

Michigan Birth Defects Registry

Reporting Manual



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Michigan Department of Health and Human Services
Bureau of Epidemiology and Population Health
Division for Vital Records and Health Statistics

Michigan Department of Health and Human Services

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Birth Defects Registry Contact Information

The Michigan Birth Defects Registry (MBDR) staff prepared this manual to provide the information needed to submit reports. The manual contains copies of the legislation mandating the Registry, the Rules for reporting birth defects, information about reportable and non-reportable birth defects, and methods of reporting. Changes in the manual will be sent to each hospital contact to assist in complete and accurate reporting. We are interested in your comments about the manual and any suggestions about information you would like to receive. The Michigan Birth Defects Registry is located within the Division for Vital Records and Health Statistics.

Registry staff can be reached at the following address:

Michigan Birth Defects Registry
Division for Vital Records and Health Statistics
333 S. Grand Avenue
Lansing, MI 48933

The Birth Defects Registry fax number is below:

Fax (517) 335-9513

For assistance with specific questions pertaining to reporting Birth Defects, Data Requests or Research Requests please contact:

Michigan Birth Defects Registry Mailbox
MDHHS-MBDR@michigan.gov

Primary Contact Erin Cooper (517) 335-9009
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General Information

The Michigan Birth Defects Registry maintains a file of case reports on children birth to two years of age, and through twelve years of age for certain medical conditions, born in Michigan or born to Michigan residents and diagnosed with a reportable condition in the State of Michigan. This information is reported to the Registry by hospitals and clinical and pathology laboratories as mandated by Public Act 236 of 1988 which amended the Public Health Code, Act 368 of 1978. Public Act 236 directs the Michigan Department of Health and Human Services to establish a comprehensive birth defects registry. The amendment is aimed at improving statewide identification of children with birth defects and facilitating the assessment of service and referral needs for these children. The Michigan Birth Defects Registry will provide the information needed to: compute baseline birth defects incidence and mortality rates and analyze trends; identify and respond to potential clusters; formulate and test hypotheses of causation; plan and develop relevant programs; coordinate assistance for long-term care and follow up; evaluate programs and services; and further educate professionals and the community at large. These activities seek to improve our knowledge concerning the prevention of birth defects and to assure that Michigan children with birth defects have access to available resources and assistance. The ability to meet these goals is largely dependent on the successful functioning of a statewide registry and the quality of the data collected.

Reporting Requirements

The Michigan Birth Defects Registry was established as part of the Public Health Code (Act 368 of 1978) by amending sections 5721 and 5805. Section 5721 of Part 57 stipulates that "(1) Each diagnosed incidence of a birth defect, including a congenital or structural malformation, or a biochemical or genetic disease, and any information relevant to incidents of birth defects, shall be reported to the department. (2) The department shall maintain comprehensive statewide records of all information reported to the birth defects registry." The Rules governing reporting, the quality, manner, collection and analysis of the data, and confidentiality regulations are proscribed by the Code and the legislation.

Confidentiality of all data is required by law and strictly maintained by the Health Department staff. Section 2631 of the Public Health Code regulates procedures protecting confidentiality and regulating disclosure of data and records.

The Michigan Birth Defects reporting rules, R 325.9072 identifies reportable defects (see attached rules for listing) Reports are to be submitted within 30 days of diagnosis on the confidential Birth Defects Registry report forms provided by the Department of Health and Human Services or by electronic media using methods which protect the confidentiality of health information, such as via FTS server, or through MDHHS's Vital Events Reporting Application (VERA).

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Reporting to the Michigan Birth Defects Registry

Accuracy and thoroughness in case identification and data abstracting determine the quality of the data and the usefulness of a registry. The quality of the information reported is dependent on the ability of personnel to abstract relevant data from the hospital chart. Prompt reporting will help to ensure that families are made aware of assistance options in a timely manner, and that data are complete and accurate in the registry.

Reporting can occur electronically via an automated FTS server, and/or through MDHHS's Vital Events Reporting Application (VERA). If you do not have a large number of reportable cases occurring at your facility, you can utilize the fillable Birth Defects Registry Report Flatfile Specification provided on the MBDR website <https://www.Michigan.gov/MBDR>

Case Definition

Any child or stillborn diagnosed with a reportable condition in the inpatient or hospital-sponsored outpatient setting under the age of 24 months, and children up to and including 12 years of age for certain medical conditions which are commonly diagnosed after the age of two years requiring surveillance and are commonly diagnosed after the age of two years, including, but not limited to, any of the following:

- (a) Fetal alcohol spectrum disorders
- (b) Cystic fibrosis
- (c) Muscular dystrophy
- (d) Autism
- (e) Cerebral Palsy

Reportable Conditions

CDC required reportable conditions listed by year are provided on the MBDR website <https://www.michigan.gov/MBDR>. Please refer to the list to determine if a diagnosis which has been confirmed on the health record is reportable to the registry. It is not necessary to report some normal variants, extremely common minor defects and conditions resulting from prematurity or birth injury. These conditions are listed with a "no" in the "reportable alone" column on the listing of defects codes and should not be reported unless there is a co-existing reportable condition present.

- Review the medical record for a reportable defect.
- Please complete a Birth Defects Registry report within 30 (thirty) calendar days after a diagnosis has been recorded in the patient's medical record or after discharge.
- The report is filled out even if a child expires.
- The report is filled out even if the defect is corrected.
- For cases readmitted to the hospital, check your files, or the medical record to see if a Birth Defects Registry report was previously completed. If a report has been filed, it is not necessary to submit another report unless there is a change in the diagnosis from that described on the original Birth Defects Registry report.

