



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Kirsten L Johnson, Secretary

April 23, 2024

The Honorable Rachael Cabral-Guevara, Chair
Senate Committee on Health
Room 323 South, State Capitol
PO Box 7882
Madison, WI 53707

The Honorable Clint P. Moses, Chair
Assembly Committee on Health, Aging and
Long-Term Care
Room 12 West, State Capitol
PO Box 8953
Madison, WI 53708

The Honorable Jesse James, Chair
Senate Committee on Mental Health, Substance
Abuse Prevention, Children and Families
Room 319 South State Capitol
PO Box 7882
Madison, WI 53707

The Honorable Patrick Snyder, Chair
Assembly Committee on Children and
Families
Room 307 North State Capitol
Madison, WI 53708

Dear Senators and Representatives:

I am pleased to submit the 2024 Wisconsin Birth Defect Prevention and Surveillance Program Biennial Report as required by Wis. Stat. § 253.12(4)(d). The report identifies surveillance activities and programmatic strategies that are critical to improving birth outcomes and the health of all children in Wisconsin.

Birth defects are a substantial cause of infant mortality and childhood morbidity. In addition, these conditions have a significant fiscal and financial impact on the child and family, as well as on the service system of care, schools, and community. It is essential to have accurate, population-based data to assess needs, plan interventions, and evaluate outcomes for prevention strategies, supportive services, and resources for families who have a child with a birth defect.

In Wisconsin, approximately 1,900 infants are born with a birth defect each year, impacting three percent of all births. In addition, birth defects are a leading cause of all infant deaths in Wisconsin, accounting for approximately 75 deaths per year.

The Wisconsin Department of Health Services continues to focus on facilitating reporting through efficient data exchanges to improve compliance with the statute and completeness of the reports. The WBDR was moved into the Wisconsin Electronic Disease Reporting System (WEDSS) in 2020. WEDSS is a secure, web-based system that is used by health care providers, laboratory staff, and local health department staff throughout the state for a variety of health conditions.

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The report details the effectiveness, utilization, and progress of the WBDR; work of the Council; and a summary of prevention and intervention strategies to decrease the occurrence of birth defects, including referral for early intervention initiatives that improve child health outcomes and access to services.

Sincerely,

A handwritten signature in black ink, appearing to read "Kirsten L. Johnson". The signature is written in a cursive style with a large initial "K".

Kirsten L. Johnson
Secretary-designee

Wisconsin Birth Defect Prevention and Surveillance Program

2024 Report to the Legislature

The Wisconsin Birth Defect Prevention and Surveillance Program's (Program) 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.

- Maintain an up-to-date birth defects registry that documents the diagnosis in Wisconsin of any infant or child who has a birth defect, regardless of residence, that facilitates:
 - The identification of risk factors.
 - The investigation of the incidence, prevalence, and trends of birth defects using epidemiologic methods.
 - The development of primary prevention strategies to decrease the occurrence of birth defects.
 - Referrals for early intervention and other appropriate services.
- Support an advisory council on Birth Defect Prevention and Surveillance responsible for determining the listing of reportable birth defects through unanimous vote.
- Outline the reporting methodology requirements for data quality and establish the reporting requirements for reporters.
- Protect the confidentiality of children born with birth defects and their families through administrative assurances.

Current status of the birth defects registry

The Program is required to maintain a birth defects registry of diagnosed birth defects of any Wisconsin child age birth to two years, born in Wisconsin and/or receiving health care services in Wisconsin per [Wis. Stat. § 253.12](#). The Wisconsin Birth Defects Registry (WBDR) is a secure, web-based system that allows pediatric specialty clinics and physicians to report either one child with a birth defect at a time or upload a batch report of children with a birth defect. Reporters may also submit a paper form to the WBDR state administrator for inclusion in the WBDR. The WBDR collects information on the child and mother, the birth, referral to services, and the diagnostic information for one or more of 64 reportable conditions. The current list of reportable conditions is available on the last page of the paper reporting form ([F-40054](#)).

Diagnosing and/or treating providers and pediatric specialty clinics are required reporters, while hospitals may report. In practice, clinics or health care systems often submit reports for multiple physicians, clinics, and hospitals. Children's Hospital of Wisconsin, SSM Health, Marshfield Clinic, and University of Wisconsin Health Systems are developing their internal infrastructure to utilize the batch electronic upload option.

