

Monitoring Infants and Children with Special Health Needs

Birth Defects Prevalence and Mortality in Michigan, 1992-2006

A report prepared by

Michigan Department of Community Health

Bureau of Epidemiology

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Executive Summary

This report presents an overview of the Birth Defects Program at the Michigan Department of Community Health (MDCH). The program aims to monitor trends, promote prevention, and link families to resources. Statewide surveillance data from the Michigan Birth Defects Registry (MBDR) are included for the birth cohort years of 1992 to 2006, along with in-depth analyses of neural tube defects (NTD), orofacial clefts, Down syndrome (trisomy 21), and congenital heart defects (CHDs).

Surveillance Michigan's formal surveillance system for monitoring the occurrence of birth defects began in 1987 when the public health code was amended by Act 48 (Public Act 368) to require establishment of a birth defects registry. Case reporting began in 1992 and continues today as a passive system that relies on reporting from hospitals, cytogenetic laboratories and pediatric genetics clinics for case ascertainment.

Goals of the Michigan Birth Defects Registry

- 1) Maintain, improve and expand Michigan's population-based birth defects surveillance system.
- 2) Use surveillance data to plan and implement population-based birth defects prevention activities.
- 3) Use surveillance data to improve access to health services and early intervention programs for children with birth defects and their families.

Prevalence During 2006, there were 10,605 children with birth defects reported to MBDR within the first year of life, which corresponds to an incidence rate of 831.5 cases per 10,000 resident live births, or approximately 8% of the annual birth cohort of 127,537 Michigan newborns. Anomalies of the heart and circulatory system constitute about 21% of the birth defects reported to the MBDR, while anomalies of the musculoskeletal system make up 20%, and anomalies of the genitourinary system make up 17% of the birth defects reported to the MBDR.

Analysis of selected MBDR data to determine birth defect prevalence shows an overall rate of 6.3 neural tube defects, 15.6 orofacial clefts, and 11.4 cases of Down syndrome, all per 10,000 live births from 1992 to 2006. Trends by birth year, sex, maternal age, and maternal race and ethnicity are presented in this report.

Mortality The infant death rate for children born from 2004 to 2006 with a reportable birth defect was 35.6 deaths per 1,000 infants diagnosed with a birth defect. This compares to an infant death rate of 7.6 deaths per 1,000 live births for all resident infants. The data highlight and reinforce the need to address birth defects as part of public health efforts aimed at reducing infant mortality.

Follow-Up The follow-up component of the Birth Defects Program helps to link families with available resources and support systems. Follow-up with families of infants with NTDs, in particular, helps to assure they receive available services and that mothers are aware of the increased doses of folic acid needed to reduce the chance of recurrence of NTD in future pregnancies. A list of available state and national resources for families of children with birth defects is included at the end of this report.

A Closer Look A closer look at congenital heart defects (CHDs) reveals that there is a disparity in the overall prevalence rate of CHDs in blacks compared to whites; the CHD rate is about 20% higher in blacks, compared to whites. From 1992 to 2006, the CHD rate in whites was about 145 cases per 10,000 live births, while for blacks, it was about 201 cases per 10,000 live births. Data from the MBDR reveal that some CHDs, such as ventricular septal defect (VSD), aortic valve stenosis, and transposition of great vessels, are more common in whites, while others, such as atrial septal defect (ASD), patent ductus arteriosus (PDA), and pulmonary artery anomalies, are more common in blacks. In the '*Closer Look*' section, prevalence rates of heart defects are analyzed by race, maternal age, and preterm births and infant fatality CHD rates are analyzed by race.

Prevention In the realm of birth defects, there are often more questions than answers concerning causality and prevention. However, certain strategies, such as maternal consumption of folic acid before conception and early in pregnancy, or controlling blood sugar levels for mothers with diabetes before and during pregnancy, are known to be effective in reducing the risk of birth defects. The Birth Defects Program supports a variety of outreach activities to help women of reproductive age know the importance of achieving and maintaining optimal health prior to conception in order to optimize babies' health.

A Sound Investment The data, analyses and program information outlined in this report represent some of the endeavors undertaken by staff members over the past years. Birth defects surveillance is a sound investment in the current and future health of all Michigan residents. The MDCH Birth Defects Program will continue working to improve health outcomes for Michigan babies by collecting and analyzing data to better understand causes and demographic patterns; by decreasing preventable birth defects; and by linking affected children and their families to services.

Introduction

This third annual birth defects report is based on data collected by the Michigan Birth Defects Registry (MBDR) from 1992 to 2006. The registry covers more than 1,050 diagnoses reported on children from birth through two years of age. The annual report serves as a way to share MBDR findings with partners and stakeholders concerned about Michigan infants and children with special health needs. The first report, produced in 2005, reviews the history of the registry, provides a focus on neural tube defects, and highlights demographic data on orofacial clefts, Down syndrome, and congenital heart defects. The second report, produced in 2006, provides a focus on infants with hearing loss, and demographic data on musculoskeletal defects, neural tube defects, orofacial clefts, and Prader-Willi syndrome. This third report provides a focus on the racial disparity in the prevalence of congenital heart defects and provides demographic data on neural tube defects, orofacial clefts, and Down syndrome. These reports can be accessed online under “Statistics and Reports” at www.michigan.gov/mdch.

The Birth Defects Team recognizes the support and direction provided by the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities, which has done so much in advancing the development and sustaining of Michigan’s birth defects surveillance.

Public Health Impact of Birth Defects

Birth defects are a serious public health problem in Michigan and across the nation. During 2006, there were 10,605 children with birth defects reported to the MBDR in the first year of life. This corresponds to a prevalence of 831.5 cases per 10,000 resident live births, or approximately 8% of the 127,537 Michigan newborns in 2006.¹ Birth defects contribute significantly to childhood mortality, morbidity, and long-term disability. The infant fatality rate for children born in 2006 with a reportable birth defect was 32.8 deaths per 1,000 infants with a birth defect. This compares to an infant death rate of 7.4 deaths per 1,000 live births for all resident infants born in Michigan for the same year.² Recent analysis of MBDR surveillance data reveals that children with birth defects are at much greater risk of death due to causes other than a birth defect (for example, accidental causes).³ The total mortality rate over ten years of life, for those born in 1997 and reported to the MBDR, was 59.6 deaths per 1,000 children with a birth defect, compared to a rate of 10.5 deaths per 1,000 resident live births overall. This is higher than the 1 in 5 infant deaths usually attributed to birth defects based on death records alone and emphasizes the need for greater attention on the impact of birth defects as a cause of early childhood death.

Children with birth defects often require highly specialized and expensive medical care. Support for the family and affected child may be provided not only by a primary care physician in a medical home and by a variety of medical

In 2006, the fatality rate was 32.8 deaths per 1,000 babies *reported with birth defects*, compared to 7.4 deaths per 1,000 live births *for all infants*.

specialists, but also by adjunct health services, the educational system, community and social organizations, and local or national programs. The ability to use comprehensive data on the incidence and types of birth defects affecting Michigan children will lead to a better understanding of total health care and educational costs for this population; prevention and intervention strategies to reduce both the financial and emotional burden on families and society; and an improvement in the quality of life for affected children and their families.

Michigan's Birth Defects Program

PREVENTION

Data from the MBDR is used to effectively plan and implement prevention activities. Prevention activities to promote good preconception health include: multivitamin distribution; creation and distribution of teen related fact cards raising awareness of the risk of adverse birth outcomes related to having uncontrolled diabetes mellitus; partnering with other programs such as Michigan Healthy Mothers, Healthy Babies, March of Dimes, and local public health; distribution of educational materials; and participation in the National Birth Defects Prevention Network (NBDPN), promoting Birth Defects Prevention Month.

From 2005 to 2007, the Birth Defects Program received a chapter community grant award from the March of Dimes, Michigan Chapter, to support a folic acid outreach initiative, with additional support from the Children's Special Health Care Services Program to continue through 2008. The project, *Folic Acid Outreach and Multivitamin Distribution in Selected Michigan Counties*, provided more than 40,000 bottles of free multivitamins with folic acid to low income women participating in the Supplemental Nutrition Program for Women, Infant and Children (WIC) and Family Planning Programs in counties identified with the highest rates of neural tube defects. As a result of this project, women reported that they would likely continue multivitamin use (buy their own) after finishing their free supply.



From 2008 to 2009, the Birth Defects Program received a March of Dimes chapter Community Grant for a project, *Teens with Diabetes Mellitus: Promoting Preconception Care to Prevent Adverse Pregnancy Outcomes*. Surveys assessed teens' and parents' awareness and concerns with the risks of adverse pregnancy outcomes related to having uncontrolled diabetes prior to pregnancy as well as routine activities related to having diabetes (such as receiving diabetes information, frequency of doctor visits). Health care providers were surveyed to assess visits with diabetic patients and information given to patients. Results revealed that only about 45% of teens and 55% of parents who responded were aware of the risks of adverse birth outcomes related to uncontrolled diabetes. As a result, a fact card directed at teens, *The Birds and the Bees...and Diabetes*, was created in English and Spanish, and a preconception toolkit for health professionals was created to provide information on reproductive risks and birth defects, management guidelines before and during pregnancy, and prevention educational resources aimed at teens and women of child bearing age.

MONITORING

Statewide monitoring of birth defects is conducted by the Michigan Birth Defects Registry (MBDR) in the Division of Vital Records and Health Statistics. The confidential registry is a passive system of ascertainment that relies on reports submitted by all Michigan hospitals and cytogenetic laboratories. Initiatives for voluntary case reporting to the MBDR by outpatient pediatric genetic clinics, and others, have contributed additional cases of birth defects that would otherwise have gone undetected. About 10,000 Michigan children are born annually with birth defects or other reportable conditions. The MBDR currently contains about 450,000 reports on more than 141,000 individual children born from 1992 to 2006. Epidemiology and vital records staff analyze registry data and conduct special studies to better understand the impact of birth defects on public health.

The Michigan Birth Defects Registry (MBDR)

The *purpose* of the MBDR is to:

- Collect statistical data on the incidence of birth defects in Michigan.
- Conduct birth defects surveillance and epidemiologic studies on the causes of birth defects.
- Provide data for birth defect prevention and intervention efforts, program planning and evaluation.
- Assure that children with birth defects and their families receive appropriate support services.

Examples of uses for MBDR data include monitoring the rate and types of birth defects in specific geographic areas, planning and evaluating service delivery to children with special needs, targeting birth defects prevention activities and conducting scientific research on the etiology of birth defects.

Reportable Conditions

The MBDR currently collects information on children from birth to two years of age who have a reportable condition and were born in Michigan or were diagnosed or treated for the condition in Michigan. Reportable diagnoses include all congenital anomalies of consequence, genetic disorders presenting at birth or in early childhood, and selected



maternal exposures to infectious disease and other teratogenic agents such as alcohol. The MBDR includes in the case definitions all those birth defects identified in the NBDPN's Guidelines for Conducting Birth Defects Surveillance—Appendix 3.1, by ICD-9-CM code. Previously, only live born children were included in the registry, but since June 1, 2003, fetal deaths with any of these conditions are also reportable to the registry. Condition coding is accomplished using the current year version of the Ninth Revision of the International Classification of Diseases: Clinical Modification (ICD-9-CM). A manual that includes a list of reportable ICD-9 codes, enabling legislation and reporting instructions is provided to hospitals, cytogenetic laboratories and other reporting facilities. A list of reportable ICD-9 codes by diagnostic category is included as Appendix B.

Currently, the Birth Defects Team is working to update the rules regulating birth defect reporting. This includes establishing the authority to expand the range for age at diagnosis for selected conditions, redefining what conditions are reportable by using terms rather than diagnostic codes, and expanding the ability of the MBDR to include specialized reporting sources and to designate agencies other than MDCH to act on behalf of the MBDR. These changes are expected to improve the effectiveness of the registry as a monitoring system for conditions such as fetal alcohol syndrome, autism, developmental delay, and others that typically become apparent later in childhood and to enhance our ability for collaborative outreach efforts.

