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**Mississippi State Department of Health
Bureau of Genetic Services
Mississippi Birth Defects Surveillance
Registry**

**Final Evaluation Report for Surveillance, Intervention and
Referral to services and activities for infants with microcephaly
or other adverse outcomes linked with the Zika virus**



**CDC-RFA-DD16-1605
National Center on Birth Defects
and Developmental Disabilities**

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EXECUTIVE SUMMARY

The Mississippi Birth Defects Surveillance Registry (MSBDSR) was implemented on January 1, 2000 as a result of Mississippi's high infant mortality rate. The objectives of the MSBDSR are to monitor the births of children with defects for changes in incidence or other usual patterns suggesting preventable causes and ensure that children identified with birth defects have access to a system of care. The primary source of data for the MSBDSR is hospital discharge data. Since its implementation, the Mississippi State Department of Health's (MSDH) Office of Child and Adolescent Health Services, has used this registry to identify and target areas in the state to promote education and prevention among women of reproductive age and make referrals to services. The goal of this CDC funding opportunity (RFA-DD16-1605) was to allow for the expansion of data sources and to improve quality and timeliness of birth defects data potentially linked to Zika virus.

Project activities strongly support project period outcomes originally identified in the work plan. The process for identification of Zika related cases has been established to promote reporting efficiency throughout the state. This process has strongly enhanced active case surveillance. In addition, the process has led to increased collaboration with intra-agency departments and external partners. Such collaboration improves coordination of care for children with special health care needs. Analysis of data and information from the MSBDSR has provided an opportunity to disseminate information that further describes the risks associated with Zika in regions of the state with populations that have increased risk for exposure.

PROGRAM DESCRIPTION

The Office of Health Services strives to improve health care services for women, infants, children, and adolescents. One of its goals is to increase efficiency and utilization of available services, while enhancing knowledge and skills of both consumers and providers of health care. The Office of Health Services has seven departments which include: Women's Health, Child and Adolescent Health, The Special Supplemental Nutrition Program for Women, Infants and Children (WIC), Oral Health, Health Data and Research, Preventive Health and Tobacco Control.

The MSDH Birth Defects Surveillance Registry Program is housed in the Office of Child and Adolescent Health under the Bureau of Genetic Services. Section 41-21-205 of the Mississippi Code of 1972 authorized the Mississippi State Board of Health to establish a Newborn Screening and Birth Defects Surveillance Registry within the State Department of Health. MSDH was authorized to adopt rules and regulations to govern the operation of the program.

As it relates to this funding opportunity, the MSBDSR has enhanced its existing population-based surveillance system to rapidly identify cases of microcephaly and other central nervous system defects potentially linked to Zika virus from all pregnancy outcomes in the state. Data sources were expanded to include programs that serve young children, such as specialty clinics. These sources also include laboratory reports of any pregnancy with positive or inconclusive Zika virus test results. Through this cross system coordination, opportunities to serve children, avoid duplication of services, reduce fragmented services and identify area of specialization for each individual child identified through the data used (surveillance) can be more easily recognized. In addition, an expedited referral process that connect infants and their families to services that improve quality of early life has been created.

MSBDSR has also enhanced features for tracking children identified with Zika related birth defects and support services provided and offered. Through data integration on short-term and long-term follow-up, and centralized, uniform reporting of confirmed Zika related birth defects more complete surveillance has been achieved. Hospitals and vital records report data to the MSBDSR Nurse Coordinator and these cases are then scheduled for abstraction. The nurse coordinator then makes referrals to child health programs and collaborates with these programs to ensure continuation of care coordination for children with birth defects that are possibly related to congenital Zika syndrome. This lends itself to a far-reaching impact which includes improvements in the quality of care by addressing health disparities through the care provided.