The 2017 Biennial Budget Bill (Assembly Bill 64 - 2017 Wisconsin Act 59), enacted on September 22, 2017, made significant changes to the WBDR and reporting, allowing the Program to better understand the prevalence of birth defects in Wisconsin. The new language improved the information in the registry by making the reporting of identifying information to WBDR an opt-out versus an opt-in. This means that reports to the WBDR contain identifiers

including name and address of the child. However, parents or guardians can request identifying information be removed from the WBDR at any time.

Overall, this change:

- Allowed linkage of the data to other data sets including vital records.
- Helped determine if the number and type of certain birth defects present are increasing or decreasing.
- Assured unduplicated counts of children identified with a birth defect(s).
- Facilitated appropriate referral to services and resources.
- Provided insight into what prevention and early intervention activities are warranted and effective.
- Helped identify environmental risk factors that may be responsible for certain birth defects or contribute to clusters of birth defects in a particular area of the state.

During 2019, the Program reviewed options to enhance the WBDR to improve functionality for reporters. The Program determined that the best solution would be to add the WBDR as a module to an existing Department of Health Services system called Wisconsin Electronic Disease Surveillance System (WEDSS). WEDSS is a secure, web-based system that is used by health care providers, laboratory staff, and local health department staff throughout the state for a variety of conditions. Reporting options for WBDR remain the same. For providers reporting an occasional case, they can either enter each case manually into WEDSS or complete the paper reporting form. For providers and clinics that report on a larger number of cases, there is an option to report through a batch upload. System testing in WEDSS was conducted early 2020 and it went live in April 2020.

Unfortunately, the timing of the system going live coincided with the start of the global COVID-19 pandemic, impacting the ability of reporters to start reporting and shifting the DHS information technology staff away from supporting WBDR, as WEDSS is also the system that collects COVID-19 case data. Some health care systems were able to start reporting, but problems were quickly identified regarding system functionality causing data collection to be put on hold until information technology staff could make the appropriate changes.

In 2022, information technology staff were able to make the necessary changes to WBDR. Program staff reached out to the hospital systems that, in 2019, were prepared to report. In 2023, Program staff worked closely with the health systems to develop the policies and procedures necessary to report through a batch upload. At this time, four health systems have been building their internal infrastructure and begun testing their data submissions. Program staff continue to conduct outreach to providers who wish to report each case manually and problem solve barriers to implementation of the batch upload report.

Birth defects in Wisconsin

Birth defects are common, costly, and critical conditions that affect one in every 33 babies born in the United States each year.¹ In Wisconsin, approximately 1,900 infants are born with a birth defect each year, impacting three percent of all births.^{1,2} In addition, birth defects are a leading cause of all infant deaths in Wisconsin, accounting for approximately 75 deaths per year.³ From 2016–2020 birth defects were the leading cause of death among children born to Laotian/Hmong families (27 per 10,000 live births) and white families (11 per 10,000 live births).³ Birth defects were the second leading cause of death among black (16 per 10,000 live births) and Hispanic families (12 per 10,000 live births).³ For infants born with a birth defect, survival is poorer among babies born to black or Hispanic families, compared to babies born to non-

Hispanic white families.⁴ While the causes of these disparities are not fully understood, it is likely that structural racism contributes through lack of access to primary and preventive health care among historically marginalized communities, as well as insufficient and not culturally-relevant pre- and post-natal care, and chronic stress.

The estimated annual cost of birth defect-associated hospitalizations (for patients affected by a birth defect regardless of their age) in Wisconsin is **\$386 million**.⁵ Preventing birth defects is an important step in reducing these costs. However, because the cause of approximately 80% of birth defects are unknown, investing in early intervention, long-term support, and case management for families impacted by birth defects is crucial.⁶ In addition, investing in a robust birth defects registry is critical to understanding the prevalence, assessing trends, and investigating risk factors and causes of birth defects.

Purpose of birth defects surveillance

The National Birth Defects Prevention Network and the Centers for Disease Control and Prevention review birth defect diagnosis annually. They both cite that birth defect surveillance systems are a leading contributor to reducing birth defects.