- If you are uncertain as to whether a report should be filed or if a Birth Defects Registry report was filed previously, remember it is better to submit the report.

Confidentiality

Personal identifiers must be collected for each case. These help to ensure that each case is only counted once and to match cases to birth/death files and other pertinent databases. Case identifiers will also aid in contacting families as required by Public Act 368 of 1978, being Michigan Compiled Laws §333.5805, regarding assistance, services, or special epidemiologic studies, when this is deemed necessary and appropriate.

All Michigan Department of Health and Human Services personnel involved in data collection, data entry, and database maintenance are bound by state laws mandating confidentiality. Confidentiality is assured by Public Act 368 of 1978, being MCL §333.2631. Completed forms will be stored in locked files, and computer files can only be accessed by authorized personnel. Any published report will only contain aggregate data and will not disclose personal identifiers.

Methods Of Electronic Case Report Transmission

This manual is a guide for establishing an electronic record for each case to be reported to the Michigan Birth Defects Registry. The methods of transmission are described below as the MBDR Template Flatfile Specification V1.2 for manual data entry, the MBDR Flatfile Specification V1.2 for coders/programmer's extracts, and VERA for birthing facilities. Questions not addressed in the manual should be brought to the attention of Erin Cooper, Ifeoma C. Okafor, or Liz MacIntyre. Contact information for these individuals can be found on the Birth Defects Registry Contact Information page.

Electronic Case Report Submission

MBDR Template Flatfile Specification V1.2 (.xslm) Format

The MBDR Template located on the MBDR website <https://www.michigan.gov/MBDR> is for manual data entry for approved reporting facilities with a small number of reportable cases each month. This template requires Excel macros to be enabled. It is important to fill out the template completely and as accurately as possible. Each sheet on the MBDR Template is outlined below.

Definitions

The definitions sheet defines each data element/variable to offer further clarification

Template

The template sheet is where reporting facilities will be hand entering case reports.

Example CSV

The example CSV sheet provides a sample of what the exported CSV should look like.

Value Sets

The value sets sheet provides the “coded value” mentioned in the “DataType” column on the definitions sheet.

Tools

The tools sheet provides a weight conversion tool from pounds and ounces to grams and explains how to enable/disable autofill in the cells and correct numbers formatted as text errors.

Change Log

The change log sheet notes all updates made in the different template versions

For assistance with the template please contact the MBDR team at MDHHS-MBDR@michigan.gov

Electronic Case Report Submission

MBDR Flatfile Specification V1.2 Format

The MBDR Flatfile located on the MBDR website <https://www.michigan.gov/MBDR> is for coders/programmers extracting data out of the reporting facilities Electronic Health Records (EHR). Each sheet on the MBDR Flatfile is outlined below.

Definitions

The definitions sheet defines each data element/variable to offer further clarification

Example CSV

The example CSV sheet provides a sample of what the CSV should look like in a text editor.

Value Sets

The value sets sheet provides the “coded value” mentioned in the “DataType” column on the definitions sheet.

Change Log

The change log sheet notes all updates made in the different template versions

For assistance with the flatfile please contact the MBDR team at MDHHS-MBDR@michigan.gov

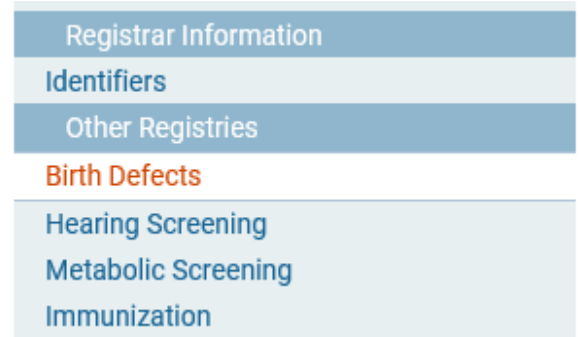
Electronic Case Report Submission

Michigan Vital Event Registration Application (VERA)

The Vital Event Registration Application software can be used to report birth defects to the Michigan Birth Defects Registry (MBDR). In most cases, when reporting in VERA you will be completing a birth defect report for a child that was born at your facility, and there is an existing birth registration for that child. Each facility must have a system in place for identifying all children with a reportable condition under the age of 24 months, and children up to and including 12 years of age for certain medical conditions (see reporting section for details). The best method to obtain detailed birth defect information for a newborn is to wait until the health record is completed and diagnosis and procedure codes have been assigned for billing. This information can be obtained from the health record coding staff in the form of a completed coding abstract or face sheet.

Adding Birth Defects Information to a New Birth Admission

This method is completed by selecting “Birth Defects” under “Other Registries” on the left side of the screen on the Registration Menu in VERA. The birth defect page will prompt you to select the “New Report” button. If a birth defect has already been reported, please double check the diagnosis code reported, as not to duplicate a report. If it is not a duplicate, you can select “New Report.” A new report for birth defect data should be filled out entirely and you must save your birth defect entry upon completion.



Birth Defect Data

Diagnosis Date	<input type="text"/>
Cytogenetics Testing	<input type="text"/>
ICD9/ICD10 Code:	<input type="text"/>
Laboratory Name	<input type="text"/>
Birth Defects Submission Facility	<input type="text"/>
Diagnosis Code	Procedure Code
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>

For assistance with the entry of birth defects cases into VERA please contact the MBDR team at MDHHS-MBDR@michigan.gov