Reporting Methods

Since the MBDR relies on data collected through passive case ascertainment, staff members help facilities to identify the reporting method best suited to their needs. Methods of reporting cases to the registry include:

- Paper Abstract: This method uses a standardized form in paper abstract for hospital admissions and cytogenetic laboratory results.

- **Electronic Submission:** This method uses facility discharge data to create an electronic record of children admitted with reportable conditions.
- **Electronic Birth Certificate (EBC):** This method utilizes Genesis, the software commonly used to create electronic birth records for children born at a facility.

Roughly 85% of all reports are received in electronic form, with about half of those being received through EBC and half as hospital-specific data files. Report processing procedures include de-duplicating and consolidating case reports, report review and query, coding and editing reported information and linking case information to Michigan birth and death files. Data from all three sources (reports, births and deaths) are used to develop a complete record on each case.

As an important public health indicator, birth defect reporting is mandated by state law and parental consent is not required in order to file a report. However, both law and rule establish that these data are confidential. Privacy and security considerations are integral to all procedural steps to assure confidentiality of information. Access to MBDR data is limited to essential registry personnel and other departmental staff whose programmatic use of the information has been approved by the Department director. Rules governing the MBDR specify the conditions and approval processes under which this information may be released.

Electronic Training Module

A web-based training module was developed and implemented in January 2006 to assist staff in training facility personnel who submit case reports. The Birth Defects Registry online training course discusses the value of the MBDR and teaches individuals how to complete both the paper-based and electronic reporting forms. Now, the training module has had more than 376 users and 658 sessions have been logged. A link to the training module can be found at: <http://training.mihealth.org/coursedetail.htm>.

Quality Assurance

Concurrent internal monitoring assures that incoming reports are screened for missing and invalid information as they are processed into the registry. MBDR staff compares demographic information on birth defects reports with that in birth and death records. They may contact reporting facility staff to correct and complete all data before they are linked with birth and death files. To further improve the accuracy and completeness of case ascertainment, the MBDR is linked with other public health program datasets. Linkages with the MBDR include: 1) data linkage with Children's Special Health Care Services Program (CSHCS); 2) case sharing of hearing loss diagnoses with the Early Hearing Detection and Intervention Program (EHDI); 3) acquiring confirmed cases from the Newborn Screening Program (NBS); 4) continued reporting from four pediatric genetics clinics; and 5) voluntary reporting from Fetal and Infant Mortality Review Program (FIMR). These linkages help to assure that the MBDR is as complete and accurate as possible.

Reporting facilities are monitored for method, accuracy, and completeness of case reporting. Unreported cases are identified and submitted to the MBDR. Subsequently, education and technical support are provided to ensure reporting facilities are in compliance with legislative mandates. Retrospective facility audits are conducted every three to four years to assess statewide performance in the reporting of birth defects and to identify opportunities for improvement. In the 1999 audit,

81.1% of the reported cases reviewed had information in the health record consistent with the information submitted to the registry, and in the 2003 audit, an accuracy rate of 95.0% was found for cases reviewed. The retrospective facility audit was conducted in 2009-2010, and included review of 550 case records from seven representative reporting facilities (Table 1). From this audit, 71.6% of sampled reports were accurate but most errors were due to demographic discrepancies (n=97). A total of 33 false positives were found for a false detection rate of 6.0%.

Besides quality improvement for birth defects reporting, an audit with on-site chart review allows for further investigation into issues affecting quality of life for children with birth defects, such as patterns of referral to needed services and access to coordinated, comprehensive medical care. More information on these audits can be found in the inaugural MBDR Report: Birth Defects Prevalence and Mortality in Michigan, 1992-2002.

Table 1: Audit results by facility type for reported cases: Retrospective facility audit, 2009-2010.

Facility Type	Total Cases Sampled	Total Reports	Number Accurate	Number Demographic Errors	Number Diagnostic Errors	Number False Positives
Minor Obstetrical	188	256	138	38	31	6
Major Obstetrical	104	126	87	1	5	11
Regional NICU	120	899	101	6	2	11
Major Referral	138	2146	68	52	22	5
Total	550	3427	394	97	60	33

**Records reviewed were from 2006 admission dates, except where it was necessary to pull from other admission years to get an adequate sample.*

MBDR Evaluation

Recommendations for state birth defects surveillance systems are put forth by the National Birth Defects Prevention Network (NBDPN), “Guidelines for Conducting Birth Defects Surveillance.”⁴ An evaluation of the MBDR was conducted in 2005 to 2006, broadly following the “Updated Guidelines for Evaluation of Public Health Surveillance Systems.”⁵ These guidelines suggest evaluation of the following system attributes: simplicity, flexibility, data quality, acceptability, sensitivity, positive predictive value (PPV), representativeness (how well cases reported represent the population as a whole), timeliness of reporting, and stability of the system over time.⁶ More information on facility audits and the surveillance system evaluation can be found in prior MBDR reports: Birth Defects Prevalence and Mortality in Michigan, 1992-2002, and Birth Defects Prevalence and Mortality in Michigan, 1992-2003 available online by clicking on Statistics and Reports at: www.michigan.gov/mdch.

FOLLOW-UP

An integral component of a comprehensive Birth Defects Surveillance Program is follow-up to ensure that children are connected with services and that the needs of families are met. The program strives to: 1) identify the special needs of children with birth defects, and 2) assure families are connected to resources and support systems. Providing information to families in a timely manner, while preserving the privacy of birth defects data, is a



priority. Among the key needs identified by families of children with birth defects are medical information and services, family emotional and spiritual support, advocacy, and prevention information.



Starting in 2004, the Birth Defects Program developed a follow-up plan for infants with neural tube defects (NTD) and their families. Additionally, MBDR data is used to identify children with hearing loss. Inter-program cooperation with the MDCH Early Hearing Detection and Intervention (EHDI) Program allows for review of hearing loss cases reported to the MBDR. The EHDI program is then able to follow-up with confirmed cases by referring diagnostic and intervention services.

A pilot project using MBDR data to identify children who might benefit from early intervention services and were not enrolled in *Early On*®, Michigan’s early intervention system for young children from birth to three years of age, was conducted in 2007. These activities make use of surveillance data to provide assistance to children and families.

To help all families of children with birth defects locate the resources they need, the program maintains a Genetics Resource Center that includes a support group directory, located at www.MIGeneticsConnection.org. A pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs*, is available at no cost to hospitals, health professionals, and families. Registry staff identified gaps in existing referral systems and as a result, staff developed a Birth Defects Referral Toolkit for health care providers containing comprehensive information about the resources and services available for families of children with birth defects and genetic conditions. Also, staff participates in the development and presentation of Genetics Trainings for parents and health providers through the Michigan Family to Family Health Information & Education Center.



Technical Notes and Definitions

Technical Notes

Important factors to consider when viewing MBDR data

- Analyses presented in the body of this report are based on cases reported to the MBDR with at least one reportable birth defect alone, by one year of age.
- Frequencies include all children reported with a birth defect who were born in Michigan and whose mother was a resident of Michigan at the time of birth. This enables the calculation of birth defects prevalence rates.
- Columns do not add to diagnostic group totals nor column totals due to cases with multiple diagnosed conditions that cross diagnostic groupings.
- Conditions are reportable if identified within the first two years of a child's life.
- Diagnoses are coded using the 9th revision to the International Classification of Diseases—ICD-9-CM.
- Diagnostic Code Groupings used for congenital anomaly codes are as those used by the Centers of Disease Control and Prevention (CDC).

Case Ascertainment

The MBDR relies on a passive system of reporting. Birth defects cases are reported by independent sources, that is, medical facilities and laboratories. The medical information obtained in the form of a case report generally is accepted as reported. In an active surveillance system, the program staff investigates data sources, finding and confirming birth defects cases. More information about case ascertainment can be found in the National Birth Defects Prevention Network's (NBDPN) Guidelines for Conducting Birth Defects Surveillance.⁴



Data Quality Considerations

- The increased numbers of children diagnosed with hearing impairment in evidence since 1997 is related directly to a rapid increase in screening of Michigan newborns for hearing loss by birthing hospitals.
- Increases in frequency of endocrine and metabolic disorders since 1998 are due to coordination of case reporting with the Newborn Metabolic Screening Program.
- A change in ICD-9-CM coding added unique codes for hypospadias and epispadias in October of 1996. This is the cause of the discontinuity in the reported frequencies for these conditions as listed under the diagnostic grouping “H04 Hypospadias and Epispadias (75261, 75262)”.
- The data and analyses presented in this report are affected by three factors that impact data accuracy and comparability:

***Inconsistent or incomplete reporting:**

There is evidence that reporting of birth defects by some facilities is not complete. Very low birth defect frequencies and significant shifts in the number of reported cases can be expected where reporting problems exist. This fact can make comparing specific birth defects rates over time or between geographic regions problematic. MBDR quality assurance work, beginning in 1999 to identify and resolve problems of under-reporting, resulted in birth defects case counts increasing due to more consistent and more complete reporting by facilities.

***Over reporting:**

Hospitals may submit cases of reportable diagnostic conditions which are later ruled out in a child, but the original report is not corrected accordingly. This can cause an over count of the number of cases. This problem can be expected to vary by facility which, in turn, can lead to inflated birth defect frequencies and geographic variation in case frequency counts for those areas where such facilities are located.

Three factors that impact data accuracy and comparability are:

- ✓ **Inconsistent or incomplete reporting**
- ✓ **Over reporting**
- ✓ **Lack of interstate resident data exchange**

***Resident interstate information exchange is lacking:**

There is presently no exchange of data with neighboring states on children born with birth defects. Thus, birth defects cases are unreported whenever a Michigan child is diagnosed with, or treated for, a birth defect in a facility not in Michigan. This problem will cause an undercount of the actual number of cases and can be expected to significantly affect the completeness of reports for counties whose residents commonly travel outside Michigan for their health care. Due to the lack of interstate resident information exchange, rates are calculated only for resident children who are also born in Michigan.

Definitions

Birth defect: An abnormality of the body's structure or inherent function present at birth, whether the abnormality is detected at the time of delivery or at a later time. Some birth defects are minor while others are life-threatening. The causes of many birth defects are still unknown, but some birth defects are caused by genetic factors while others result from exposure to certain drugs, medications, or chemicals.

Case: The count or number of children who were diagnosed with at least one reportable birth defect by one year of age (and were reported to the Michigan Birth Defects Registry). See Appendix B for list of reportable conditions.

Infant fatality rate: The number of deaths by one year of age among those with a specific birth defect divided by the total number of births with the specific birth defect of interest, multiplied by 1,000.

Mortality rate: The number of deaths by one year of age divided by the total number of live births, multiplied by 1,000.

Premature birth: An infant who is born at less than 37 weeks of gestation.

Prevalence rate: The number of cases with a particular reportable birth defect divided by the total number of live births for the specific year of interest. This number is then multiplied by 10,000 to determine the rate per 10,000 live births.

Birth Defect Trends

The overall prevalence rate of birth defects reported by one year of life has increased slightly over the past 14 years. There were about 650 reported defects per 10,000 live births in 1992 and 830 reported defects per 10,000 live births in 2006, as seen in Figure 1. This increase may in part be due to improved reporting and diagnostic techniques, or to changes in population demographics. Population changes may include a shift in the distribution of births by maternal age or race, or a change in the rate of preterm infants. In 2006, the majority of reported birth defects fell into three diagnostic categories: the heart and circulatory system (23%), the musculoskeletal system (20%), and the genitourinary system (17%), as seen in Figure 2. Other birth defects fell into the respiratory system (9%), the integument (8%), the digestive system (7%), and the central nervous system (CNS) (5%) categories. All other diagnostic categories had less than 5% of all reported birth defects. Categories are not mutually exclusive, meaning that an infant could be counted more than once if diagnosed with birth defects in multiple categories. This means that the numbers, and therefore rates, of specific types of birth defects may not reflect the rates of Michigan children with birth defects because some children have multiple defects and are therefore counted more than once by the MBDR.