To prevent birth defects, it is important to know the cause of birth defects. To identify causes, researchers and analysts need to know the frequency of individual birth defects and need to compare the occurrence of specific birth defects in the presence of potential causative factors. Ongoing, real-time collection of birth defect data is needed to continually assess whether the occurrence of birth defects is increasing, decreasing, or staying the same overall and whether individual birth defects are clustered in a particular geographic area of population. This can be accomplished through comprehensive birth defects surveillance.

Addressing birth defects in Wisconsin

Support for the Program is provided through two 0.3 full-time equivalent (FTE) employees with the Maternal and Child Health (MCH) Title V, Children and Youth with Special Health Care Needs (CYSHCN) Program. In addition, an information system specialist provides technical support for the WBDR. For a fully functional birth defects surveillance system to meet all current legislative requirements, the National Birth Defect Prevention Network recommends the support to be increased to at least 2.0 FTE.

Birth defect prevention and early intervention initiatives

A Healthier Tomorrow Starts Today

Through a minimally competitive application process in 2021, the Program contracted with Wisconsin Women's Health Foundation, Well Badger Resource Center to conduct a two-year statewide birth defects prevention campaign. The Well Badger Resource Center is a health information and referral program available to all individuals in Wisconsin through phone, text, email, or live chat. The Well Badger Resource Center has implemented a direct-to-consumer, digital outreach campaign called [A Healthier Tomorrow Starts Today](#). Well Badger has created and disseminated materials that aim to increase people's knowledge about birth defect prevention and connect them with services in six key areas:

- Folic acid and supplemental nutrition
- Vaccination
- Tobacco, alcohol, and other substance use
- Prenatal care and health care coverage

- Sexually transmitted infections
- Basic needs

The campaign is scheduled to end in June 2024. A full evaluation of the campaign’s impact will be written to help guide future prevention activities conducted by the Program.

Council on Birth Defect Prevention and Surveillance

The Council on Birth Defect Prevention and Surveillance (Council) was created by [Wis. Stat. § 253.12](#) to advise the Department of Health Services (DHS) regarding the development of the birth defects surveillance system. The Council meets at least four times a year in order to fulfill its responsibilities, including:

- Making recommendations to DHS regarding the WBDR.
- Coordinating with the Early Intervention Interagency Coordinating Council (Wisconsin Governor’s Birth to 3 Program Interagency Coordinating Council) to facilitate the delivery of early intervention services.
- Submitting a biennial report to the legislature detailing the effectiveness, utilization, and program of WBDR.

The members are appointed to four-year terms by the DHS Secretary. Membership is outlined in [Wis. Stat. § 15.197.12](#). In the past two years, seven vacancies were filled, and the Council is currently at membership capacity. As specified by statute, the council includes a pediatric nurse or a nurse with expertise in birth defects, a parent or guardian of a child with a birth defect, a representative of a local public health department, and representatives of the following organizations:

- Birth to Three Program, DHS
- Bureau of Health Informatics, DHS
- Children and Youth with Special Health Care Needs Program, DHS
- Wisconsin Board for People with Developmental Disabilities
- Medical College of Wisconsin
- University of Wisconsin – Madison, School of Medicine and Public Health
- Wisconsin Chapter of the American Academy of Pediatrics
- Nonprofit organization

Children’s Resource Centers

To ensure access to services, the Children and Youth with Special Health Care Needs (CYSHCN) Program contracts with five Children’s Resource Centers (CRC):

- CRC – Northeast, Children’s Hospital of Wisconsin – Fox Valley
- CRC – North, Marathon County Health Department
- CRC – Southeast, Children’s Hospital of Wisconsin - Milwaukee
- CRC – South, University of Wisconsin – Waisman Center
- CRC – West, Chippewa County Department of Public Health

Each CRC is dedicated to supporting families with children and youth with special health care needs (including children born with birth defects) and the providers who serve them. The CRCs are staffed by children’s resource guides who can answer questions, find services, provide training, and connect providers, families, and youth to community resources. Their services are free and private. Physicians may refer a child with special health care needs to a CRC using the “Consent to Release Medical Information Referral” form ([F-01238](#)). Other resources can be found at: www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm.

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