Sample Narrative - Congenital Syphilis: Working Together to Mend Systems Gaps

Wicked Problem

Nothing is as heart breaking as delivering a stillborn infant. The biggest culprit in this rise of stillbirths in our community is the rise in maternal syphilis cases. Mother-to-child transmission of syphilis occurs when a mother with syphilis does not receive adequate treatment for her infection while pregnant. Congenital syphilis (CS) leads to a number of negative birth outcomes, including causing serious illness in the baby, miscarriage, stillbirth, or early infant death. [1]

Unfortunately, the rise in syphilis cases is not unique to my community and is now recognized as a national problem. Since 2012, the national CS rate increased from 8.4 to 11.6 cases per 100,000 live births, reflecting an increase in the rate of syphilis among women at that same time.[1] In my state the rate is even higher, with 19.4 cases per 100,000 persons.[2] This is disproportionately impacting communities of color, with a national CS rate of 33.1 cases per 100,000 among black live births, a rate 12.3 times the rate among whites.[3] In addition to CS disproportionately impacting the black community, on a small scale in my practice, I see the rise in CS cases among women living in poverty and women living in unstable housing situations.

Congenital syphilis is completely preventable; however, adequate screening and diagnosis have to occur in order to treat the syphilis infection in a timely manner. Often in the stillbirths we see, we have never met the mother prior to delivery and they have had limited access to prenatal care. This is being seen on the national level as well. [1] Women most at risk for mother-to-child syphilis transmission are women who have not had access to prenatal care for a variety of complex reasons. Another major risk factor for CS is when a mother contracts syphilis during her pregnancy. Mothers at high-risk of contracting syphilis should be screened at multiple points during their pregnancies to ensure they receive adequate treatment prior to delivery.

Our system does a great job of treating mothers if they are engaged in care. The biggest challenge for us, however, is being unable to tackle the many factors preventing mothers from getting adequate prenatal care to prevent this tragedy from occurring in the first place. Transportation to health care services, poverty and the competing demands of subsistence needs, unsafe neighborhoods, unstable housing, and a variety of other social determinants of health are impacting the mothers and their families. These cases are just the tip of the iceberg, and the experiences of mothers indicate a missed opportunity for prevention and demonstrate larger systemic gaps in our community that need to be addressed for women of reproductive age, specifically for minority women and women living in disadvantaged communities.

Proposed Project

Addressing these large, systemic gaps in our community is not the job of the health system alone. Our proposed project will gather interdisciplinary teams to tackle these systems gaps and work to prevent the wicked problem of congenital syphilis. The project will use a modified version of the Fetal and Infant Mortality Review (FIMR)

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[1] Bowen, V., Su, J., Torrone, E., Kidd, S., & Weinstock, H. (2015). Increase in Incidence of Congenital Syphilis—United States, 2012-2014. *Morbidity and Mortality Weekly Report, 64(44),* 1241-1245.
[2] Texas Department of State Health Services HIV/STD Program. (2015). Congenital Syphilis in Texas. Retrieved from www.dshs.state.tx.us/hivstd on December 20, 2015.
[3] Centers for Disease Control and Prevention. (2016). Health disparities in HIV/AIDS, Viral Hepatitis, STDS, and TB. Retrieved from http://www.cdc.gov/nchhstp/healthdisparities/africanamericans.html on February 1, 2016.

methodology[4] (an evidence-based process identifying systemic gaps contributing to infant mortality[5]) to identify and address systemic gaps in our community that are contributing to cases of congenital syphilis. This case review and community action methodology includes four phases:

1. **Data gathering**: congenital syphilis cases are identified, information from the mother and baby is abstracted from medical records, and maternal interviews are conducted to hear the unique perspective of the mother—a critical component of the methodology, giving first-hand account of the mother's perspective, something not found in the medical records
2. **Case review**: an interdisciplinary case review team (CRT) is convened to examine the de-identified case review information. This team identifies systems gaps occurring across the reviewed cases. The CRT then makes recommendations for changes based on these systemic gaps and gives the recommendations to the community action team
3. **Community action**: an interdisciplinary community action team (CAT) is convened to tackle the suggested recommendations and propose changes within community systems
4. **Changes in community systems**: the CAT makes changes within community systems to address systemic gaps, improving systems of care for women of reproductive age and preventing future cases of congenital syphilis

This methodology is a continuous quality improvement process. Once cases are reviewed and actions are taken, future cases will reveal if the community changes that have occurred are working, or if additional changes need to take place to address a particular issue. This project will provide a place for our community to come together to examine and improve services and systems of care for women who are most at-risk for poor birth outcomes, something that does not exist in our community currently and is sorely needed.