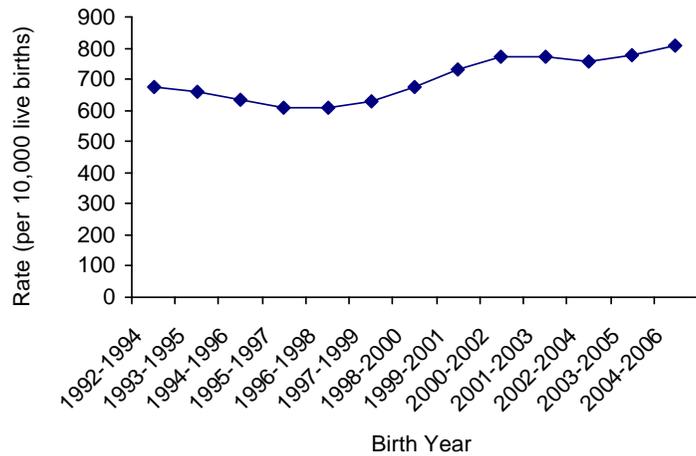


Figure 1: Three year moving average of all birth defects reported by one year of age: MBDR, 1992-2006.

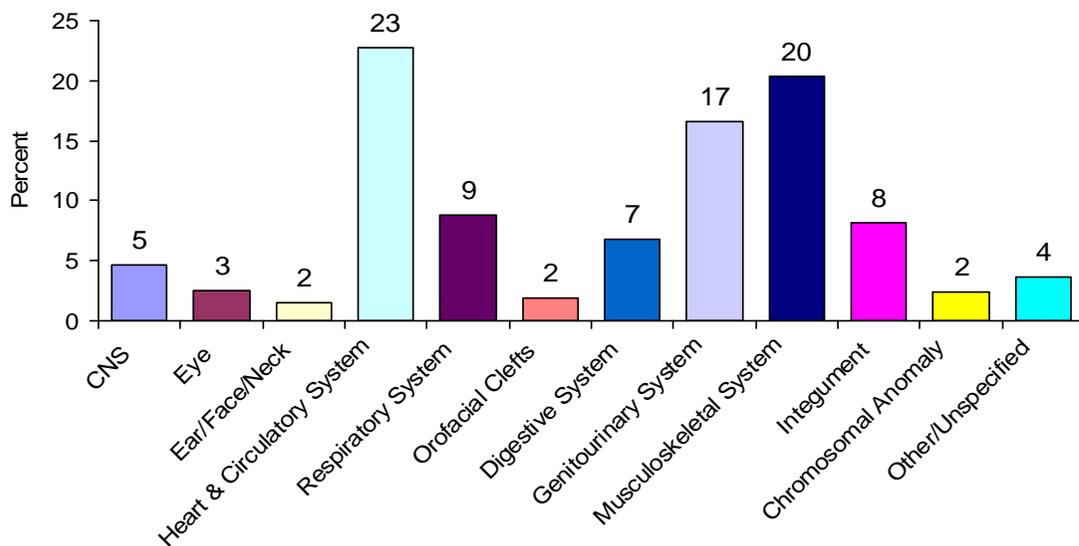


Figure 2: Distribution of birth defect categories in Michigan: MBDR, 2006.

Birth Defects by Race and Ethnicity

Birth defect trends differ by a variety of characteristics, including maternal age, race, ethnicity, and prematurity (infants born at less than 37 weeks gestation). Figure 3 shows the three year moving prevalence rate of all birth defects reported by one year of age, by maternal race and ethnicity from 1996 to 2006. Race is not exclusive to ethnicity and includes both Hispanic and non-Hispanic. Overall, the prevalence rate in blacks was about 34% higher than whites in 1996 and about 75% higher than whites in 2006. For blacks overall, the rate of birth defects increased steadily from about 760 to 1280 cases per 10,000 live births from 1996 to 2006. The birth defect rate in whites remained relatively stable, increasing from about 565 to 700 cases per 10,000 live births from 1996 to 2006. The prevalence of birth defects in Hispanics remained at about 500 cases per 10,000 live births from 1996 to 2006.

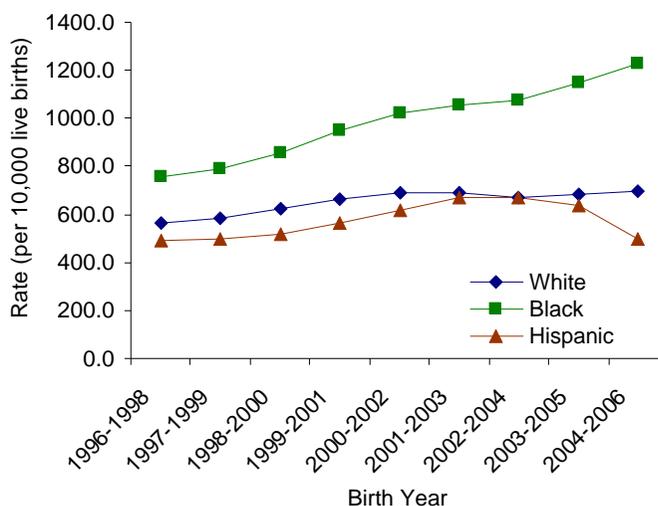


Figure 3: Three year moving average of all birth defects reported by one year of age by maternal race/ethnicity: MBDR, 1996-2006.

Birth Defects by Race and Preterm Births

Infants born preterm are at higher risk of having a birth defect, and analysis of MBDR data reveals that the racial disparity seen in all infants with birth defects may be smaller among infants who are born preterm with a birth defect. The gap in the rate of birth defects between blacks and whites was narrower among infants born preterm compared to all infants. From 1996 to 2006, the prevalence of birth defects in preterm blacks was about 14% higher than the rate of birth defects in preterm whites. In preterm blacks, the birth defect rate increased from about 1380 cases in 1996 to 2160 cases per 10,000 live births in 2006. In preterm whites, the rate of birth defects increased from about 1300 cases in 1996 to about 1890 cases per 10,000 live births in 2006. The rate of defects in preterm Hispanics varied throughout the years, increasing from about 970 cases in 1996 to 1450 cases in 2002 and decreased to about 1110 cases in 2006, all per 10,000 live births (Figure 4).

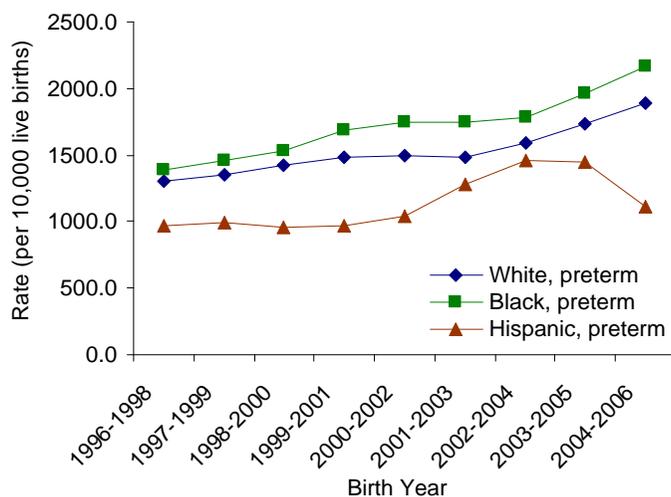


Figure 4: Three year moving average of all birth defects reported by one year of age by maternal race/ethnicity and prematurity: MBDR, 1996-2006.

Birth Defects by Maternal Age

Some birth defects, such as Down syndrome, are more common among infants born to older mothers, while other birth defects, such as orofacial clefts, are more common in infants born to younger mothers.^{7,8} The number of births to older mothers has been increasing over the years. For example, the birth rate for mothers age 35 to 39 increased from 30 to 40 births per 1,000 women from 1996 to 2006.⁹ Figure 5 shows the three year moving prevalence rate of all birth defects reported by one year of age, by maternal age from 1996 to 2006. Rates of birth defects for mothers less than 18 years old or 18 to 44 years old

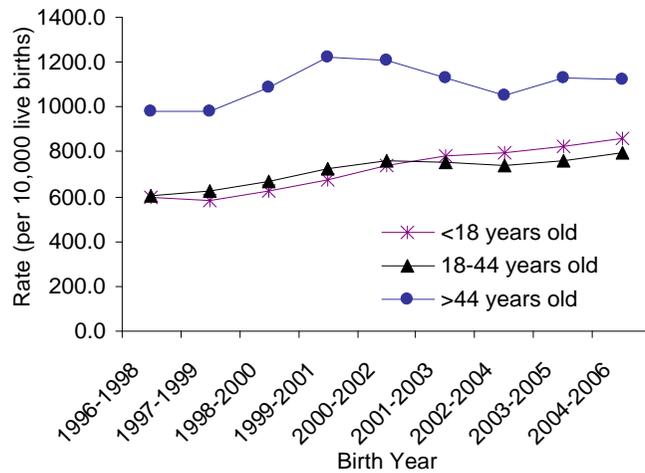


Figure 5: Three year moving prevalence rate of all birth defects reported by one year of age by maternal age: MBDR, 1996-2006.

increased from about 600 cases to 850 cases per 10,000 live births from 1996 to 2006. The rate of birth defects in mothers age 44 years or older remained relatively stable at about 1,100 cases per 10,000 live births from 1996 to 2006.

Birth Defects by Maternal Age and Preterm Births

Analysis of MBDR data reveals that rates of birth defects in infants born preterm differ by maternal age, compared to rates of birth defects in all infants. The rate of birth defects in preterm infants was higher among those age 18 to 44 than in those who were less than 18 years old, compared to birth defect rates in all infants. For preterm births, the rate of birth defects was about 20% higher for women age 18 to 44 than women less than 18 years old. From 1996 to 2006, the rate of birth defects increased from about 1,120 cases to 1,500 cases per 10,000 live births in those who were less than 18 years and had a preterm infant.

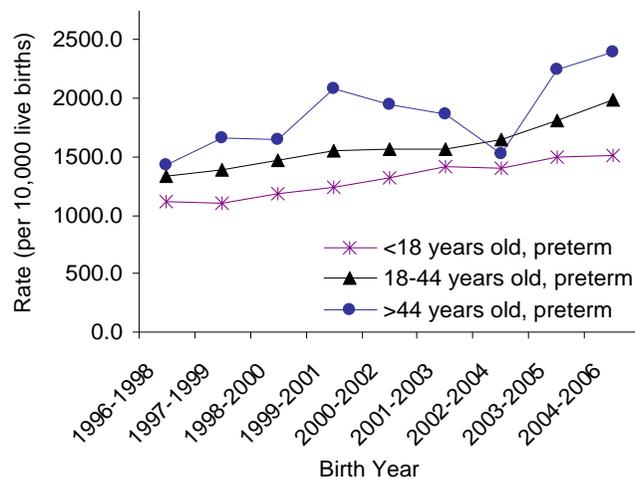


Figure 6: Three year moving prevalence rate of all birth defects reported by one year of age by maternal age and prematurity: MBDR, 1996-2006.

The rate of birth defects in women age 44 years or older and gave birth to a preterm infant varied over the years, but increased overall from about 1,400 cases in 1996 to about 2400 cases per 10,000 live births in 2006 (Figure 6). It is important to analyze birth defect trends on multiple levels in order to identify potential reasons for health disparities and differences in trends by more broad categories such as race or maternal age.

Selected Birth Defect Rates, 1992-2006

Prevalence rates of neural tube defects, orofacial clefts, and Down syndrome (trisomy 21) were analyzed by maternal age, maternal race and ethnicity, and sex of the infant. The three year moving prevalence rates were also calculated to assess trends over time. By analyzing birth defect rates stratified on a variety of factors, health disparities among certain populations can be assessed so that prevention, intervention, and special services can be targeted to high-risk populations. Data on prevalence and mortality rates for additional birth defects in Michigan in local communities and counties can be found online at www.michigan.gov/mdch. Requests for additional birth defects data can be made by contacting the MBDR registrar at: (517) 335-8677.

Of note, the race variable does not include ethnicity information such as Hispanic or Arab, and race categories can include individuals of any ethnicity. Rates were calculated for all children reported with at least one reportable birth defect by one year of age who were born in Michigan and whose mothers were residents of Michigan at the time of birth, from 1992 to 2006. An asterisk indicates that there were fewer than five cases reported during the specified time period.

Table 2: Prevalence of selected birth defects in Michigan diagnosed by one year of age: MBDR, 1992-2006.