Trainings to enhance capacity for public health nurses and social workers to conduct case findings across the state have been completed. This supports competency in rapid identification of cases, referral of services, and the development of a sustainable system for monitoring and evaluation. Baseline data captured on the number of referrals made and the number of children receiving PHRM/ISS and Early Intervention services has allowed for contacts to be made with primary care providers and for the sharing of information on available services to families through care coordination efforts by Child Health Programs – Newborn Screening, Early Intervention Services, and Children and Youth with Special Health Care Needs (CYSHCN), (Title V) Block Grant.

Culturally tailored public health awareness messages and materials have also been developed and shared through outreach in coordination with the MSDH Division of Cultural and Linguistic Services in an effort to impact positive behavior practices. Messages have focused upon travel to high risk areas, safe sex or abstaining from sex, and protecting one's self and family from mosquitoes by staying indoors and using repellent with DEET (diethyltoluamide) while outside. The program worked with a bilingual interpreter for high risk Hispanic populations to ensure that trainings, messages, materials and services were culturally and linguistically appropriate for the state's population. The enhanced surveillance activities have had an overall impact of creating new knowledge about birth defects in the state.

EVALUATION METHODOLOGY

MSBDSR utilized the CDC's framework for program evaluation in public health for evaluation of all program activities. This framework was applied to the evaluation processes used to achieve objectives. It incorporated six steps from engaging stakeholders to ensuring use of evaluation results to sharing lessons learned with stakeholders. The Mississippi Public Health Institute assisted with development of the overall evaluation plan for the registry and provided external evaluation for all activities. Such evaluation was conducted throughout the funding period according to the developed plan. Evaluation focused upon three major categories of the grant project as described by CDC. These categories included (1) Surveillance, (2) Intervention and (3) Referral to Services. The overall evaluation plan allowed the external evaluator to answer a series of evaluation questions specific to each category through the use of a data collection tool and set indicators. These questions include:

Surveillance

- What strategies have been implemented to provide a means of continuous evaluation throughout the state program?
- Is program data being used effectively and shared with stakeholders for further program development and implementation?
- Has an active case surveillance plan been developed and implemented using NBDPN surveillance guidelines for select birth defects?
- Has the active case surveillance system improved information exchange through the use of EHR technology?
- Has data collection and reporting of microcephaly and CNS defects linked to Zika virus of pregnant women with positive and inconclusive test results been developed through the coordination of Health Department programs?

Intervention

- How has the Mississippi Bureau of Genetic Services/Birth Defects Surveillance Registry fostered awareness about birth defects among residents of the state?
- How has the Mississippi Bureau of Genetic Services/Birth Defects Surveillance Registry improved the knowledge about birth defects and means for prevention throughout the state?
- How have interagency programs and stakeholders (state organizations) worked collaboratively to leverage resources and address prevention and monitoring within the state?
- Have collaborative strategies been developed among partners as part of the state Zika action plan?
- Have staff nurses and social workers been identified and trained in medical record case abstraction in order to build capacity and infrastructure about active case identification, referral for services and follow-up related to Zika?

Referral to Services

- How have services provided to the state's population integrated the continuum of care (through referral) to those most in need?
- What strategies have been implemented to provide a means of continuous evaluation throughout the state program?
- Is program data being used effectively and shared with stakeholders for further program development and implementation?
- What is the time frame for client linkage to care or referral?

Staff from the Mississippi Bureau of Genetic Services were asked to report data periodically to the external evaluator. Such data was used to determine levels for several indicators that were related to the evaluation questions listed previously. This helped to determine program effectiveness.

FINDINGS

Findings from the formal evaluation process lend to favorable outcomes from this project. Such outcomes are reported according to the three major categories previously outlined.

Surveillance

Several measures have been utilized in order to foster a means of continuous evaluation. To begin, an algorithm for the process of finding Zika related cases was established. The process for rapid notification and data collection as it pertains to MSDH's Office of Child and Adolescent Health Services can be found in **Table 1**.

