

# Integrating Birth Defects Surveillance in Maternal and Child Health at the State Level

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## ROLE OF DATA IN MATERNAL AND CHILD HEALTH

Maternal and child health (MCH) programs across the country rely on data to carry out the three core functions or 10 essential services of public health. Funded by Title V of the Social Security Act, state MCH programs serve as the point of accountability for all women of reproductive age, infants, children, youth, and their families. The goal of MCH programs is to build community-based, family-centered systems of care that promote the health and well-being of all women, children, and families (Hayes and Walker, '97). MCH directors, including those responsible for children with special health care needs (CSHCN), must have adequate data and information systems in place in order for them to do their jobs well.

State MCH programs need population-based community-level data in order to conduct local and state needs assessments; to monitor state- and local-mandated programs, services, and screenings; to direct program planning and management; to conduct program and service evaluations; and to ensure that people identified through screening receive appropriate follow-up services.

A data system capable of generating information to meet these objectives must use standard definitions, be comprehensive in scope, be accessible via the internet or other information highways in the future, be updated regularly with the most current year's data, protect individual confidentiality, and be available for

a range of population groupings, such as by census tract, zip code, city, county, or region (Walker, '95). The categories of data desired by MCH programs include health status indicators (e.g., measures of mortality and morbidity such as infant mortality and children with developmental delay), behavioral risk indicators (e.g., measures of adolescent risk behaviors such as smoking and drinking), sociodemographic indicators (e.g., measures of parental education levels or incomes), environmental measures (e.g., measures of crowding in housing and levels of air pollution), and service access and utilization indicators (e.g., measures of children who are uninsured or who do not have a regular primary health care provider) (Walker, '95).

Many sources of data are needed to carry out core public health functions and provide essential public health services for mothers and children. Potential population-based data sources include vital statistics (e.g., birth and death records), surveys (e.g., school-based Youth Risk Behavior Survey, Pregnancy Risk Assessment Monitoring System), surveillance systems and disease registries (e.g., birth defects registries, cancer registries) and program or service management information systems (e.g., hospital

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discharge or special education reports).

The Association of Maternal and Child Health Programs (AMCHP), which represents MCH and CSHCN directors in each state, is working with its federal partners in the Maternal and Child Health Bureau in the Health Resources and Services Administration, as well as those in the Division of Reproductive Health and other MCH programs throughout the Centers for Disease Control and Prevention (CDC), to build information and data analysis capacity for all state MCH programs. AMCHP has an active network of state MCH data contacts who are working to ensure that each state has adequate surveillance systems and the expertise needed to collect and analyze surveillance data.

A goal for the next decade is to ensure that all states have all the basic population-based data systems, including a birth defects surveillance system, as well as the resources to ensure the timely collection of quality data throughout the country. Educating policy makers and others about the importance of this data infrastructure for maternal and child health will have to be a joint priority for all stakeholders interested in birth defects surveillance and follow-up. And the arguments that stakeholders make for data and research related to birth defects will need to show how these activities will contribute to improvements in the health and well-being of children.

### IMPORTANCE OF PARTNERSHIPS IN INTEGRATING BIRTH DEFECTS SURVEILLANCE IN MCH

State and local maternal and child health workers need birth defects surveillance system to monitor the prevalence and incidence of birth defects, to understand the causes and sequelae of various birth defects, and to study and understand effective strategies for primary and secondary prevention. The goal in each state that develops a birth defects system

should be to integrate birth defects surveillance into maternal and child health programs and activities in order to create a seamless system of data collection, analysis, research, and follow-up interventions.

An integrated data-collection and follow-up system can be created only if a variety of state public health programs and other entities are working together on an ongoing basis. Since these entities will probably not all be housed in the same organizational unit within a health department, it is important to create mechanisms for communication and joint activities. At a minimum, the following programs and personnel should be included in this coordinated approach: the Title V maternal and child health programs, including programs for children with special health care needs; statistics and evaluation personnel from vital statistics and MCH programs; environmental health personnel (who will work with local communities to follow up on birth defects clusters); and members of a state health department's policy and legislative staff.

Partnerships and collaborative activities across these units within a health department are often difficult because of barriers such as categorical funding, which encourages a "silo mentality," organizational barriers, organizational sensitivities about turf and power control, training and education biases, and lack of time and resources. Every state maternal and child health program should advocate the creation of a birth defects surveillance system and model the collaborative relationships that need to be in place to fully implement the data system as well as the policies and programs that will be generated from its findings.

Although partnerships in public health often focus on those of state health departments with local communities and the private sector, equal attention should be paid to the partnerships within the public health

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“family” to ensure that optimal birth defects systems are developed and implemented in each state.

### QUESTIONS FOR PARTNERS ATTEMPTING TO ESTABLISH BIRTH DEFECTS SURVEILLANCE SYSTEMS

Because partnerships among public and private organizations at all levels of government (federal, state, local) are essential for the development and implementation of a successful birth defects surveillance system, the following list of questions needs to be addressed at the federal and state levels. Each set of questions can serve as guidelines for the development of high-quality birth defects surveillance systems that can help improve the health and well-being of children and their families. Many of the questions suggest a point at which health departments and their partners can begin addressing the concerns of those who are stakeholders in the birth defects surveillance system, including children and parents, health care providers, researchers, policy-makers, public health professionals, voluntary advocacy agencies, and area residents.