Congenital Anomaly (ICD-9-CM)	Rate (per 10,000 live births)¹
Neural Tube Defects (740-742)	6.4
Anencephaly (740.0, 740.1)	1.0
Spina bifida (without anencephaly) (741.0, 741.9, w/o 740.0, 740.1)	4.3
Encephalocele (742.0)	1.1
Orofacial Clefts (749)	15.8
Cleft palate without cleft lip (749.0)	5.7
Cleft lip/palate (749.1, 749.2)	10.0
Down Syndrome (Trisomy 21) (758.0)	11.5

¹Prevalence rates are based on resident occurrences. Data are current through August, 2009.

From 1992 to 2006, the prevalence of neural tube defects (NTD) was 6.4 cases per 10,000 live births. The NTD rate includes 1.0 cases of anencephaly, 4.3 cases of spina bifida, and 1.1 cases of encephalocele, all per 10,000 live births. The prevalence of orofacial clefts was 15.8 cases per 10,000 live births from 1992 to 2006. There were 5.7 cases per 10,000 live births of cleft palate without cleft lip and 10.0 cases per 10,000 live births of cleft lip with or without cleft palate from 1992 to 2006. Overall from 1992 to 2006, the prevalence of Down Syndrome (trisomy 21) was 11.5 cases per 10,000 live births. Rates of these selected defects by Michigan counties and regions approximating hospital-based pediatric specialty services areas can be found in Appendix E and F.

**Approximately 8%
of the 127,537
Michigan newborns
in 2006 were
diagnosed with a
birth defect by one
year of age.**

Neural Tube Defects (NTD)

NTD are serious and often lethal birth defects of the brain and spine that occur during the first 28 days after conception when the neural tube is closing. Anencephaly is a fatal anomaly in which the neural tube fails to close. The brain does not develop properly and may be essentially absent. Spina bifida is the more common form of NTD in which the lower end of the neural tube fails to close, resulting in problems with development of the vertebrae and spinal cord. Encephalocele results from an opening in the skull associated with a skin covered

Children with NTD face high mortality due to the defect itself and to associated medical conditions.

sac-like structure containing central nervous system (brain) tissue or spinal fluid. It is usually fatal but babies who do survive typically have severe mental impairment. To help prevent NTD, the Centers for Disease Control and Prevention (CDC) encourages all women to consume at least 400 micrograms of folic acid every day before and during pregnancy.¹⁰



Figure 7: NTD: Ancephaly (Top), Encephalocele (Middle), and Spina Bifida (Bottom).¹¹

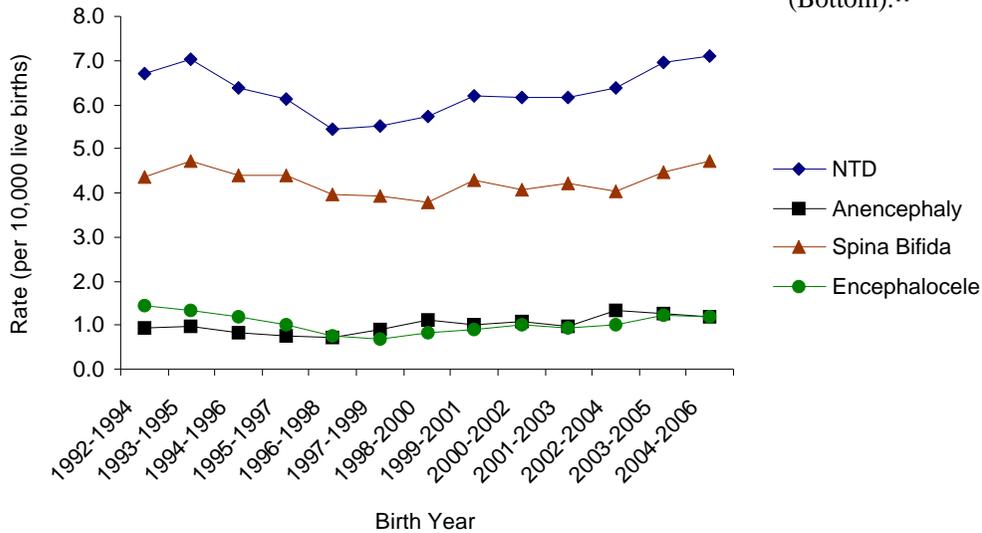


Figure 8. Three year moving prevalence rates of neural tube defects: MBDR, 1992-2006.

From 1992 to 2006, the overall rate of NTD was 6.4 cases per 10,000 live births. The NTD rate remained relatively stable from 1992 to 2006, ranging from about 6.5 to 7.0 cases per 10,000 live births, with a slight increase in 1998 (Figure 8). This slight increase may be due to improved reporting and tracking of NTD. Rates of spina bifida remained stable over the last 14 years at about 4.5 cases per 10,000 live births. Both encephalocele and anencephaly remained stable from 1992 to 2006 at about one case per 10,000 live births for each type of defect.

Table 3: Prevalence rate of neural tube defects stratified by selected demographic variables: MBDR, 1992-2006.

Demographic Variable	Prevalence ^{1,2}			
	Total Neural Tube Defect	Anencephaly	Spina bifida	Encephalocele
Maternal Age				
<20	6.8	1.1	4.2	1.5
20-24	6.5	1.1	4.2	1.2
25-29	6.3	0.9	4.5	0.9
30-34	5.5	0.8	3.9	0.9
35+	6.4	0.8	4.6	1.1
Maternal Race				
Whites	6.3	1.0	4.4	1.0
Blacks	6.2	0.7	3.8	1.7
Other ³	4.6	*	3.8	*
Maternal Ethnicity				
Hispanic	6.3	0.9	4.3	1.2
Arab	3.7	1.0	2.7	*
Sex of Infant				
Male	6.1	0.9	4.1	1.1
Female	6.6	1.1	4.4	1.1

¹Prevalence rates are based on resident occurrences. Data are current through August 2009.

²Prevalence rate expressed as cases per 10,000 live births.

³Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

Overall, infants born to mothers less than 20 years old had a slightly higher rate of NTD with 6.8 cases per 10,000 live births (Table 3). Infants born to mothers who were 30-34 years old had lower rates of all neural tube defects, with about 5.5 cases per 10,000 live births, compared to about 6.5 cases per 10,000 live births in the other age groups.

The overall NTD rate is slightly higher in whites than in blacks (Table 3). The pattern is seen for all types of NTD except for encephalocele. Those of an other race (not white or black) had a lower rate of NTD with 4.6 cases per 10,000 live births compared to about 6.2 cases per 10,000 live births for those who are white or black. Of note, the number of neural tube defects is very low (fewer than 5 cases from 1992 to 2006) for those of an other race, so rate calculations can be unstable. Spina bifida was more prevalent in whites than in blacks, while encephalocele was more prevalent in blacks than in whites.

Overall, the prevalence of NTD was higher in the Hispanic population than in the Arab population (Table 3). The rate of NTD among Hispanics was 6.3 cases per 10,000 live births while the rate of NTD among Arabs was 3.7 cases per 10,000 live births.

The prevalence of NTD was higher in females than in males (6.6 per 10,000 live births compared to 6.1 per 10,000 live births, respectively) (Table 3). This trend was seen among all NTD subtypes except encephalocele.

Orofacial Clefts

An orofacial cleft is a separation or split in part of the face that should normally be closed or joined together. Clefts can occur in the developing lip, as well as in the hard and soft palate of the mouth. Two major categories of orofacial clefts are cleft lip with or without cleft palate, and isolated cleft palate. Orofacial clefts occur very early in embryonic development—by 5 to 6 weeks after conception for clefts of the lip and by 10 weeks for palate malformations. A cleft may affect only one side of the lip and/or palate (unilateral) or both (bilateral). It may also affect the way the nose is formed and/or extend into the gum or upper jawbone. Rarely, oblique, lateral transverse and complex facial clefts occur. Babies with an orofacial cleft usually do not have other health problems unless the cleft is part of a genetic syndrome associated with other birth defects. Children with orofacial clefts usually undergo one or more surgical repairs early in life and may later need orthodontic care and speech therapy. They may also require special feeding techniques, and have a greater risk of ear infections. Babies with an orofacial cleft usually do not have other health problems unless the cleft is part of a genetic syndrome associated with other birth defects. Both genetic and environmental factors play a role in the etiology of orofacial clefting. Recent studies by the CDC indicate that maternal use of multivitamin with folic acid may reduce the risk of some orofacial clefts.¹²



Figure 9: Cleft Lip (Top) and Cleft Palate (Bottom).¹¹

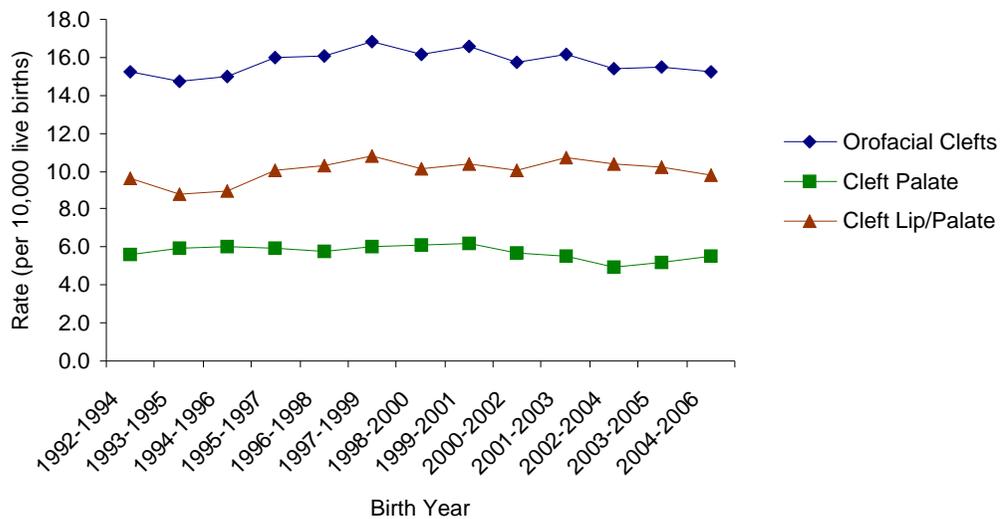


Figure 10: Three year moving prevalence rates of orofacial clefts: MBDR, 1992-2006.

Overall, from 1992 to 2006, the prevalence of orofacial clefts was 15.8 cases per 10,000 live births. Rates of orofacial clefts remained relatively stable from 1992 to 2006 at about 16 cases per 10,000 live births. Rates of each category of orofacial clefts also remained stable with about 6 cases of isolated cleft palate, and about 10 cases of cleft lip/palate per 10,000 live births (Figure 10). The prevalence rate of cleft lip with or without cleft palate was about twice the rate of cleft palate alone.

Table 4: Prevalence rate of orofacial clefts stratified by selected demographic variables: MBDR, 1992-2006.

Demographic Variable	Prevalence ^{1,2}		
	Total Orofacial Cleft	Cleft palate	Cleft lip/palate
Maternal Age			
<20	17.0	6.0	11.1
20-24	17.0	5.3	11.8
25-29	14.5	5.8	8.6
30-34	15.2	5.6	9.6
35+	15.2	5.7	9.5
Maternal Race			
Whites	16.7	5.9	10.8
Blacks	11.0	4.7	6.3
Other ³	15.8	5.4	10.4
Maternal Ethnicity			
Hispanic	13.5	3.4	10.1
Arab	8.5	3.9	4.5
Sex of Infant			
Male	17.3	5.1	12.2
Female	14.0	6.3	7.7

¹ Prevalence rates are based on resident occurrences. Data are current through August 2009

² Prevalence rate expressed as cases per 10,000 live births.

³ Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

Overall, orofacial clefts were more prevalent in infants born to younger mothers (less than 24 years old) (Table 4). For mothers who were 24 years of age or younger, the rate of orofacial clefts was 17.0 cases per 10,000 live births while for mothers older than 24, the rate was about 15 cases per 10,000 live births. This trend has also been seen at the national level by previous research.⁷ In Michigan, the higher rate of orofacial clefts among younger mothers appears to be driven by rates of cleft lip with or without palate since the prevalence of cleft palate seems to be consistent across all maternal age categories.

