

ID: 34284388

Birth Defects and NAS - Host Site Description

Massachusetts Department of Public Health

Assignment Location: Boston, US-MA
Massachusetts Department of Public Health
Center for Birth Defects Research and Prevention

Primary Mentor: Mahsa Yazdy, BS, MPH, PhD
Director
Massachusetts Department of Public Health

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CDC Maternal and Child Health Epidemiology Assignee
Massachusetts Department of Public Health

Work Environment

Hybrid

Assignment Description

The Division for Surveillance, Research, and Promotion of Perinatal Health (DSRPPH) envisions a Commonwealth where all pregnant people and families are supported toward the best possible health outcomes. To this end, the Division's mission is to conduct surveillance, research, training, and promotion of perinatal health to inform fellow public health professionals, researchers, healthcare providers and the general public about perinatal health outcomes and prepare tomorrow's researchers to carry the Division's work forward. The Division houses multiple surveillance and research efforts: the Birth Defects Monitoring Program (BDMP), Neonatal Abstinence Syndrome (NAS) Surveillance, the Maternal Mortality and Morbidity Review Team, and data from two national case-control studies on birth defects (the National Birth Defects Prevention Study [NBDPS] and the Birth Defects Study To Evaluate Pregnancy exposures [BD-STEPS]). DSRPPH also partners with infectious disease colleagues in the Bureau of Infectious Diseases and Laboratory Sciences for the Surveillance of Emerging Threats to Pregnant People and Babies Network (SET-NET).

The BDMP was established in 1999 and is a statewide, population-based active surveillance program for birth defects among Massachusetts residents. In 2020, the BDMP was expanded to include NAS as a reportable condition. The program uses multiple sources of ascertainment, including delivery and specialty care hospitals, laboratories and pathology departments, and reports of prenatally diagnosed birth defects. Vital records serve as an additional source of information, providing demographic information on cases, and acting as an additional source of case-finding for birth defects and NAS. Potential cases with a birth defect or NAS, identified through these varied sources, are assigned to highly trained medical record abstractors who review maternal and infant medical records. They collect information on diagnostic tests, autopsy reports, and lab results to confirm diagnoses. Relevant demographic, clinical, family history and birth characteristics are also recorded. The BDMP is a rich data source that can be utilized to: 1) monitor the prevalence of birth defects across the state and to better understand the causes of birth defects and 2) provide timely and accurate data on NAS in MA in order to better understand the impact of NAS and have population level data available for DPH programs.

The DSRPPH participated in the NBDPS and currently participates in the BD-STEPS; both of these are case-control studies aimed at understanding the causes of birth defects. BD-STEPS was recently expanded to also focus on understanding risk factors associated with stillbirths without birth defects. Together NBDPS and BD-STEPS are the largest population-based studies on birth defects ever undertaken in the U.S. and include data from over 43,000 telephone interviews. These data are available for etiologic research examining risk factors for birth defects, as well as risk for stillbirths.

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The DSRPPH began working closely with the Bureau of Infectious Diseases and Laboratory Sciences at the time of the Zika Virus epidemic and has continued that collaboration through the CDC's Surveillance for Emerging Threats to Mothers and Babies (SET-NET). As part of SET-NET, the Division led the COVID-19 Pregnancy Surveillance and assessed the impact of COVID-19 on pregnant people and their infants. The Fellow will have the opportunity to participate in the SET-NET efforts, as well as on collaborative projects related to pregnancy and infectious diseases.

In addition to data within the DSRPPH, data outside the Division are available for analyses and include: birth certificates, fetal death certificates, infant and maternal death certificates, the Pregnancy to Early Life Longitudinal (PELL) data system, and data through such programs as the Massachusetts Home Visiting Initiative and Early Intervention. The Fellow will also have the opportunity to collaborate with staff and students from the MA DPH, local universities including Harvard University, Boston University, Tufts University, and the University of Massachusetts.

The Fellow will be able to conduct epidemiological studies from a diverse array of data systems and the Division will work with the Fellow to tailor their experience based on their interest and expertise to ensure a fulfilling experience. In addition, the Fellow will have the opportunity to present their work internally as well as externally (e.g., the Birth Defects Monitoring Program External Advisory Committee, national conferences and meetings, local universities) and will be encouraged to publish their work in peer-reviewed journals.