Planned Approach

There are three core team members for our project: Wilma Anderson, MD, Lisa Simpson, PhD, RN, Maria Smith, MSW, and Albert Reyes, PharmD. One of the first steps in the project will be to obtain IRB approval within my hospital care system. Our hospital will be targeted first for case reviews, as we have the largest number of births to mothers with syphilis in the area. Dr. Anderson will be identifying cases for review, using the FIMR/HIV priority assessment for CS.[6] Simultaneously, Ms. Smith will be working with members of her team to train the on maternal interview, including Dr. Simpson and Mr. Reyes (training materials for both are available online www.fimr.org or www.fimrhiv.org).

Once IRB approval is obtained and cases are identified for review, Dr. Simpson will use data abstraction forms to collect information from the medical records of the mother and baby. Ms. Smith will be contacting identified mothers and conducting maternal interviews. The information from the data abstraction and maternal interview processes will be de-identified and compiled by Dr. Simpson and Ms. Smith to be presented at the case review team (CRT) meeting.[7]

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[4] FIMR/HIV Prevention Methodology: www.fimrhiv.org

[5] Msira, D., Grason, H., Strobina, D., McDonnel, K. & Allson, A. (2004). The nationwide evaluation of Fetal and Infant Mortality Review (FIMR) programs: Development and implementation of recommendations and conduct of essential maternal and child health services by FIMR programs. *Maternal and Child Health Journal, 8, 4,* 217-229.

[6] http://www.fimrhiv.org/elearning.php

[7] Detailed information about the data gathering process and HIPAA/legal issues related to the data abstraction and maternal interview process can be found in the FIMR/HIV Prevention Methodology Manual of Operations: www.fimrhiv.org

The CRT (see list of team on page X) will then be convened to examine the de-identified cases. Dr. Anderson will be responsible for leading the CRT meetings. During these meetings we will review cases to identify systemic gaps in the community. The CRT is a group of providers from our community representing various health and social service sectors that interface with mothers and families. Because of the interdisciplinary nature of the team, issues can be identified from a wide variety of perspectives. During the first year of the project it is anticipated that two CRT meetings will be held, then held quarterly.

Once recurring issues are identified, the CRT will make recommendations for systemic changes. These recommendations are then taken to the community action team (CAT). The CAT is comprised of a group of "movers and shakers" in our community that can make change happen (see list of team on page 5). We have identified a few members of our CAT and will be expanding this list as we identify some of the systemic changes that need to occur. For example, Mr. Reyes is community pharmacist and in a leadership role of the regional pharmacist association and will offer guidance for engaging pharmacists and patients in syphilis prevention and treatment. The CAT will meet once at the end of the first project year and then twice during subsequent years. Dr. Anderson will be responsible for facilitating the CAT meetings and working with health department staff to follow-up with team members and ensure work is moving forward. A portion of the requested funds will be used to implement CAT changes based on CRT recommendations. For example, developing and implementing a training for home visitors about CS.

The issues and actions that take place in our community will no doubt have implications for similar communities across the country. At the end of the project, our team will submit abstracts to present the findings and actions of at our state public health conference and at other clinical care conferences in our area.

Anticipated Outcomes

Below you will find a chart of anticipated immediate, intermediate, and long-term outcomes of this project, including outcome measures and the tools that will be used to obtain the outcome measures. These outcomes are based on findings of the FIMR/HIV project.[8]

Immediate Outcomes	**Measures**	**Tools**
Identified new stakeholders	Self-report from team members	Annual survey with CRT and CAT members
Development of non-traditional partnerships	Number/type of actions taken by CAT	Annual report
Women linked to care through maternal interviews	Number of women seen in my clinic obtaining prenatal care	Electronic health record
Intermediate Outcomes	**Measures**	**Tools**
Engaged stakeholders	Self-report from team members	Annual survey with CRT and CAT members

[8] Thompson, J. Johnson, R., Lampe, M., Fitz Harris, L., et al. (2015). A Generation Free of HIV: Improving communities through a case-review, community-action approach to perinatal HIV prevention. Presented Dec. 8, 2015 at the National HIV Prevention Conference.

