promotion information that helps families make healthy decisions for their children on issues such as nutrition, exercise, screen time, avoiding secondhand smoke, child safety, etc. We partnered with National Family Voices in their IMPACT project, conducting focus groups with diverse families of children with and without special needs on Bright Futures topics as well as on life course theory. We also participated in a national study by Family Voices and Tufts University demonstrating that families of children with special needs were better able to implement health promotion messages when paired with trained parent mentors compared to simply receiving written information or participating in workshops. SPAN has conducted focus groups with Black and Latina women of child-bearing age about where they get their health information and effective strategies to help them learn and change behavior. SPAN conducted a scan of national and NJ birth defects prevention initiatives including projects funded by the Governor’s Council on 4 Prevention of Developmental Disabilities and coordinated activities of stakeholders aimed at preventing and reducing birth defects. We have also facilitated numerous focus groups with teens, college age students, and adult women of childbearing age from diverse racial, cultural and language backgrounds to learn from them about what they need to maximize their health and how to provide it.

SPAN proposes to provide leadership training and education, and 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) in NJ, via the Empowering Women in Community Leadership for Healthier Families project. By the end of the 3rd year, the project will have reached communities in nearly every county and developed peer leadership skill of 315-420 diverse women to participate in and have a voice in local and statewide decision making and advocacy forums concerning FAS/FASD and lead
poisoning prevention. Framed within the innovative paving the way to a Collective Impact approach, the project will take preliminary steps toward a cross-sector collaborative approach to impact outcomes over time.

**CORE COMPONENTS & PRACTICE ACTIVITIES**

**Goal 1:** Build community capacity to enhance engagement and leadership opportunities to prevent FASD and lead poisoning for women of childbearing age in underserved communities using the paving the way to Collective Impact model of engagement.

**Goal 2:** Increase knowledge among women of childbearing age, including women with relevant lived experience, to build parent leader capacity and action in high-risk communities on IDD, specifically FAS/FASD and lead poisoning prevention.

See Empowering Women Core Components and Activities for more information.

SPAN has conducted focus groups with Black and Latina women of child-bearing age about where they get their health information and effective strategies to help them learn and change behavior. SPAN conducted a scan of national and NJ birth defects prevention initiatives including projects funded by the Governor’s Council on Prevention of Developmental Disabilities and coordinated activities of stakeholders aimed at preventing and reducing birth defects. We also facilitated numerous focus groups with teens, college age students, and adult women of childbearing age from diverse racial, cultural and language backgrounds to learn from them about what they need to maximize their health and how to provide it. SPAN has multiple projects focused on educating and enhancing the capacity of families and of the professionals who serve children and families to be able to partner to improve services to and outcomes for children, and to prevent birth defects and developmental disabilities and improve birth outcomes. We have demonstrated capacity to motivate providers to change practice with our parent-led trainings on topics such as screening, medical home, and health promotion. We partner with the NJ Departments of Health, Human Services, and Children and Families to coordinate the Community of Care Consortium for Children and Youth with Special Healthcare Needs, and with the NJ Department of Health on Partners for Prevention, an initiative focused on prevention of birth defects and developmental disabilities, in which we have partnered with organizations focused on reducing alcohol and substance abuse/use among pregnant women and women of childbearing age. We also house the Essex County Community Doula pilot project, connecting underserved women of childbearing age to Community Doulas and Community Health Workers for prenatal, birth, and post-natal support, as well as other social/emotional support, services, and resources. Through that project, we have worked with women involved in alcohol and substance abuse as well as families for whom lead and lead poisoning are critical health issues. We have also identified and provided leadership development to a cadre of diverse women from the targeted communities to facilitate local peer support groups.
HEALTH EQUITY

The program addresses health inequities and systemic oppression in the following ways:

- Focus groups of people with lived experience informed provider education. Black, Hispanic/Latina and women of color with lived experience, and who participate in the program are empowered as community leaders as well as self-advocates to have a voice at the table alongside policy makers, health care providers and other community leaders.
- An education and leadership presentation on diversity, equity and inclusion was created and presented by Empowering Women staff for family leaders, providers, state and local partners during the Statewide Family Leadership conference and the Empowering Women Annual Summit.