Day-to-day activities will include:

- Literature reviews
- Developing research plans
- Data cleaning and conducting analyses
- Preparing and presenting results of their analyses
- Preparing and leading meetings
- Submitting IRB applications, as needed
- Meeting and providing updates to mentors and collaborators
- Working with Service Programs and Initiatives to use the Division's data to inform their work
- Writing, submitting, and reviewing manuscripts
- Presenting to internal and external collaborators
- Participating in meetings, trainings and webinars
- Joining one of the Division's quality improvement team projects
- Becoming familiar with the BDMP from reporting to ascertainment to case confirmation

Describe Statistical and Data Analysis Support, Such as Databases, Software, and Surveillance Systems Available to the Fellow

The Birth Defects Monitoring Program (BDMP) data are currently stored in an Access database and the Fellow will have the opportunity to learn to access, query, and retrieve data from the system. The system is being upgraded to an Oracle database and the Fellow will have the opportunity to participate in trainings on how to utilize this state-of-the-art data system; once the transition is complete, the Fellow will be able to actively put the training to use and query and retrieve data from the new system. Many of the epidemiologists in the DSRPPH have been trained in utilizing Tableau to create data visualizations and are available to provide instructions and support for the Fellow; additionally, the DSRPPH has a library of Tableau learning resources available for use. The Division uses REDCap databases for both the NAS Surveillance System and SET-NET; therefore, the Fellow will gain familiarity with querying REDCap, pulling data from the systems, as well as modifying the data collections tools, as needed.

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The Division recently migrated the majority of our datasets to SAS Studio, allowing for web-based analyses and data sharing; the Division also maintains desktop SAS as a resource for all analysts. Support using SAS is available both in the DSRPPH, as well as via a Department-wide SAS user group. Additionally, once a month the DSRPPH has research meetings where epidemiologists solicit feedback on their projects and are able to discuss any data issues or programming challenges they have encountered.

Projects

Surveillance Activity Title: Expanding Multisource Ascertainment in the Massachusetts Birth Defects Monitoring Program

Surveillance Activity Description:

The Massachusetts Birth Defects Monitoring Program (BDMP) is an active statewide surveillance system for birth defects. Potential cases of birth defects are ascertained from multiple sources including: birthing and non-birthing hospitals, clinical geneticists and genetic counselors, commercial laboratories, selected outpatient records, emergency departments, pathology departments, and vital records. Medical records for all reported cases are reviewed and if a case meets the inclusion criteria, the data are abstracted by highly-trained abstractors who pursue various sources to confirm the diagnosis of a birth defect and collect relevant demographic, clinical, family history and birth characteristics. The BDMP strives for complete ascertainment of infants and fetuses diagnosed with a birth defect, which is why multisource reporting and ascertainment are essential. As testing and screening improves over time, birth defects are being diagnosed earlier in pregnancy; therefore, the potential for missing cases due to early losses is always a concern. The Division has already identified a potential new source of reporting through hospital laboratories that conduct genetic tests; the Division plans to pilot the incorporation of two hospital laboratories into BDM's reporting sources. The Fellow would support the integration of this reporting source and assess if this source would yield additional cases that would otherwise be missed. Additionally, the Fellow will work with the BDMP staff to assess other potential new sources of ascertainment (e.g., reports from ultrasound clinics, reports from out of the state hospitals). Once an ascertainment source has been identified, the Fellow would lead the integration of that ascertainment source into the BDMP, as well as assess the potential yield of new cases, feasibility, and challenges in integrating the new ascertainment source into the BDMP.

Surveillance Activity Objectives:

Objective:

- The objective of this project is to broaden the ascertainment sources for BDMP to ensure that cases are not being missed, especially those that might have resulted in an early pregnancy loss.

Deliverables:

- Successfully integrating two new ascertainment sources into BDMP.
- Assess if case ascertainment has been improved and if cases were identified that would have otherwise been missed.
- Evaluate if the new sources lead to a reduction of workload of medical record abstractors in reviewing reports of less-specific ICD-10 codes.