#### Questions for Personnel from State Birth Defects Systems

- Do staff members from the birth defects system meet regularly with those from maternal and child health, children with special health care needs, statistics and evaluation, environmental health, genetics, etc.?
- Are regular mechanisms in place for sharing data from the system with members of the public health department?
- Is there an active advisory committee with representatives from all the stakeholders in the system, including parents, researchers, health care providers and voluntary agencies?
- Is joint planning a mechanism in place for suggesting legislation and providing feedback to policy-makers?
- Is joint planning a mechanism in place for providing feedback to the media?
- Are parents and other family members of children with birth defects involved in the development and implementation of policies based on information learned from the system?
- Is the March of Dimes an active participant in planning and implementing all aspects of the birth defects surveillance system?
- Are members of the academic community actively participating in planning and implementing the system?
- Is a process in place for implementing findings from research on birth defects? More specifically, is there a current statewide plan for disseminating information about the importance of folic acid in the prevention of spina bifida?
- Is this plan incorporated in the Title V MCH block grant application?
- Does the folic acid plan include a component on development of materials, training, policy development, social marketing, and evaluation?
- Does the folic acid plan include strategies for integrating folic acid information into all MCH programs, including programs for adolescent health, family planning, children with special health care needs, primary care, WIC and other nutrition programs, home visiting, and school health?
- Does the public health department have the environmental health resources necessary to explore clusters and investigate the possible correlation between birth defects and exposure to toxins and other substances found in the environment?

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- Are there established mechanisms for rapid communication with local officials and residents about the meaning of birth defect clusters in their communities?
- Are ongoing educational seminars and other training opportunities available for physicians and other health care providers?
- Do state birth defects surveillance systems and maternal and child health programs collaborate and share information?

### Questions for Personnel from Federal Birth Defects Systems

- Are there regular meetings or communication links among representatives from the CDC's National Center for Environmental Health and the Maternal and Child Health Bureau in the Health Resources Services Administration (HRSA), the National Center for Health Statistics, and other key centers within CDC?
- Is there an advisory committee with representatives from the relevant federal agencies, the March of Dimes, parents and families, health care providers, state programs, and academic institutions?
- Does the emerging birth defects network include the relevant Association of State and Territorial Health Officials (ASTHO) affiliate members from each state, e.g., Association of Maternal and Child Health Programs (AMCPH), which includes the directors of programs for children with special health care needs and the genetics coordinators; environmental health directors; the National Association for Public Health Statistics and Information Systems (NAPHSIS), and the Council of State and Territorial Epidemiologists (CSTE)?
- Is there a joint mechanism for planning and funding research on birth defects among the key federal agencies that fund research, e.g., CDC, MCHB/HRSA, the National Institute for Child Health and Human Development (NICHD), and the Agency for Health Care Policy Research (ACHPR)?
- Is there a joint mechanism for planning and producing materials to educate the public and the health care community? Are the materials available at the appropriate reading levels and in relevant languages? Are the key agencies with programs affecting the MCH population involved, e.g., MCHB/HRSA/DHHS, WIC in the Department of Agriculture, CDC, the Health Care Financing Administration (HCFA), and the March of Dimes?
- Is there joint planning across federal programs serving the MCH populations for the implementation of preventive strategies to reduce birth defects? More specifically, is there joint planning among CDC programs, MCHB/HRSA, WIC, the Department of Education, and others to develop and implement folic acid campaigns in every state and local community?
- Is there a joint strategy for educating the Congress and the public about birth defects surveillance systems and related programs? Is there a national agenda for birth defects surveillance and follow-up? Which stakeholders are involved in setting the agenda and in developing the social strategies and political will to implement the agenda?
- Do CDC and HRSA have a joint information-planning and data-sharing mechanism to support the development of a birth defects surveillance system in every state, a system that is programmatically integrated into MCH and environmental health programs? Is there joint support for the development of integrated information systems rather than categorical systems?
- Is there a federal public health approach to providing technical assistance and

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support for states and local entities in the implementation of birth defects systems? Do federal agencies provide consistent response and assistance concerning issues regarding confidentiality and the development of state-level legislation?

- Are CDC and HRSA collaborating on training about birth defects systems and their applications for improving the health and well-being of children?
- Has information about birth defects systems and the applications of findings learned from the data collected been incorporated in all MCH-related training contracts and grants funded by CDC and HRSA?

### **Questions for Non Governmental Partners at the State and Federal Levels**

- Does each state chapter of the March of Dimes have a collaborative relationship with the state Title V MCH program in order to develop and implement a statewide plan for a folic acid campaign, to plan and implement a statewide birth defects surveillance system, and to jointly sponsor educational forums and training for the public and providers?
- Are researchers involved in state and federal advisory committees to provide expertise and advice, to network with other researchers and health care providers, to educate the public and other researchers, and to support a public health information infrastructure?

- Are parent and consumer groups, such as Family Voices and the Spina Bifida Association involved in state and federal advisory committees to support the development of programs and policies, to participate in educational programs for the public and health care providers, and to support a public health infrastructure needed for data collection and program implementation?

The tasks and strategies mentioned above are not new to the public health workforce. All of us in public health know that persistent team work with a variety of concerned partners is hard but often does lead to goals no one player alone could achieve. If we keep on the path we have begun, we will accomplish our goal of integrating birth defects surveillance in maternal and child health programs in every state in the United States.

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