EVIDENCE OF EFFECTIVENESS

See Appendix: Logic Model for evaluation design and data collection methods.

Goal: In New Jersey, data shows low income and communities of color face disproportionate risk and incidence of health inequities including disproportionate rates of childhood lead and fetal alcohol exposure. This project seeks to address these health inequities to lower the incidence of Fetal Alcohol Syndrome (FAS), Fetal Alcohol Spectrum Disorders (FASD), and lead poisoning in New Jersey by building community capacity to enhance engagement and leadership opportunities among women of childbearing age for the prevention of FAS/FASD and lead poisoning.

Results from training evaluation data collected to date suggest that the SPAN Empowering Women leadership training is successful in increasing participant (N=29) knowledge in all seven program key content areas, with a total average knowledge score that increased from 3.3 (before the training) to 4.5 (after the training) on a 5-point scale. Based on open-ended feedback, participants have found the training valuable, with specific themes that include listening to the stories of other participants; learning about how to conduct meetings; the key elements of leadership; inclusion and representation; and learning about cultural competence. Participants also expressed plans to use what they learned and expressed confidence and optimism about becoming more involved in their communities; sharing what they learned with others; applying new skills in cultural competence; leading groups; and organization skills. In addition, participants expressed feelings of empowerment and plans to be an advocate in their communities, as well as appreciation for the sense of community and support.

Based on results from the program’s peer support groups, participants (N=24) report high levels of learning in all six of the program’s key content areas, including the risks of alcohol use during pregnancy; risks of drug use; lead poisoning prevention; social determinants of health; where to find help in their communities; and how to advocate to improve their communities. In addition, participants gave the highest ratings on their experiences with peer groups on indicators of engagement, effectiveness, usefulness, and satisfaction. Participants reported the aspects of the group they liked best were “Information and learning about specific topics;” followed by “Hearing about other people’s experiences;” “Group interaction;” and “Feeling supported by the other people
in the group.” While preliminary, these results suggest that, to date, the initiative’s peer groups appear to be sustaining the positive impacts reported in Year One, despite the challenges of the COVID-19 pandemic.
### STAKEHOLDER EMPOWERMENT & COLLABORATION

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>How are they involved in decision-making throughout practice processes?</th>
<th>Does this stakeholder have lived experience/come from a community impacted by the practice?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black, Hispanic and women of color</td>
<td>Regional focus groups are conducted with women of childbearing age to determine effective communication strategies regarding FAS/FASD and lead poisoning prevention and learn what should and should not be included in the IDD peer leadership training series as well as the best ways to engage diverse women in targeted communities</td>
<td>Yes, all women have lived experiences who participated live in at-risk areas in parts of NJ</td>
</tr>
<tr>
<td>Black, Hispanic and women of color</td>
<td>Women receive leadership training to build their capacity to impact prevention in their communities and at the state level.</td>
<td>Yes, all women have lived experiences that participated live in at-risk areas in parts of NJ.</td>
</tr>
<tr>
<td>Black, Hispanic and women of color</td>
<td>Women serve on local advisory boards, serve on local advisory groups, school and community boards and other community leadership meetings</td>
<td>Yes, all women have lived experiences that participated live in at-risk areas in parts of NJ.</td>
</tr>
</tbody>
</table>

Tracking and evaluating program outcomes is central to the project. SPAN contracts with Kelley Analytics to conduct a comprehensive evaluation that includes formative (process) and summative (outcome) measures and will collect quantitative and qualitative data. The primary purpose of the formative evaluation will be to provide program leaders and stakeholders with information that can assist with decision-making related to program improvements and scale-up.
To assess the program’s effectiveness, the evaluation uses a multi-method design that includes the following key components:

1. **Training Pre-Posttest:** Short term outcomes related to increases in participant knowledge, skills, and attitudes/confidence (Goal 1: Objectives 1a; 1e; Goal 2: objectives 2b; 2c) are evaluated using retrospective pre-posttest methodology (participants rate their pre-training knowledge, etc. and their post-training knowledge, etc. immediately following the training. This approach often more accurately reflects pre-training knowledge, etc. because prior to the training participants may overestimate their knowledge whereas after the training, they are more likely to know what they didn’t know!) A pre-posttest questionnaire has been developed for each program training. Participants’ scores on the pretest will be compared to posttest scores with higher posttest scores interpreted as an increase. The target objective is for at least 75% of training participants to demonstrate increased pre to post scores. We measure overall knowledge, skills, and attitudes/confidence related to risk reduction/ prevention of IDD, with special focus on FASD and lead poisoning, and leadership knowledge, skills and confidence. Specific competencies assessed include knowledge of IDD, early screening, trauma informed care, social determinants of health, risk factors, nutrition, opioids, effective community leadership strategies, shared decision making; goal setting and developing an action plan; types of groups and their functions; communication skills; engaging diverse stakeholders; and managing conflict in groups.

2. **Follow Up Survey:** Long term outcomes related to participants’ enhanced capacity to be IDD prevention community leaders (Goal 3, Objective 3a) are assessed using a survey administered to all training participants at baseline (prior to receiving the training) and again six-months after the training. It assesses the participants’ level of engagement in community groups; number and types of groups and leadership roles; and contributions to group efforts and leadership activities, before and after receiving the program training. The survey also collects qualitative data on participants’ experiences in becoming leaders, including successes, lessons learned, and strategies to overcome challenges. Improvement in long-term outcomes will be interpreted as an increase in the number, type, and level of engagement on advisory groups and in IDD prevention activities in their local community at the six month follow up, compared to baseline with a target objective of at least 75% of participants reporting increases in these measures at six months compared to baseline.

3. **Program Document Review:** To measure the effectiveness of the program’s processes, including procedures, practices, and activities in implementing the project and in meeting project milestones in accordance with the proposed timeline, as well as to assess the extent to which program outcomes can be attributed to its activities, a formative evaluation will be conducted using primarily program document review methods. These will include quarterly review of all relevant documents including training curricula developed (Goal 1: Objective 1e); training registration and attendance sign-in sheets (Goal 1: Objective 1a; Goal 2: Objectives 2a-c; Goal 3: Objectives 3a-c); meeting minutes (Goal 1: Objective 1b); focus group summaries (Goal 1: Objectives 1c, 1d) and other program activities tracking systems. Kelley Analytics will provide quarterly progress updates with preliminary formative and summative results that align with state reporting deadlines. These updates will facilitate the use of evaluation results to gauge the program’s progress and make any needed modifications. Kelley Analytics will
also prepare annual evaluation reports that will present the formative and summative results for each program year

REPLICATION

When the Empowering Women project started 2 years ago we had stated the information sessions, leadership trainings and gatherings would take place in person. It was necessary in year 2 to doing the activities in a virtual setting. The lessons learned that in the virtual setting doing the activities proved to be beneficial in engaging more women to participate in the activities.

INTERNAL CAPACITY

- Empowering Women in Community Leadership for Healthier Families Team:
  - One Project Director
  - One Administrative Coordinator
  - Four Family Resource Specialist

The team is provided with continual professional develop on many topics such as: FAS/FASD, Lead Poisoning Prevention, Stress Management, Self-Care, Implicit Bias training to name a few. The team skills also include providing information sessions in a virtual forum, outreach to organizations and extensive communication skills. These skills are needed to implement it information sessions women gathering, leadership training activities

The Project Director provides the team with ongoing support to continually improve how the project is implemented.