The prevalence rate of orofacial clefts in whites was 16.7 cases per 10,000 live births, while blacks had a lower prevalence with 11.0 cases per 10,000 live births (Table 4).

Mothers of Hispanic ethnicity had a higher rate (13.5 cases per 10,000 live births) of orofacial clefts than those of Arab ethnicity (8.5 cases per 10,000 live births) (Table 4).

Orofacial clefts were slightly more common in males than in females with 17.3 cases per 10,000 live births in males and 14.0 cases per 10,000 live births in females (Table 4). Again, these patterns tend to be due to differing rates of cleft lip with or without cleft palate since the rates of cleft palate alone are quite similar between these groups. Cleft lip/palate and cleft palate alone may have different etiologies as evidenced by the disparity in cleft lip/palate rates and the relative consistency of the cleft palate rates across maternal age, maternal race, maternal ethnicity, and infant sex groups.

Infants with orofacial clefts may have problems with feeding, speech, and hearing.

Down Syndrome (Trisomy 21)

Down syndrome, also referred to as trisomy 21, is a lifelong condition caused by the presence of an extra copy of the twenty-first chromosome. It is the most common chromosome abnormality occurring in live born infants, and is associated with varying degrees of mental retardation. About 50% of children with Down syndrome also have a congenital heart defect. Other characteristics may include a variety of physical signs such as particular facial features, digestive system problems, increased risk of infections as well as increased risk of hearing and vision problems. The most common known risk factor for Down syndrome is advanced maternal age (35 years of age or older).⁸



Figure 11: Down syndrome.¹¹

Approximately 50% of children with Down Syndrome also have a congenital heart defect.

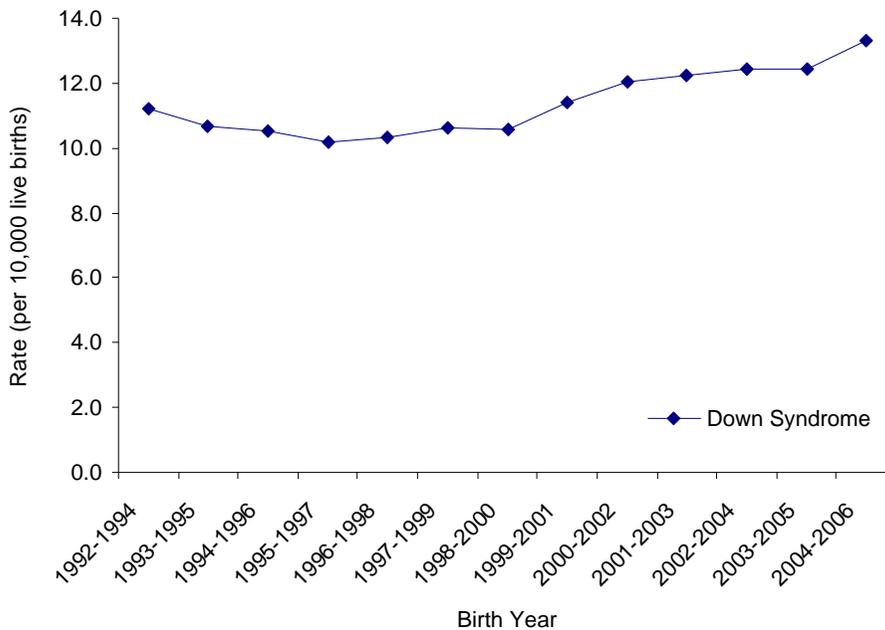


Figure 12: Three year moving prevalence rates of Down syndrome: MBDR, 1992-2006.

The overall rate of Down syndrome from 1992 to 2006 was 11.5 cases per 10,000 live births. The rate of Down syndrome has been increasing since about 1999 (Figure 12). In 1992, there were about 11 cases per 10,000 live births and in 2006 there were about 13 cases per 10,000 live births. Other chromosomal anomalies are much less prevalent than Down syndrome. Of note for other chromosomal defects, the prevalence of Trisomy 13 was 0.6 cases per 10,000 live births in 2006 and the prevalence of Trisomy 18 was 1.1 cases per 10,000 live births in 2006.

Table 5: Prevalence rate of Down syndrome stratified by selected demographic variables: MBDR, 1992-2006.

Demographic Variable	Prevalence of Down Syndrome ^{1,2}
Maternal Age	
<20	6.0
20-24	7.0
25-29	6.8
30-34	11.1
35+	37.4
Maternal Race	
Whites	12.1
Blacks	8.7
Other ³	10.9
Maternal Ethnicity	
Hispanic	12.2
Arab	11.4
Sex of Infant	
Male	12.2
Female	10.7

¹ Prevalence rates are based on resident occurrences. Data are current through August 2009.

² Prevalence rate expressed as cases per 10,000 live births.

³ Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

As seen in Table 5, the highest prevalence of Down syndrome was in infants born to women over 35, with a rate of about 37 cases per 10,000 live births, compared to all other age groups with prevalence as follows: 6.0 cases in women less than 20 years old, 7.0 cases in women 20-24 years old, 6.8 cases in women 25-29 years old, and 11.1 cases in women 30-34 years old, all per 10,000 live births.

The prevalence rate of Down syndrome was lower in blacks with 8.7 cases per 10,000 live births, compared to whites with a prevalence of 12.1 cases per 10,000 live births (Table 5). Those of another race (not black or white) had a Down syndrome prevalence of 10.9 cases per 10,000 live births from 1992 to 2006.

Those of Hispanic ethnicity had a higher prevalence rate of Down syndrome with 12.2 cases per 10,000 live births, compared to those of Arab ethnicity with 11.4 cases per 10,000 live births (Table 5). Additional analyses of these populations should be performed to assess maternal age differences in order to help determine if this plays a role in the prevalence rate difference.

Males had a slightly higher prevalence of Down syndrome with about 12 cases per 10,000 live births, compared to females with about 11 cases per 10,000 live births (Table 5).

Fatality and Mortality Rates in Children with Birth Defects, 2004 – 2006

The mortality experienced by Michigan children with birth defects is appreciably higher than for children in general. Birth defects registry data indicate that the contribution of birth defects to infant and childhood fatality is more than twice that indicated by cause of death data alone. The relative risk of death for children with birth defects is roughly five times that of other children. The elevated relative risk of death for children with birth defects is highest in children age one to two years old. Children with birth defects constitute 46% of the deaths in this age group, with relative risk of mortality that is six times the mortality rate of other children. Elevated mortality is experienced by children in the registry for all ages examined, including through the age of 14 years.

Children with birth defects make up 46% of the deaths in those age one to two years old.

Table 6: Infant fatality and mortality rates for Michigan children with selected birth defects: MBDR, 2004-2006.

Congenital Anomaly (ICD-9-CM)	Fatality Rate (per 1,000 cases)¹	Mortality Rate (per 1,000 live births)¹
Neural Tube Defects	234.4	0.17
Anencephaly	891.3	0.11
Spina bifida (without anencephaly)	66.3	0.03
Encephalocele	239.1	0.03
Orofacial Clefts	75.0	0.11
Cleft palate without cleft lip	47.4	0.03
Cleft lip/palate	90.4	0.09
Down Syndrome (Trisomy 21)	66.4	0.09
All Reportable Birth Defects	35.6	2.9

¹Infant fatality and mortality rates are based on resident occurrences of cases identified in the first year of life. Data are current through August 2009.

Infant *fatality* is defined as the number of deaths in the first year of life divided by the number of infants with a specific birth defect (and then multiplied by 1,000 to determine the rate per 1,000 infants). This is different than *mortality* which is defined as the number of deaths in the first year of life divided by the number of all infants born within the specified time period.* Table 6 shows the fatality and mortality rates in children born from 2004 to 2006 with NTD, orofacial clefts, and Down syndrome. For infants with one or more reportable birth defect, the fatality rate was 35.6 deaths per 1,000 cases while the mortality rate was 2.9 deaths per 1,000 live births. This compares to the overall infant mortality rate for **all** resident infants of 7.6 deaths per 1,000 live births from 2004 to 2006. The fatality rate in infants with NTD was 234.4 deaths per 1,000 cases of NTD and the mortality rate was 0.17 deaths per 1,000 live births. Fatality associated with spina bifida is far less than fatality associated with anencephaly or encephalocele. While anencephaly is uniformly fatal, reporting errors likely explain the rates presented here. The orofacial cleft fatality rate was 75.0 deaths per 1,000 cases of orofacial clefts and the mortality rate was 0.11 per 1,000 live births. Among infants with Down syndrome, there were about 66 deaths per 1,000 cases and the mortality rate was 0.09 deaths per 1,000 live births.

*Previous Michigan Birth Defect Reports used the term mortality to refer to fatality.

The mortality of children in the registry is routinely monitored using a passive system of annual birth-death matching for all children in the registry. To examine the resulting data in a meaningful way, comparative data on the mortality of all Michigan children is also routinely developed. The result is a unique resource for studying the long-term effects of birth defects on infant and childhood health and survival. These data can be used to evaluate the risk of mortality for children with specific defects. Mortality rates and relative risk by age can also be monitored using this information, along with trends in mortality over time.

Children with birth defects are at much greater risk of death due to causes other than a birth defect (for example, accidental causes).³

Presently, the MBDR contains data on mortality in children through 14 years of age. The information includes the mortality experience of 139,396 children born with birth defects over the years from 1992 through 2006 and for 1,864,290 Michigan resident/occurrent births (see *Technical Notes*) over these same years for children without reported birth defects. Altogether, approximately 16,700 deaths have occurred within both cohorts with about 3,000 of those deaths in children with birth defects and 13,700 deaths among those without birth defects.

These striking statistics underscore the increased need for support experienced by so many of these families and children who have life-limiting conditions. Hospice and palliative care programs provide pain management, symptom control, psychosocial support, and spiritual care to patients and their families. They also serve as important sources of information about care options. Hospice and palliative care programs with a focus on pediatric care can be found throughout the state.

HOSPICE is a philosophy of care created to help individuals with life-limiting conditions live with dignity, comfort, and compassion. Hospice and palliative care programs provide pain management, symptom control, psychosocial support, and spiritual care to patients and their families. They also serve as important sources of information about care options.

—National Hospice and Palliative Care Organization

A Closer Look: Congenital Heart Defects

Overall, the birth defect rate is higher among blacks than in whites and in this section, we assess the racial disparity in the rate of congenital heart defects (CHDs). CHDs are one of the most common congenital anomalies, affecting 1 in 100 to 1 in 200 infants born in Michigan every year.¹³ The heart starts to develop about 20 days after fertilization and a CHD can occur at any stage of development. There are many different types of heart defects affecting the atria, ventricles, arteries, and any other area of the heart. The most common types of CHDs are ventricular septal defect (VSD) and atrial septal defect (ASD), in which a hole in the wall (septum) separating the heart chambers interrupts the flow of blood to the body. Heart defects can range from minor conditions that may go undiagnosed for many years to severe malformations that cause death soon after birth. Treatment may include surgery or regular monitoring depending on the severity of the condition.