Enhanced understanding of CS and maternal and child health (MCH) service systems	Self-report from team members	Annual survey with CRT and CAT members
Identification of syphilis testing issues during pregnancy	Number/type of actions taken by CAT	Annual report
Improved communication between STD and MCH systems of care	Self-report from team members	Annual survey with CRT and CAT members
Long-Term Outcomes	**Measures**	**Tools**
Increased rates of syphilis testing during first and repeat testing during the third trimester	Number of syphilis tests being conducted within my health system	Electronic health record
Decrease in the number of women of reproductive age with syphilis	Number of women of reproductive age with syphilis	Health department surveillance data
Increased rates of early engagement in prenatal care	Number of women seen in my clinic obtaining prenatal care	Electronic health record
Reduction in the number of CS cases	Number of CS syphilis cases	Health department surveillance data

Evaluation Plan

Evaluation will occur throughout the duration of the project. At the first CRT and CAT meetings, meeting attendees will take a survey indicating their level of knowledge about syphilis, CS, service systems in the community, and their feelings around their level of engagement with the group. This will serve as baseline data for the immediate and intermediate outcomes (see above). Annually, the CRT and CAT members will take this survey to measure new partnerships, knowledge gained, and level of engagement. A number of process outcomes will be captured annually, including:

- Number of cases identified for review
- Number of data abstractions completed
- Number of maternal interviews completed
- Number of CRT & CAT meetings held/attendance at CRT & CAT meetings
- Number of CAT meetings held/attendance at CAT meetings
- Number of issues identified/number of recommended changes
- Number of actions taken by CAT
- Number of women seen in my clinic obtaining prenatal care
- Number of syphilis tests being completed

Process outcome information will be included in an annual report that will be presented to the CRT and CAT members. In addition, this information will be examined quarterly for continuous quality improvement. If, for instance, attendance in CRT meetings has declined, corrective actions will take place to ensure people are able to participate. Midcourse adjustments will ensure that the project is meeting the needs of the participants and the community.

Health department surveillance data will be provided by the health department to examine the long-term outcomes of the project. This information will be included in the annual report.

Case Review Team		
Name	**Organization**	**Role**
Carol Jones, MD	County Hospital	Emergency Room Director
Allison Provo, MPH	County Health Department	Home Visiting Program Lead
Marcel Pruitt	County Health Department	STD Project Director
Maria Justice, MPH	State Health Department	Syphilis Prevention Coordinator
Denise O'Neill, MSW	Department of Children and Family Services	Social Worker
Chad Lincoln, MSW	Mental Health Clinic	Substance Abuse Counselor
Jo Pueblo	Org Y Homeless Shelter/Women's Center	Homeless Outreach Specialist
Jessica Johnson, MD	Big Major City Health System	Infectious Disease Medicine
Community Action Team		
Name	**Organization**	**Role**
Regan Thompson, MPH	County Health Department	STD/HIV Program Director
Albert Reyes, PharmD	County Hospital	Hospital Pharmacy Director
Maureen Larson, MPH	County Health Department	MCH Director
Janet Sesame, MSW	Department of Children and Family Services	Division Manager
Monica Sutton, PhD	Mental Health Clinic	Clinical Director
Jo Pueblo	Org Y Homeless Shelter/Women's Center	Homeless Outreach Specialist
Theresa Robinson	none	Consumer

Sample Budget Narrative (Note: Budget Narrative is submitted separately from project narrative)
Project Title: Congenital Syphilis: Working Together to Mend Systems Gaps
Application ID: XXXXX
Applicant Organization Name: X County Hospital

Dr. Wilma Anderson

Salary		**Year 1**	**Year 2**	**Year 3**
Effort	8%			
Annual Salary	$303,131			
Amount Requested	$98,192			
Fringe Benefits	$7,518			
TOTAL		**$31,768**	**$32,721**	**$33,703**

Salary: *Dr. Wilma Anderson, X County Hospital*. Dr. Anderson is an obstetrician/gynecologist. As project co-lead, she will participate in the Clinical Scholars program and attending trainings, be responsible for identifying cases, leading case review and community action team meetings, identifying systemic gaps and developing and implementing recommendations for change. Dr. Anderson's salary will cover participation case identification, leading case review and community action team meetings, identifying systemic gaps and developing and implementing recommendations for change.

Lisa Simpson, PhD, RN

Salary		**Year 1**	**Year 2**	**Year 3**
Effort	20%			
Annual Salary	$108,000			
Amount Requested	$76,778			
Fringe Benefits	$3240			
Total		**$24,840**	**$25,585**	**$26,353**

Salary: *Lisa Simpson, PhD, RN, County Health Department*. Dr. Anderson is the home visitation program manager. She will participate in the Clinical Scholars program and attend trainings, be responsible for data abstraction (12-15 cases/year), coordinating and planning case review and community action meetings, inviting CRT and CAT members, compiling case review data for team meetings, participating in meetings and implementing changes in the home visitation program.