Surveillance Activity Impact:

Estimates of the prevalence of birth defects are essential in order to assess any increasing trends (e.g., due to new medications or infections such as SARS-CoV-2), to identify community clusters, or to understand and plan for service utilization; however, any prevalence estimate reflects the sources of the underlying data. If cases are missing from the data, the prevalence estimates will be an underestimate of the true population and may miss important variations. The

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goal of this project is to ensure there is as complete as possible ascertainment of cases, so that those using the data are able to do so reliably.

Surveillance System Evaluation Title: Evaluation of the Massachusetts Fetal Death Certificate

Surveillance System Evaluation Description:

In order to prevent fetal deaths and the devastating impact on families, we need to understand the causes and factors that led to the loss, which means data are needed to monitor these outcomes. The Fellow will do an evaluation of the Massachusetts Fetal Death Certificate to better understand how we can conduct surveillance for fetal deaths in the state. Currently, Massachusetts does not have an active, population-based surveillance system for fetal deaths; the only available source of data on fetal deaths (deaths occurring in utero at >20 weeks gestation or >350 grams) is the fetal death certificate. In addition to assessing if the fetal death certificate is an effective surveillance system for monitoring fetal losses, the Fellow could potentially focus on two areas for the evaluation: 1) evaluating the completeness and accuracy of the cause of death field or 2) evaluating the completeness and accuracy of the autopsy field.

Surveillance System Objectives:

Objective:

- The objective of this project is to assess the accuracy and completeness of the fetal death certificate, as well as to evaluate the effectiveness of the fetal death certificate as a mechanism for surveillance of fetal losses.

Deliverables:

- Assess the completeness of selected variables on the fetal death certificate.
- Develop a report that includes data on fetal deaths, as well as activities and supports available to residents around pregnancy losses.
- Make recommendations for conducting surveillance for fetal deaths in Massachusetts.

Surveillance System Impact:

There is a significant racial and ethnic disparity, with the rate of fetal deaths being more than twice as likely among non-Hispanic Black women and non-Hispanic Native Hawaiian or Other Pacific Islander. In addition, the loss of a baby in utero can have devastating impacts on maternal mental health; studies have found that following a perinatal loss, mothers have significantly higher rates of psychological distress, lower self-esteem, and significantly elevated levels of anxiety and depression. Given little is known about fetal deaths, more data are needed to better understand the causes and guide prevention efforts; therefore, this project would help us identify how best to monitor and collect data on fetal deaths.

Major Project Title: Outcomes among families with a child with neonatal abstinence syndrome (NAS).

Major Project Description:

Studies have found that children with NAS have a higher rate of death, in particular from external causes. Additionally, the 10-year mortality risk among the birthing parent who had a child with NAS has been found to be 10-12 times higher than control populations. The aim of this project is to assess mortality among families affected with NAS. The family unit will be the unit of measure and mortality will be evaluated among the birthing parent, the non-birthing parent, and the infant. In addition, we will explore the ability to link to siblings and assess their outcomes as well. Given that Massachusetts has a Maternal Mortality and Morbidity Review Committee and Child Fatality Review Committees, we will also explore whether we can obtain more detailed cause of death and recommendations that came from reviewing any of the deaths identified in this population.

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Major Project Objectives:

Objective:

- The objective of this project is to better understand outcomes among families with a child with NAS, with a focus on whether these families (either of the parents or the infant) are at increased risk of death.

Deliverables:

- Conduct a literature search on mortality in this population.
- Link the birth certificate data from children who have NAS to the death records. This linkage will be done three times, once using the infant's name to identify infant deaths, a second time using the birthing person's name to identify deaths among birthing parents, and a third time with the non-birthing parent's name to identify deaths among non-birthing parents. If feasible, link the birth certificates of the infant's siblings to the death records.
- Identifying the mortality rate among the birthing parent, the non-birthing parent, and the infant for families affected by neonatal abstinence syndrome in Massachusetts.
- Assessing if there are common themes in the noted cause of deaths.
- Sharing the findings of this project with both internal and external partners.

Major Project Impact:

Often time studies on mortality in this population focus on one individual (e.g., the birthing parent or the infant), this project is unique in that it will consider the entire family unit, including any siblings. This project will help us better understand outcomes among these families and can assist in identifying disparities, potential needs and supports for family members, and provide data that could inform clinical recommendations to improve long-term outcomes of families and their infants with NAS.