Only about 15% of CHDs have a known cause.¹⁴ Although the cause of many CHDs is unknown, some genetic and maternal factors have been shown to be risk factors. Non-inherited risk factors for CHDs include: harmful prenatal exposures such as tobacco and alcohol; maternal conditions such as obesity, diabetes and hypertension; maternal infections such as rubella and influenza; and maternal medications such as isotretinoin (used as acne medicine) and anti-seizure medications.¹⁵

The three year moving prevalence of all *major* CHDs is shown in Figure 13. All major CHDs includes all those found in Table 7 (page 29) *except* ‘all other heart and circulatory anomalies.’ In Michigan, the prevalence of CHDs reported by 1 year of age for whites increased slightly from about 99 cases per 10,000 live births in 1992 to about 135 cases per 10,000 live births in 2006 (Figure 13). For blacks, the prevalence of CHDs increased from about 110 cases per 10,000 live births in 1992 to about 183 cases per 10,000 live births in 2006 (Figure 13). On average, the CHD rate was about

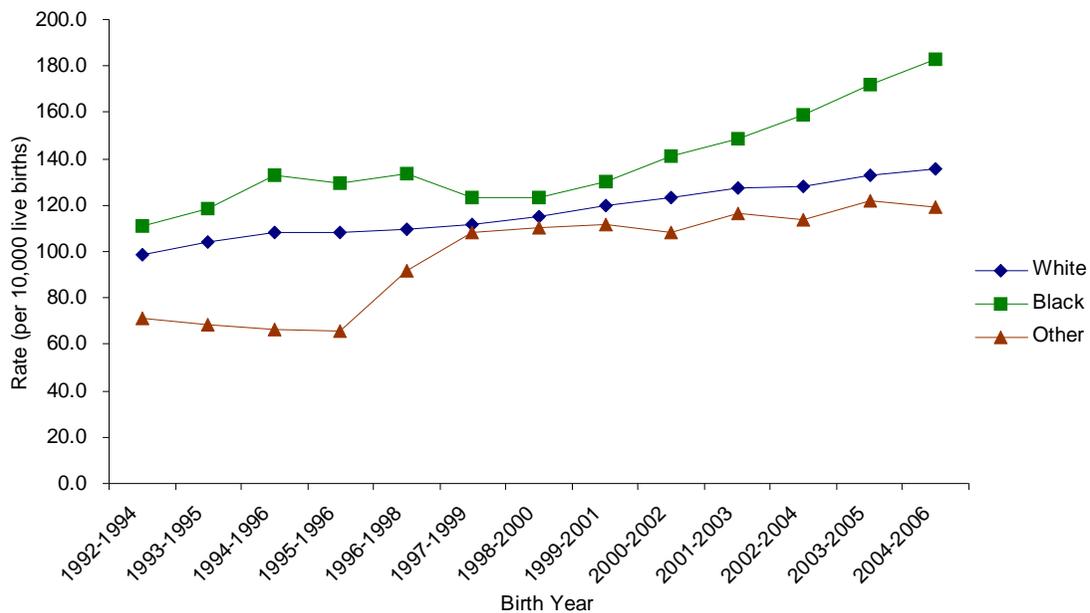


Figure 13: Three year moving average of major congenital heart defects by race: MBDR, 1992-2006.

20% higher in blacks, compared to the rate in whites. For those of some other race (neither black nor white) the CHD prevalence increased from about 71 cases per 10,000 live births in 1992 to about 118 cases per 10,000 live births in 2006 (Figure 13).

The rate of congenital heart defects in blacks is 20% higher than the rate in whites.

Research has shown that some increase in prevalence may be due to advances in technology and improved diagnostic techniques, but the explanation for this disparity in CHD prevalence between white and black populations remains unknown.¹⁰ Some possible explanations for the racial disparity include improved access to care for blacks, differences in maternal age, and differences in diagnostic evaluations for infants with multiple anomalies or low birth weight. In this section, heart defects are assessed by type of CHD, maternal age, and preterm birth, all stratified by race.

Certain types of CHDs are more common in whites while others are more common in blacks. Overall from 1992 to 2006, the prevalence rate of VSD was 42.1 cases per 10,000 live births in whites while in blacks, the rate was 34.3 cases per 10,000 live births (Table 7). The rate of ASD was 59.5 cases per 10,000 live births in whites while for blacks, the rate was 70.8 cases per 10,000 live births (Table 7). In whites, the prevalence of patent ductus arteriosus was 39.2 cases per 10,000 live births while in blacks the prevalence was 49.6 cases per 10,000 live births (Table 7). Prevalence rates of other types of CHDs by race are shown in Table 5. The ‘all other’ category includes some minor and unspecified heart defects and they are not included in the analysis of CHDs on the following pages.

Table 7: Prevalence rate of congenital heart defects by race: MBDR, 1992-2006.

Heart Defect	Rate (per 10,000 live births) ¹			
	Total	White	Black	Other ²
All Heart Defects	155.8	145.4	201.3	125.9
Common Truncus	1.2	1.3	1.1	0.5
Transposition of Great Vessels	4.8	4.9	3.9	3.7
Tetralogy of Fallot	5.4	5.5	5.2	4.6
Ventricular Septal Defect (VSD)	40.9	42.1	34.3	40.2
Atrial Septal Defect (ASD)	61.3	59.5	70.8	48.3
Endocardial Cushion Defect	5.0	5.0	4.9	4.0
Pulmonary Valve Atresia and Stenosis	11.2	10.4	14.6	10.9
Tricuspid Valve Atresia and Stenosis	1.3	1.2	1.7	1.1
Ebstein's Anomaly	1.3	1.4	0.7	0.9
Aortic Valve Stenosis	2.4	2.7	1.0	2.9
Hypoplastic Left Heart Syndrome	3.8	3.8	3.5	3.7
Patent Ductus Arteriosus	41.1	39.2	49.6	31.6
Coarctation of Aorta	5.6	5.8	4.8	4.9
Pulmonary Artery Anomalies	17.8	15.8	26.1	16.0
All other Heart & Circulatory Anomalies	72.8	65.2	106.2	53.8

¹Prevalence rates are based on resident occurrences. Data are current through August, 2009.

²Encompasses women who do not define themselves as black or white and includes Native American, Asian/Pacific Islander, etc.

CHD by Maternal Race and Age

Maternal age may be a risk factor for having an infant with a CHD. Some research has shown that mothers who were 35 years or older were at increased risk of having an infant with all types of heart defects, including tricuspid atresia and right outflow tract defects, while younger mothers, age 20 to 24, had decreased risk of having an infant with other heart defects, such as transposition of the great vessels.⁷ Other researchers found that tetralogy of Fallot, coarctation of the aorta, VSD, ASD, and others were associated with increased maternal age.¹⁷

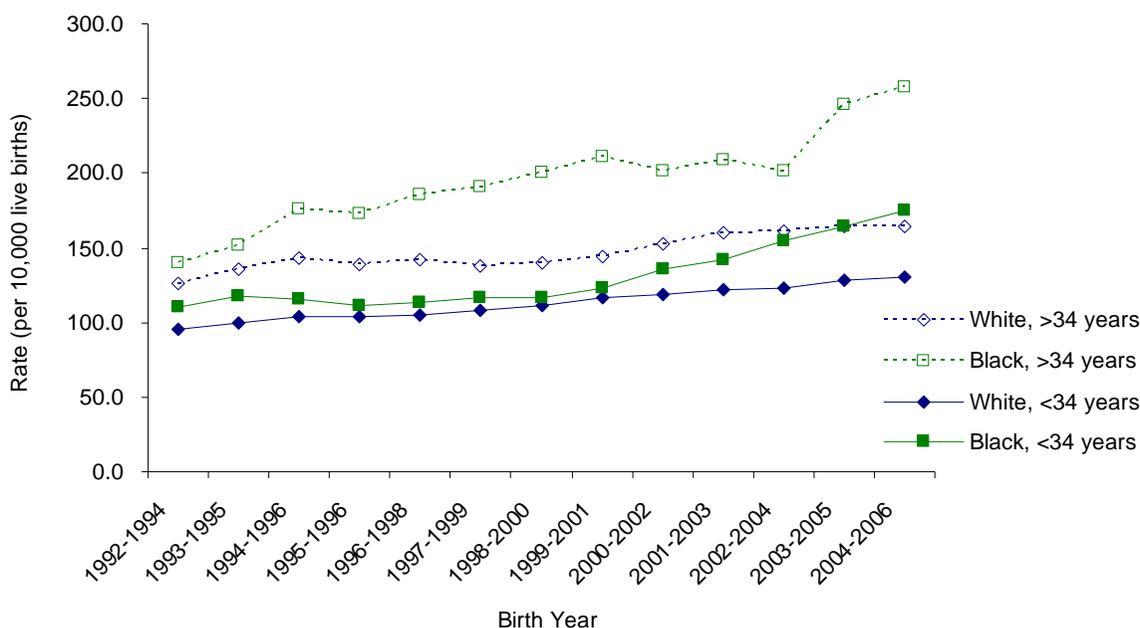


Figure 14: Three year moving average of major congenital heart defects by maternal race and age: MBDR, 1992-2006.

Analysis of the MBDR data reveals that for both blacks and whites, the CHD rate was higher for mothers older than 34 years compared to mothers who were less than 20 to 34 years old. *Black* mothers age 34 or older had a higher prevalence of CHDs than *whites* or younger mothers.

For **whites**, the rate of major CHDs for *younger* mothers (less than 34 years) increased from about 96 cases per 10,000 live births in 1992 to about 130 cases per 10,000 live births in 2006. This compares to *older* white mothers (age 34 or older) where the CHD rate increased from about 127 cases per 10,000 live births in 1992 to about 165 cases per 10,000 live births in 2006 (Figure 14). On average, the CHD rate for white mothers older than 34 years was about 30% higher than the rate for younger white mothers.

For **blacks**, the rate of major CHDs for *younger* mothers (less than 34 years) increased from about 110 cases per 10,000 live births in 1992 to about 175 cases per 10,000 live births in 2006. Moreover, the CHD rate for *older* black mothers (age 34 or older) increased from about 140 cases per 10,000 live births to about 258 cases per 10,000 live births in 2006 (Figure 14). The CHD rate for black mothers older than 34 years was about 50% higher than the rate for younger black mothers.

CHD by Maternal Race and Preterm Birth

Infants who are born preterm (less than 37 weeks gestation) may have increased risk of having CHDs. Some researchers found that preterm infants had more than twice as many heart defects as infants who are born at term (greater than 37 weeks) and that preterm infants were more likely to have pulmonary atresia with VSD and ASD.¹⁸ Moreover, other researchers found that the risk of being born premature with CHDs was higher among blacks than among whites.¹⁹ Premature infants are often born at a low birth weight (less than 2500 grams) and are at higher risk of having a birth defect or other medical issues because organs do not have enough time to grow and develop normally.

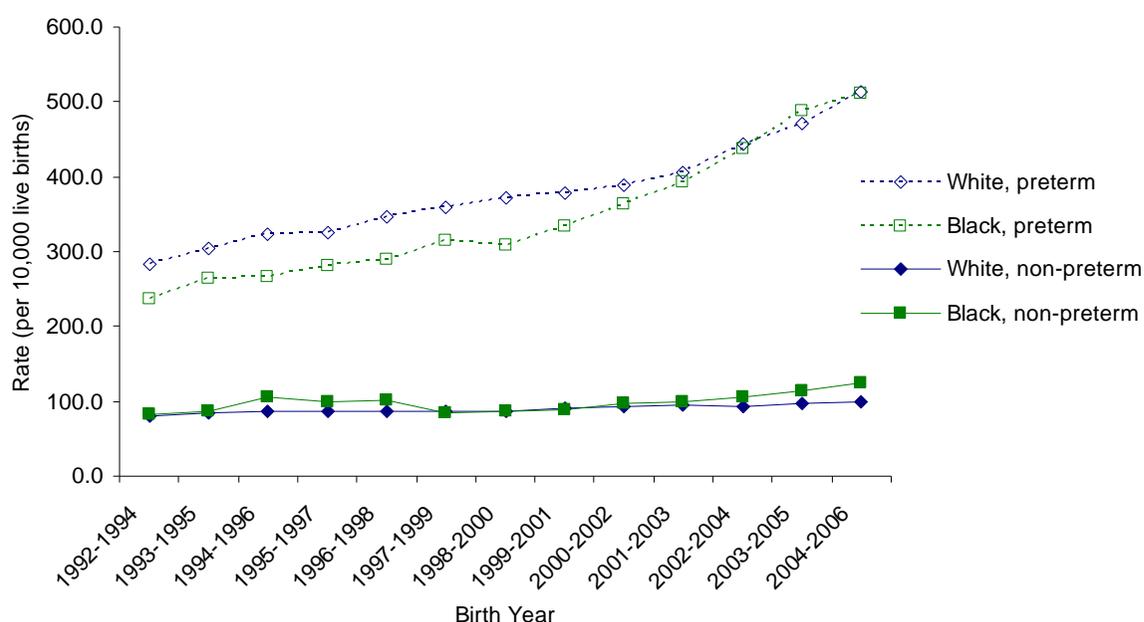


Figure 15: Three year moving average of major congenital heart defects by race and prematurity: MBDR, 1992-2006.