Maria Smith, MSW

Salary		**Year 1**	**Year 2**	**Year 3**
Effort	15%			

Annual Salary	$140000			
Amount Requested	$74,645			
Fringe Benefits	$3,150			
Total		$24,150	$24,875	$25,621

Salary: *Maria Smith, MSW, Mental Health Clinic.* Ms. Smith is a social worker. She will participate in the Clinical Scholars program and attending trainings, be responsible for maternal interviewing (12-15 mothers/year), including finding contact information for the mothers, conducting the interview, researching and providing referrals to resources for the mothers, compiling interview information at team meetings, participating in team meetings and implementing changes within the mental health clinic when applicable

Albert Reyes, PharmD

Salary		**Year 1**	**Year 2**	**Year 3**
Effort	15%			
Annual Salary	$135,6040			
Amount Requested	$72,301			
Fringe Benefits	$,3051			
Total (salary increase of 3% factored into budget)		**$23,392**	**$24,093**	**$24,816**

Salary: *Albert Reyes, PharmD, X County Hospital.* Mr. Reyes is a pharmacist and chair of the regional pharmacy association. He will participate in the CRT and CAT and propose protocols and training for pharmacists in community and hospital settings to advise and signpost patients to sexual health services.

Marcel Pruitt

Salary		**Year 1**	**Year 2**	**Year 3**
Effort	30%			
Annual Salary	$50,000			
Amount Requested	$53,318			
Fringe Benefits	$2,250			
Total		**$17,250**	**$17,768**	**$18,301**

Salary: *Marcel Pruitt, X County Hospital.* Mr. Pruitt is the STD director and will be responsible for compiling data reports and providing updates to the CRT and CAT.

Nonpersonnel

Office Operations				
Communications and Marketing		$3500	$3500	$3500
Travel		$1700	$1700	$1700
Meeting Expenses		$16,202	$16,202	$16,202
Polls and Surveys		$1125	$1125	$1125
Equipment		$200		
Other				
Community Action Team Efforts		$10,140	$10,140	$10,140
Indirect Costs*	The Community Health Center will waive directs and accept the Foundation's Admin Fee	4000	4000	4000

Office Operations: Salesforce software modification will facilitate tracking for this project ($500 annually).

Communications and Marketing: Funds will be used to establish the CRT and CAT and develop training materials, protocols, and resources to increase awareness and action to prevent CS. An example of a product resulting from a case review team finding is the development and distribution of a resource guide for women living in homeless shelters. ($1500 annually).

Travel: Staff travel to extract data is estimated at 10 trips x $50 = $500; 15 trips for maternal interviews x $50 = $750; Conference travel for 1 team member $2250. ($3500 annually).

Meeting Expenses: Funds will be used to implement changes identified by the Case Review Team. An example of a large product resulting from a case review team finding is developing and conducting a training for all nurse case managers, pharmacists, community agencies about CS. Another example of an action resulting from a case review team finding is developing outreach efforts to integrate mental health referral services into STD clinics. Funds will be applied to the development of resources, providing space and catering for the training, and providing compensation to the trainers. These changes may include policy or programmatic changes at the community, institutional, or state levels. 16 Meetings x $200 = $2,900 in Yr 1; 8 meetings in Yr 2; 7 meetings in Yr 3; Conference registration $1400 for 1 team member Yr 1. ($5,500 Yr1; $2200 Yr2; $2000 Yr 3).

Polls and Surveys: Funds will be used to cover transportation of Ms. Smith and the mothers to maternal interviews, a digital recorder to capture the interviews, $75 gift card incentives for the participating mothers, and the development and publication of a resource guide for women who are participating in the maternal interviews. (15 interviews x $75 =$1125 annually)

Equipment: Digital Recorder to conduct interviews ($200 Yr 1)

Contract Budget and Fact Chart

Contractor Name	County Health Department
Scope of Work	Team member – Lisa Simpson
Deliverables	Team member – Lisa Simpson
Total Cost	$76,778
Cost Calculation	Team member – Lisa Simpson

Contract Budget and Fact Chart

Contractor Name	Mental Health Clinic
Scope of Work	Team member – Marla Smith
Deliverables	Team member – Marla Smith
Total Cost	$74,645
Cost Calculation	Team member – Marla Smith

Contract Budget and Fact Chart

Contractor Name	Org Y Homeless Shelter/Women's Center
Scope of Work	Personnel and Fringe: $4000 is budgeted for Jo Pueblo to participate in the development and implementation of the project and offer insights. Meeting Expenses: 5 focus groups will be hosted at community organizations and provide a meal x 200 =$1000 Participant incentives: participants incentives budgeted for 20 participants x $100 =$2000 Honoraria for mother's experiencing CS: budgeted $1000 x 2 community experts = $2000
Deliverables	• Co-develop training materials for community education about CS • Participate in regular meetings • Recruit for and assist with focus groups • Assist with focus group interpretation and provide strategic advice on the partnership • Distribute and track participant incentives

Total Cost	$9000
Cost Justification	Org Y Homeless Shelter/Women's Center will serve as the contractor with the project. We will leverage existing partnerships to accomplish the aims of the project.