Additional Project #1 Title: Immunization Coverage among Children with Birth Defects

Project #1 Type: Major Project

Project #1 Description:

Immunizations are regarded as one of the best public health interventions in preventing illness in young children and have been associated with a marked reduction in morbidity and mortality. Vaccinations are a cost-effective and safe means of decreasing the risk among children of vaccine-preventable infectious diseases and interrupting their transmission and outbreaks in the community. The Advisory Committee on Immunization Practices (ACIP) recommends vaccination of children against 15 infectious diseases during the first 24 months of life. CDC uses National Immunization Survey-Child (NIS-Child) data to monitor routine coverage with ACIP-recommended vaccines among children in the United States. Despite the fact that chronic underlying conditions, including birth defects, may make children more susceptible to vaccine-preventable infections and complications of these infections, little is known about vaccine coverage in children with birth defects. A limited number of reports that have explored vaccination coverage in this population have found lower rates of vaccination among children with Down syndrome or children with congenital heart defects in comparison with children without birth defects. This project will explore immunization coverage among children with birth defects in Massachusetts.

Project #1 Objectives and Expected Deliverables:

The Massachusetts Immunization Information System (MIIS) is a complete, accurate, secure, real-time immunization record for residents of Massachusetts of all ages. The Fellow will facilitate linkage of immunizations records of all children with MA birth certificates and BDMP records for a period of 10 years between 2014 and 2023 and then compare the vaccination coverage between children with a selected number of birth defects and children without a birth defect. They would examine whether the rates of vaccination of children with birth defects differ by vaccine type, by birth defect severity (isolated versus complex versus multiple birth defects) or by sociodemographic characteristics such as maternal age, race/ethnicity, country of birth, education, insurance type, and delivery hospital level. The Fellow

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would have the opportunity to explore changes in vaccination coverage before and during the COVID-19 pandemic to identify the impact of COVID-19 pandemic, due to the disruption of pediatric health services, in immunization coverage among children in MA, especially among children with birth defects.

Project #1 Impact:

Data on vaccination coverage among children with birth defects would be valuable for informing communication messaging to health care providers and emphasizing the importance of routine vaccination among these children. This project will allow us to assess if there are any disparities in vaccine uptake among different groups, the results of which could be utilized by vaccination campaigns to develop targeted interventions to increase vaccine uptake and protect children with birth defects and the communities around them from vaccine-preventable infectious diseases.

Additional Project #2 Title: Descriptive Assessment of the Co-occurrence of Birth Defects and Autism Spectrum Disorder

Project #2 Type: Major Project

Project #2 Description:

Autism spectrum disorder (ASD) is a biologically based neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, and activities. The causal mechanisms underlying ASD are to a large extent not known. However, previous studies suggest that both genetic predisposition and environmental risk factors might play a role. Consideration of co-occurring birth defects with ASD may provide clues to gestational periods or developmental stages in pregnancy that may be important in its etiology. A number of studies have examined the association and while most have found a positive association between birth defects and ASD, the specific classes of birth defects exhibiting overlap with ASD have been inconsistent. In addition, birth defects and ASD have been reported to be associated with multiple risk factors including pregnancy exposures and sociodemographic factors (e.g., alcohol consumption, cigarette smoking, maternal and paternal age). This project will consider whether birth defects identified before one year of age, by class and specific defect where possible, occur more frequently in children later diagnosed with an autism spectrum disorder (ASD) than in children not diagnosed with ASD.

Project #2 Objectives and Expected Deliverables:

Objective:

To assess the co-occurrence of birth defects and ASD, the Fellow will link BDMP data with EI data.

Deliverables:

The EI data will be used to identify children with ASD or other distinct entities based on the World Health Organization ICD-10 such as atypical autism, Asperger's syndrome, other childhood disintegrative disorder, and other pervasive developmental disorder. The Fellow will assess if specific birth defects occur more frequently in children diagnosed with ASD than in children not diagnosed with ASD when considering parental characteristics and other risk factors as covariates. In addition, they will assess temporal trends in the co-occurrence of birth defects and ASD, as well as evaluate whether adjusted prevalence ratios of ASD among children with birth defects versus without birth defects varies by other developmental disabilities including intellectual disabilities.