Analysis of the MBDR data reveals that for both blacks and whites, the CHD rate in preterm infants was higher than the rate in non-preterm infants. In 2006, the CHD rate in preterm infants was about 4.5 times the rate in non-preterm infants, for both black and white populations (Figure 15). The racial disparity among black and white populations seen in the overall CHD prevalence was not seen when the rate was categorized by prematurity. MBDR data also revealed that *white* preterm infants had higher CHD rates from 1992 to 2002, compared to blacks. From 2002 to 2006, CHD rates in preterm infants were similar among whites and blacks.

For **whites**, the rate of major CHD in *non-preterm* infants remained stable at about 95 cases per 10,000 live births from 1992 to 2006, while the rate for *preterm* infants increased from about 284 cases per 10,000 live births in 1992 to about 510 cases per 10,000 live births in 2006 (Figure 15).

For **blacks**, the rate of major CHD in *non-preterm* infants remained stable at about 95 cases per 10,000 live births from 1992 to 2006. The CHD rate for black *preterm* infants increased from about 236 cases per 10,000 live births in 1992 to about 510 cases per 10,000 live births in 2006 (Figure 15).

CHD Infant Fatality by Race

Heart defects can range from minor conditions that may not be diagnosed for many years to severe malformations that cause death soon after birth. Figure 16 shows the five year moving average of CHD infant fatality rates (the number of deaths in the first year of life divided by the number of CHD cases) from 1992 to 2006. Overall, the infant fatality rate due to major congenital heart defects decreased by about 50% from 1992 to 2006. The CHD infant fatality rate for both blacks and whites decreased at about the same rate over the years, but was about 25% higher in blacks, compared to whites from 1992 to 2002. The average infant fatality rate for both blacks and whites was 4.2 deaths per 1,000 CHD cases from 2002-2006.

For **whites**, the infant fatality rate decreased from 9.2 deaths per 1,000 CHD cases in 1992 to 4.2 deaths per 1,000 CHD cases in 2006. For **blacks**, the infant fatality rate decreased from 10.1 deaths per 1,000 CHD cases in 1992 to 4.2 cases per 1,000 CHD cases in 2006 (Figure 16). Of note, racial disparities are seen in overall infant fatality and mortality rates. The cause for disparities in CHD fatality or mortality is still unknown, but may be explained by access to care, complications from additional defects, or other factors.¹⁶

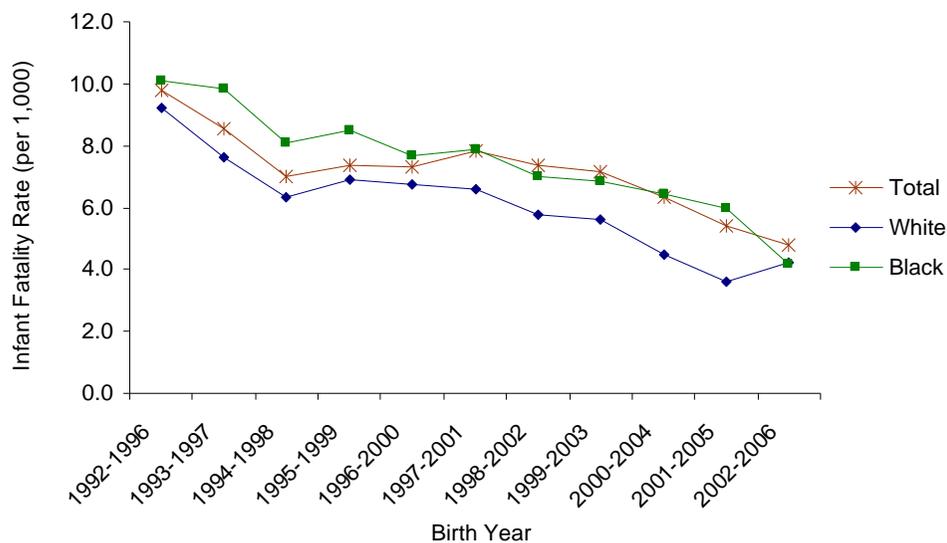


Figure 16: Five year moving average of infant fatality rates for major congenital heart defects by race: MBDR, 1992-2006.

Studies and Publications (2007-2010)

Presentations

Lauber C, Silva W. **A Public Health Approach to FASD Prevention: An Urban Clinic Intervention with At-Risk Women and Database Linking to Identify At-Risk Children.** The 1st International Conference on Fetal Alcohol Spectrum Disorder Research, Policy and Practice Around the World 2007.

Reimink B, Ehrhardt J, Bach J, Grigorescu V. **Teens with Diabetes Mellitus: Promoting Preconception Care to Prevent Adverse Pregnancy Outcomes.** NBDPN Annual Conference 2010, Healthy Mothers, Healthy Babies Conference 2010.

Reimink B, Ehrhardt J, Langbo C, Bach J, Grigorescu V. **Clinical Genetic Services: A View from Michigan's Children's Special Health Care Services' (CSHCS) Families.** NBDPN Annual Conference 2010, Michigan Epidemiology Conference 2010.

Reimink B, Kleyn M, Grigorescu V. **Identification of Birth Defects in Michigan Infants with Sickle Cell Disease and Sickle Cell Trait: MI NBS and MBDR Data, 2004-2006.** Maternal and Child Health Epidemiology Conference 2010.

Reimink B, Kleyn M, Grigorescu V. **Risk Factors Associated with Early Hearing Diagnostic Evaluation Among MI Infants: MI EHDI and MBDR Data, 2004-2006.** Michigan Epidemiology Conference, 2010.

Articles

Copeland G, Kirby R. **Using Birth Defects Registry Data to Evaluate Infant and Childhood Mortality Associated with Birth Defects: An Alternative to Traditional Mortality Assessment Using Underlying Cause of Death Statistics.** Birth Defects Research Part A: Clinical and Molecular Teratology 79:792-797 2007.

Hirsch J, Copeland G, Donohue J, Kirby R, Grigorescu V, Gurney J. **Population-based Analysis of Survival for Hypoplastic Left Heart Syndrome.** Accepted for Publication Journal of Pediatrics.

Yanni EA, Copeland G, Olney RS. **Birth Defects and Genetic Disorders Among Arab Americans-Michigan, 1992-2003.** J Immigr Minor Health. 2008 Oct 30.

Newsletters

Kleyn M, Pollett J, Ehrhardt J, Bach J, Grigorescu V. Michigan Department of Community Health. *Michigan Monitor.* Volume 2, Issue 1. Fall 2008.—**Children's Special Health Care Services**

Reimink B, Ehrhardt J, Bach J, Grigorescu V. Michigan Department of Community Health. *Michigan Monitor.* Volume 4, Issue 1. Spring 2010.—**Health Disparities and Congenital Heart Defects**

Reimink B, Ehrhardt J, Grigorescu V, Bach J. Michigan Department of Community Health. *Michigan Monitor.* Volume 4, Issue 2. Summer 2010.—**Birth Defects and Hearing Loss**

Schierbeek B, Ehrhardt J, Bach J, Korzeniewski S, Grigorescu V. Michigan Department of Community Health. *Michigan Monitor.* Volume 3, Issue 1. Fall 2009.—**Teens with Diabetes**

Thumma J, Ehrhardt J, El Reda D, Bach J, Grigorescu V. Michigan Department of Community Health. *Michigan Monitor.* Volume 1, Issue 1. Summer 2007.—**Folic Acid**

State and National Resources

After the birth or adoption of a child with special needs, parents sometimes have questions. There are many programs in Michigan available free of charge. Many programs are run by parents who want to share information.

Family Support

The Birth Defects Follow-up Program at the Michigan Department of Community Health (MDCH) can help with referrals for support and services. The program provides resource information for families and health care providers. To speak with the follow-up coordinator or receive materials, call toll-free (866) 852-1247, e-mail BDRFollowup@michigan.gov or visit www.MIGeneticsConnection.org.

Families of children with all types of special needs share information and support in the **Family Support Network of Michigan**. To contact the network, call the Children's Special Health Care Services (CSHCS) Family Phone Line at (800) 359-3722.

The purpose of the Michigan **Family to Family Health Information Education Center (F2FIEC)** is to improve access to quality care and support for children with special needs in their communities by empowering families. The Center is administered by the **Parent Participation Program (PPP)** a section of Children's Special Health Care Services (CSHCS). For details, phone the CSHCS Family Phone Line at 1-800-359-3722.

Bridges4Kids is a parent organization providing a comprehensive system of information and referral for parents of all children from birth to adult life with a special focus on those who have disabilities, special needs, or who are at-risk. For more information visit www.bridges4kids.org.

Family Support Services are offered through local community mental health agencies. Case management can help arrange services. Behavior intervention, family skills development, and respite care services are also available. Through respite care, families get a short break from caring for a child with special needs. To apply for family support services, call your local **Community Mental Health Services Program** listed in the business section or yellow pages. If you need help finding the telephone number, call the Michigan Association of

Community Mental Health Boards at (517) 374-6848.

Parent HELPLine is a service of Gateway Community Services, funded by the Department of Human Services. It is available to anyone who needs help right away. The HELPLine is open 24 hours a day, seven days a week. Trained counselors provide crisis counseling, support and information. The free, confidential number is (800) 942-HELP.

The **Parent Empowerment Project** serves families caring for children who are medically fragile or technology dependent. Parent advocates can provide information and informal support. For more information, call (800) 262-0650.

Project PERFORM is a support and resource center for families of children with special needs. The project provides information folders, a lending library, and one-on-one support. Parents oversee the center and answer calls at (800) 552-4821.

Special Health Care: Local health departments provide information about **Children's Special Health Care Services (CSHCS)**. CSHCS helps to coordinate and pay for hospital and outpatient medical *specialty* care. Help may also be available for travel expenses related to a child's medical care. More than 2,000 diagnoses are eligible for coverage. For more information about CSHCS call (800) 359-3722. Children with developmental disabilities who reside with their birth or adoptive parents and are in need of intensive community living supports and/or private duty nursing services may be eligible for the **Children's Waiver Program**. Contact your local Community Mental Health Services Program directly for more information. If you need the telephone number, call (517) 374-6848.

Special Products

Advances in technology and new products help many children with special needs. **Michigan's Integrated Technology Supports (MITS)** has product information from more than 3,000 companies. Staff can help you find adaptive devices, special toys, clothing, equipment, and much more. Call (517) 908-3916, or see www.mits.cenmi.org.

Early Intervention

One of the most important support systems for young children with special needs is called **Early On® Michigan**. It provides services for eligible children from birth to age three and their families regardless of income. Examples of included services are: occupational, physical and speech therapy. For more information, call (800) EARLY-ON (800-327-5966) voice and TDD; or visit www.1800EarlyOn.org.

Special Education

Special education may help children who have physical, emotional, or mental conditions that prevent them from keeping up with others their age. Many services are offered free of charge by your public school system. **Project Find** helps to arrange a free evaluation through the local school district for any child who might need special education. For more information, call (800) 252-0052 or visit www.projectfindmichigan.org.

The **Center for Educational Networking** responds to the information needs of families, educators, and others who have a vested interest in the education of individuals with disabilities. Visit www.cenmi.org to view the Michigan directory of services providers for infants, toddlers, and students with disabilities or call (888) 463-7656.

Financial Support

State and federal programs provide financial support to many families. Eligibility is usually based on the child's diagnosis and family income.

Supplemental Security Income (SSI) is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional and physical disabilities. The family income must meet certain guidelines. To

find out more, call the Social Security Administration at (800) 772-1213.

The **Family Support Subsidy Program** provides monthly payments to some families whose child is severely mentally or multiply impaired, or autistic impaired as determined by the public school system. To apply for the **Family Support Subsidy Program**, call your local Community Mental Health Services Program. If you need the number, call (517) 374-6848.

The **Children with Special Needs Fund** provides funds for equipment such as therapeutic tricycles or wheelchair ramps when there is no other source of payment. Families with a child enrolled or medically eligible to enroll in Children's Special Health Care Services (CSHCS) may apply at their local health department or by calling (800) 359-3722 or (517) 241-7420.