PRACTICE TIMELINE

Empowering Women activity timeline:

- Leadership training following up meeting take place in the fall.
- Information Session topics schedule and conducted monthly in English in the Spanish (topics include, FAS/FASD, Lead poisoning prevention, Stress Management, Self-Care, Dental-care and Women to name a few)
- New cohort of women to take the Leadership training will take place in the winter between February and March
- Empower Women Two-day Summit will take place in June

For more information on this practice’s timeline and specific practice activities, please contact Nicole Pratt directly at npratt@spanadvocacy.org.
PRACTICE COST

For more information on practice startup costs and budgets, please contact Nicole Pratt directly at npratt@spanadvocacy.org.

LESSONS LEARNED

We learned, especially during Covid-19, that women feel isolated and have increased stress, and are looking for professional mental health support as well as social-emotional support. Women want to continue to connect virtually and expand their network to connect with diverse women to share resources and information. Women are interested in learning and participating in organic ways to de-stress that can be integrated into their everyday lives for themselves and their families. As a result of what we learned, we have incorporated social/emotional support including opportunities to participate in mindfulness activities.

We also learned that women who have children in school and with special health care needs, want to be connect to learn more about variety of community resources that we can help connect them to. We will have monthly gatherings in English and Spanish that project staff will facilitate. We understand that to gain more knowledge about what additional support women need will develop a survey with the assistance of the project evaluator. The survey topics of the survey will be focused on self-care needs of women and their families. We will survey women who have taken the leadership training and women who attend our monthly information session that will be on specific topic.

NEXT STEPS

Plans to continue the Empowering Women project is continuing to collaborate with organizations, look for funding opportunities and continue to look at ways we can improve /providing information to women to be leaders in their community. The Empowering Project is in its third year of the current grant we have from The (OPDD) Office of the Prevention of Development Disabilities/NJ Department of Human Services we are looking forward to the next RFP the OPDD will be putting out sometime in the spring to write a new grant proposal to continue our work with women and their families.

RESOURCES PROVIDED

- N/A.
APPENDIX

- Logic Model

Empowering Women in Community Leadership for Healthier Families Logic Model

Goal: To lower the incidence of Fetal Alcohol Syndrome (FAS), Fetal Alcohol Spectrum Disorders (FASD), and lead poisoning in New Jersey by building community capacity to enhance engagement and leadership opportunities among women of childbearing age for the prevention of FAS/FASD and lead poisoning.

**Inputs**
- Conduct focus groups
- Prepare training curricula
- Train Family Resource Specialists (FRSs) to train women to be leaders and advocates in preventing FAS/FASD and lead poisoning prevention.
- Existing community partnerships

**Activities**
- Number of focus group participants
- Type of focus groups held (target: 1 English, 1 Spanish)
- Training presentation slide decks and supporting materials
- Number of FRSs trained and number of women trained by trained FRSs.
- Number of women who participate in peer support groups
- Number of mini summits held, number of attendees, topics addressed.

**Outputs**
- Increased knowledge and skills in program key content areas:
  - FRSs
  - FAS/FASD - Risks of alcohol use
  - Lead poisoning prevention
  - Social Determinants of Health
  - Health Equity
  - Leadership skills
  - Advocacy skills

**Short-Term Outcomes**
- Women in Target Communities - FAS/FASD
- Risks of alcohol use
- Lead poisoning prevention
- Social Determinants of Health
- Health Equity
- Leadership skills
- Advocacy skills

**Mid-Term Outcomes**
- Participating women increase healthy behaviors to prevent FAS/FASD and lead poisoning.
- Participating women engage in local and/or state leadership and advocacy efforts related to FAS/FASD prevention and lead poisoning prevention.

**Long-Term Outcomes**
- Women abstain from alcohol use before and during current and future pregnancies.
- Lower incidence of infants born with FAS/FASD.
- Lower incidence of lead poisoning.

Note: The long-term outcomes will not be evaluated in the current project but are included in the logic model for completeness.