Project #2 Impact:

The prevalence of ASD has risen to about 1 in 44 children. It affects an estimated 1.5 million American children and is increasing at a rate of 10% each year. Despite being the most common developmental disability in the United States, little is known about the causal mechanisms underlying this complex disorder and there is currently no cure. Understanding the co-occurrence of birth defects and ASD may shed some light on the potential etiologic relationship and advance our understanding of ASD.

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Additionally, the results of this project could improve early diagnosis of ASD and earlier initiation of appropriate developmental services; advise increased surveillance of targeted populations (e.g., children with specific birth defects) by primary care practitioners and EI personnel; enhance the definition of phenotypes that might require special or different testing and interventions and might require additional instruction to EI staff; advance the classification of severity of ASD (a combination of autism and certain birth defect conditions may indicate a level of severity that one diagnosis alone would not imply); and inform EI and other public health programs, policies and practices and ultimately improve health and developmental outcomes for children with ASD.

Please Describe the Fellow’s Anticipated Role in Preparedness and Response Efforts – Include Activities and Time Allocation (Required Competency of Fellowship)

The Fellow will have the opportunity to work within the Bureau of Family Health and Nutrition (which includes the Division of Pregnancy, Infancy and Early Childhood, Division for Children and Youth with Special Health Needs) and the Bureau of Emergency Preparedness to focus on special population groups such as pregnant women and children with special health needs that may require additional assistance beyond what the general population needs in a disaster. In addition, the Fellow will have the opportunity to participate in emergency preparedness exercises or responses (e.g., assisting with the Boston Marathon) or potentially work with the Bureau of Infectious Disease and Laboratory Sciences should there be an emerging issue related to pregnant women and infants.

Please Describe the Fellow’s Anticipated Role in Cluster and Outbreak Investigations – Include Activities and Time Allocation (Required Competency of Fellowship)

The DSRRPH works closely with the Community Health Assessment team within the Bureau of Environmental Health, including convening quarterly meetings between the groups to discuss any potential concerns from the community (e.g., community members, clinicians) around clusters of birth defects. When concerns are brought forth, data from the BDMP are utilized to answer their questions. Additionally, given the close relationship with the Bureau of Infectious Diseases and Laboratory Sciences, previous Fellows have joined investigations conducted in the Bureau with topics ranging from foodborne outbreaks to outbreaks of COVID-19 vaccine breakthrough infections.

Please Describe the Fellow’s Anticipated Role in the COVID-19 Response – Include Activities and Time Allocation

The Division led the COVID-19 Pregnancy Surveillance program; as part of this work data linkages were conducted between vital records (e.g., birth certificates, fetal death certificates) and the infectious disease database to identify people infected with COVID-19 during their pregnancy. A sub-set of cases were randomly selected for medical record abstraction of prenatal and delivery records, as well as following the infant for 6 months post-delivery. The Fellow would be able to use this data source for analytic projects to better understand the impact of COVID-19 on pregnant people and infants.

Please Describe Opportunities for Fellows to Work in Health Equity as well as Incorporating Diversity, Equity, and Inclusion into their Work

The Bureau of Family Health and Nutrition (BFHN) is undertaking a Racial Equity Initiative with the following two goals:

1. Eliminate structural racism in all BFHN policies, programs, and practices to promote health equity and racial justice; and
2. Foster a healthy and equitable work environment in BFHN, where staff feel confident and supported to interact and communicate openly and respectfully.

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The Fellow will have an opportunity to participate in this important endeavor and assist with data collection, analysis, and interpretation. Additionally, they will be invited to join the Racial Equity Strategic Pathway Implementation Team, which support staff and programs to use data to inform racial equity work, as well as the Cross Department Racial Equity Collaborative Coordination Committee which supports the Racial Equity Movement across the Department. Additionally, the Department of Public Health offers monthly Racial Justice Lunch and Learns, monthly Racial Equity Townhalls, affinity groups, two-day racial equity trainings, and racial justice learning labs - all of which the Fellow will be encouraged to participate in to help broaden their own understanding of racial equity in the context of public health and support the infusion of equity into their work.