**Wisconsin Birth Defect Prevention and Surveillance System
Mission and Responsibilities**

**Preamble**

The Wisconsin Birth Defect Prevention and Surveillance System (System) is made up of the Wisconsin Birth Defects Prevention and Surveillance Program (Program) and the Wisconsin Council on Birth Defect Prevention and Surveillance Council as outlined in Wis. Stat. § 253.12. This system is located under the Children and Youth with Special Health Care Needs Program (CYSHCN), within the Bureau of Community Health Promotion, Division of Public Health. The system supports the Wisconsin Department of Health Services’ (DHS) vision of everyone living their best life and DHS’ mission of protecting and promoting the health and safety of the people of Wisconsin.

**Mission and Responsibilities**

1. **Wisconsin Birth Defect Prevention and Surveillance Program**

The program’s mission and work focuses on the three public health core functions of assessment, assurance, and policy development in conjunction with the following requirements set out in statute Wis. Stat. § 253.12(3), which addresses departmental duties and powers or responsibilities.

Responsibilities of the program:

1. Maintain an up-to-date registry that documents the diagnosis determined of any infant or child residing in Wisconsin who has a birth defect, regardless of residence, that facilitates:
* Identification of risk factors for birth defects.
* Investigation of the incidence, prevalence, and trends of birth defects.
* Development of primary prevention strategies to help decrease the occurrence of birth defects.
* Referrals of those with birth defects to early intervention programs and other support services.
1. Support an advisory council on birth defect prevention and surveillance. This Council is responsible for determining the listing of reportable birth defects, and forward recommendations to the DHS Secretary.
2. Outline reporting methodology requirements for data quality, and establish reporting requirements for reporters of birth defects.
3. Protect the confidentiality of children born with birth defects and their families through administrative assurances, including the option to refuse to release name and address of the infant or child.

In addition, the program will:

* Follow, support, and promote the mission of the CYSHCN Program in assuring that CYSHCN (i.e. birth defects) are properly identified and referred, receive high-quality coordinated care, and, with their families, obtain the supports they need.
* Promote birth defects policy, program integration, and education to assist families and their providers in advancing primary and secondary disability prevention.
* Collaborate with national, state, regional, and local health care providers supporting the collection, analyses, and dissemination of state and population-based birth defects surveillance data.
* Provide staffing support, guidance, and program content expertise to the Council.
1. **Wisconsin Council on Birth Defect Prevention and Surveillance**

The mission of the Council is to make recommendations to the DHS (including the Wisconsin Birth Defect Prevention and Surveillance Program) regarding the establishment of the Birth Defects Registry (i.e. content, format, procedures for reporting as outlined in statute), advise the DHS Secretary and make recommendations related to the diagnosed conditions reported in the registry and the impact of those conditions on children, families, and the health care system.

Responsibilities of the Council

1. Make recommendations to the DHS Secretary regarding the registry that documents the diagnosis of an infant or child who has a birth defect, what specific birth defects are to be entered into the registry, and the general content and format of this information, including the method for submitting the information.
2. Coordinate with the Early Intervention Interagency Coordinating Council[[1]](#footnote-1) to facilitate the delivery of early intervention services to children from birth to 3 years with developmental needs.
3. Advise the DHS Secretary and make recommendations regarding the registry.
4. Submit a biennial report to the legislature detailing the effectiveness, utilization, and progress of the registry.
5. The Council will meet at least four times a year to accomplish the following things:
* Review the Diagnosed Condition Review Criteria Policy for determining what birth defect conditions are to be reported and monitored.
* Determine the listing of reportable birth defects through unanimous vote and provide the list to the DHS Secretary.
* Review the biennial report to the legislature.
* Review the content, format, and procedures for submitting a birth defect report to the registry.
* Annually review statute language and advise the program accordingly.
1. Governor's Birth to 3 Interagency Coordinating Council: <https://b3icc.wisconsin.gov/>. The Wisconsin Birth to 3 Program Interagency Coordinating Council (ICC) established by the Governor of Wisconsin to advise and assist the Department of Health Services (DHS) in the performance of the responsibilities established under Part C of the Individuals with Disabilities Education Act (IDEA).

Revised Oct 29, 2019 [↑](#footnote-ref-1)