TABLE 1. RAPID NOTIFICATION AND DATA COLLECTION PROCESS



Using the algorithm, all steps in processes for rapid notification and data collection are followed. In addition, trainings were held to enhance capacity for public health nurses and social workers from across the state who conduct case findings. Trainings were held on May 4, 2017, March 7, 2018, and May 25, 2018. This enhanced competency in rapid identification of cases, referral of services, follow-up and in monitoring and evaluation.

MSBDSR staff has coordinated with other organizations and interagency offices to create family centered access to services and care. This has included other maternal health programs in MSDH, community-based programs and 14 healthcare professionals from around the state who have been trained in rapid notification and data collection during May 2017 and May 2018. A total of 342 referrals have been made to other state programs by the MSBDSR Nurse Coordinator. These referrals have been made based upon National Birth Defects Prevention Network (NBDPN) surveillance guidelines for select birth defects which indicates the effectiveness of active case surveillance throughout the state according to established procedures.

Information exchange through the use of Electronic Health Record (EHR) technology has improved regarding active case surveillance through the established rapid notification process. A total of forty-three data sharing agreements between MSDH and birthing facilities throughout the state have been developed and approved. This has allowed MSDH to coordinate data collection and reporting activities throughout the state. In the future, it is predicted that the program will be able to rapidly identify localized Zika transmission if the need ever arises.

Intervention

It has been determined that MSDH Bureau of Genetic Services has successfully fostered awareness about birth defects related to Zika among residents of the state. This was evidenced by the fact that seven out of the nine public health districts in the state accepted funding to provide outreach at the local level. This fostered an increase in knowledge and promoted prevention throughout Mississippi. Schools and community organizations also assisted with outreach activities to promote prevention which led to further collaboration. Such organizations were recruited for participation in activities by the MBDSR Coordinator. Contacts with these organizations have been maintained in order to enhance continued collaboration. Distribution of educational materials were tracked and it was found that 61,000 materials, which included coloring books, Zika kits and fact sheets, were handed out to residents of the state. In addition, culturally and linguistically appropriate materials were disseminated throughout the state to Hispanic populations through a system of interpreters. A total of 23 different educational materials were developed in Spanish to serve this portion of the population. This allowed for education of those who may have increased opportunities for international travel.

Zika awareness training was held for Community Health Directors and Community Educators in an effort to enhance outreach throughout the state. The level of awareness and knowledge during community outreach events was assessed by Community Health Directors and Educators through the use of the Zika Awareness Questionnaire. Data was collected from 151 participants. Analysis of data using the Qualtrics software system revealed significant improvements in three knowledge categories. This included contraction of Zika, mode of transmission, and best products to use when traveling to a location where the Zika virus has been located. These findings suggest increased awareness related to Zika prevention.

Referral to Services

The established process for rapid notification and data collection allows for integration of the continuum of care to those most in need through referral. The MSBDSR Coordinating Nurse identifies Zika related birth defects through medical record abstraction after cases are reported to MSDH by healthcare providers. Medical records are then reviewed to ensure that case criteria is met. Patients are then linked to services based upon need and availability of services near the mother's residence. The established time frame for client linkage to care is dependent upon individual program requirements of the services that are needed.

Finally, MSDH Bureau of Genetic Services has collaborated with other departments within the health department and around the state to support the efforts of the MS Birth Defects Surveillance Registry. A total of 175 projects and activities have been completed in collaboration with program stakeholders and partners. This has led to the development of a centralized database system that will allow more efficient access to both pregnancy and birth defects data. Such collaboration has also allowed for leveraging of resources that will continue to enhance overall reporting and provision of updates to the registry as needed for years to come. Also, a centralized database provides a more efficient means of continuous evaluation since the process for data input and access to that data will be maintained at MSDH.

Overall evaluation findings relate to program success since awareness of Zika virus and prevention has been improved throughout the state. In addition, identification of cases and data reporting procedures have become more efficient for healthcare providers. This also lends to success of the program and supports sustainability for the future.

Acknowledgments

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