Genetic Counseling

Genetics clinics offer evaluation and counseling. The clinic visit may provide information about a child's diagnosis, what to expect in the future, and whether the same condition could affect other people in the family. The **Genetics Program** of the Michigan Department of Community Health maintains partnerships with a statewide network of genetics clinics. Call toll-free (866) 852-1247 or visit www.MIGeneticsConnection.org for more information.

Newborn Screening

Newborn babies in Michigan are screened for more than 40 rare, but treatable, disorders. Michigan's **Newborn Screening (NBS) Follow-up Program** at the Michigan Department of Community Health (MDCH) assures that all newborns are screened and that infants with positive tests receive confirmatory diagnosis and treatment. For more information about newborn screening in Michigan, including updates for hospitals and information for parents, visit www.michigan.gov/newbornscreening.

The **Early Hearing Detection and Intervention (EHDI) Program** is a part of the Michigan Department of Community Health and works with hospitals and clinics to assure statewide screening of newborns for hearing loss and to build a statewide system for newborn hearing services. Please visit www.michigan.gov/EHDI for more information.

National Organizations

Information about many different conditions, even rare ones, is available from national support organizations and information centers.

To find out if there is a national group that deals with a child's diagnosis, call the **Genetic Alliance** at (202) 966-5557, or see www.geneticalliance.org.

The **MUMS: National Parent-to-Parent Network** connects families of children who have a rare diagnosis. Call (877) 336-5333, or see www.netnet.net/mums.

The **National Dissemination Center for Children with Disabilities (NICHCY)** is a clearinghouse that offers information, referral, and free publications to families of children with special health needs. Call (800) 695-0285, or see www.nichcy.org.

The **National Organization for Rare Disorders (NORD)** is dedicated to helping people with rare "orphan" diseases that affect only a small number of people. Call (800) 999-6673, or see www.rarediseases.org to access this information clearinghouse.

The **Fathers Network** celebrates and supports fathers and families raising children with special health care needs and developmental disabilities. For more information call (425) 653-4286, or see www.fathersnetwork.org.

Birth Defects Prevention Resources

The Michigan Department of Community Health's (MDCH) **Prenatal Smoking Cessation (PSC) Program** is designed for pregnant smokers who are receiving health services in prenatal programs. The intervention model, "Smoke Free for Baby and Me", assesses the readiness to quit smoking and delivers clear, strong, personalized, and consistent intervention messages to support smoking cessation. The intervention is easily integrated into other medical, health and support services. For more information call (517)-335-9750.

The goal of the MDCH **Fetal Alcohol Syndrome (FAS) Program** is to reduce the number of children born in Michigan with FAS, to provide timely diagnosis, and to assist those that are diagnosed with needed support services. Targeting women of childbearing age, education is offered at substance abuse treatment centers. Children identified with poor growth, learning disabilities or behavioral problems are targeted for screening, diagnosis and support. For more information, visit: www.michigan.gov/fas.

The National Center on Birth Defects and Developmental Disabilities at the **Centers for Disease Control and Prevention** offers a wide range of resources for families and professionals including the ABCs of having a healthy baby, basic facts about birth defects, birth defects research, folic acid promotion and fetal alcohol spectrum disorder. Visit www.cdc.gov/ncbddd for more information.

The mission of the **March of Dimes Birth Defects Foundation** is to improve the health of babies by preventing birth defects and infant mortality. Please visit www.marchofdimes.com for a wealth of information on folic acid, prevention of prematurity, birth defects and genetics, and preparing for pregnancy.

The **National Birth Defects Prevention Network (NBDPN)** is a network of birth defects programs and individuals working at the local, state, and national level in birth defects surveillance, research and prevention. See www.nbdpn.org for annual 'Birth Defects Prevention Month' materials, surveillance reports and NTD/folic acid information.

Additional information and educational resources on folic acid are available from the **National Council on Folic Acid** at www.folicacidinfo.org and **Folicacid.net** at www.folicacid.net

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Appendices

- A. Birth Defects Program Fact Sheet
- B. Reportable Conditions by Diagnostic Group
- C. Hospital Birth Defects Reporting Form
- D. Cytogenetic Laboratory Birth Defects Reporting Form
- E. MBDR Data, 1992-2006

Figure 1: Geographic regions approximate pediatric specialty care service areas.

Table 1: Prevalence of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2006.

- F. Mapping of Birth Defects by County, 1992-2006

Figure 1: Prevalence of neural tube defect (NTD) by county: MBDR, 1992-2006.

Figure 2: Prevalence of orofacial clefts (lip and/or palate) by county: MBDR, 1992-2006.

Figure 3: Prevalence of Down syndrome (trisomy 21) by county: MBDR, 1992-2006.

Figure 4: Prevalence of congenital heart defects (CHD) by county: MBDR, 1992- 2006.

Birth Defects Prevention, Monitoring & Follow-up

The three key components of the Birth Defects Program

» Prevention «

Identifying preventable birth defects and educating communities and professionals about prevention strategies

Certain maternal illnesses, infections, or exposures, such as alcohol, can cause birth defects that are potentially preventable.

MDCH works with many prevention partners including the March of Dimes, Healthy Mothers, Healthy Babies, reproductive genetic centers, and the National Birth Defects Prevention Network.

Highlights include:

- Promoting national Birth Defects Prevention Month in January.
- Informational materials including *Look and Feel Your Best with Folic Acid*, and *Preventing Birth Defects—Important Information for Michigan Families*.
- Conducting outreach to populations at risk, such as teen women with diabetes mellitus.

For information on folic acid and birth defects prevention, contact:

Joan Ehrhardt, Coordinator

Call: toll-free at 1-866-852-1247

Visit: www.migeneticsconnection.org
www.michigan.gov/genomics

E-mail: BDRFollowup@michigan.gov

» Monitoring «

Building the foundation of information to improve understanding and care.

The Michigan Birth Defects Registry (MBDR) was established in 1992 by state law.

- The MBDR monitors over 1,000 types of birth defects and contains reports on about 200,000 children.
- The confidential registry relies mainly on reports submitted by hospitals and laboratories and is supplemented by sources that serve children with special health needs and pediatric genetic clinics.
- About 10,000 Michigan children with birth defects are reported each year.
- Conditions include structural birth defects, genetic disorders and other conditions present at birth and identified by 24 months of age.
- MBDR data are analyzed by an epidemiologist to track the rate of birth defects, measure efforts to prevent birth defects and help Michigan communities evaluate and improve state services for children and families.

Statistical birth defect data can be found at:

www.mdch.state.mi.us/pha/osr

Reporting information and forms at:

www.michigan.gov/mbdr

For questions contact:

Glenn Copeland, MBDR Director

Phone: (517) 335-8678

» Follow-up «

Understanding the special needs of children with birth defects and linking their families to resources and support systems

Established to help Michigan families obtain information, services, and support, the program provides a:

- Genetic support group directory online at www.MIGeneticsConnection.org.
- Pamphlet, *Resources for Families of Infants and Toddlers with Special Health Needs* at no charge to hospitals, health professionals and families.
- Birth Defects Resource Toolkit that includes a *Hospital Referral Guide* for healthcare providers, the *Special Care for Special Kids* guide for families and many other resources.
- Partnership in the Family-to-Family Health Information and Education Center established by the Family Center for Children and Youth with Special Health Needs.

To find information on services for children with birth defects, contact:

Joan Ehrhardt, Coordinator

Call: toll-free at 1-866-852-1247

Visit: www.migeneticsconnection.org
www.michigan.gov/genomics

E-mail: BDRFollowup@michigan.gov

Appendix B

Conditions Reportable to the Michigan Birth Defects Registry	
A	Congenital Anomalies of the Central Nervous System (740-742)
B	Congenital Anomalies of the Eye (743)
C	Congenital Anomalies of the Ear, Face and Neck (744)
D	Congenital Anomalies of the Heart and Circulatory System (745-746)
E	Congenital Anomalies of the Respiratory System (747-748)
F	Cleft Palate and Cleft Lip (749)
G	Congenital Anomalies of the Upper Alimentary Canal/Digestive System (750-751)
H	Congenital Anomalies of the Genital and Urinary Systems (752-753)
I	Congenital Anomalies of the Musculoskeletal System (754-756)
J	Congenital Anomalies of the Integument (757)
K	Chromosomal Anomalies (758)
L	Other and Unspecified Congenital Anomalies (759)
M	Infectious Conditions Occurring in the Perinatal Period (09.00-096.09, 771.0-771.2)
N	Familial/Congenital Neoplasms (237.70-237.72)
O	Endocrine/Metabolic Disorders (243, 252.00-252.08, 252.1, 253.2, 253.8, 255.2, 255.8, 257.8, 259.4, 270.0-273.9, 275.3, 277.0-277.9, 279.11, 279.2)
P	Diseases of the Blood and Blood Forming Organs (282.0-282.9, 284.0, 286.0-286.9, 287.3)
Q	Other Diseases of the Central and Peripheral Nervous System (330.1, 331.7, 331.89, 331.9, 334.1, 334.2, 335.0, 337.9, 343.0-343.9, 345.6, 348.0, 352.6, 356.0-356.9, 358.0-359.9)
R	Other diseases of the Eye (362.60-362.66, 363.20, 369.00-369.9, 377.16, 378.0-378.9, 379.50-379.59)
S	Hearing Deficiency (389.9)
T	Other Diseases of the Heart and Circulatory System (425.0-425.4, 426.0, 426.10-427.42, 427.81-427.9, 434.0-434.9, 453.0)
U	Other Diseases of the Gastrointestinal System (520.0-520.9, 524.00-524.19, 537.1, 550.00-550.93, 553.00-553.9, 560.2, 560.9, 565.1, 569.2, 569.81)
V	Other Diseases of the Genital and Urinary Systems (593.3, 593.5, 593.82, 596.1, 596.2, 596.9, 599.1, 599.6, 619.0-619.9)
W	Other Fetal/Placental Anomalies (653.7, 658.8)
X	Other Musculoskeletal system Diseases (733.3)
Y	Maternal Exposures Affecting the Fetus (760)

Appendix C

MICHIGAN BIRTH DEFECTS REGISTRY REPORT

Vital Records and Health Data Development Section
Michigan Department of Community Health

Correction

1. Name of Child (Last) _____ (First) _____ (Middle Initial) _____		
2. If the child has been identified by another name (AKA – also known as) _____		
3. Child's Current Street Address _____		Apartment No. _____ P.O. Box No. _____
City _____	State _____	Zip Code _____ Telephone No. _____
4. Child's Social Security Number (if known) _____	5. Medical Record Number _____	6. Sex <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated
8. Child's Medicaid # (if known) _____	9. Date of Birth (Month) (Day) (Year) _____	7. Plurality <input type="checkbox"/> Single <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third or More
10. Hospital / Place of Birth _____		
City _____	State _____	11. Mother's Social Security Number _____
12. Mother's Name (Last) _____ (First) _____ (Middle Initial) _____		
13. Name of Facility Submitting Form _____ City _____ State _____		
14. Patient Status <input type="checkbox"/> Inpatient <input type="checkbox"/> Outpatient	15. Admission Status <input type="checkbox"/> Any Admission <input type="checkbox"/> Transferred	16. Admission Date (Month) (Day) (Year) _____
		17. Discharge Status <input type="checkbox"/> Alive <input type="checkbox"/> Transferred <input type="checkbox"/> Dead
		18. Discharge Date (Month) (Day) (Year) _____
19. Birth Status <input type="checkbox"/> Live Birth <input type="checkbox"/> Stillborn Birth Weight _____		
20. Diagnoses (attach additional forms if more than 5 diagnoses)		21. Procedure Codes – ICD-9-CM Codes
1. _____		_____
2. _____		_____
3. _____		_____
4. _____		_____
5. _____		_____
Syndrome _____		_____
22. Cytogenetics <input type="checkbox"/> Not Stated <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Pending <input type="checkbox"/> No Growth <input type="checkbox"/> Not Done		_____
If Abnormal, Describe _____		ICD-9-CM Code _____
23. Name of Laboratory _____ City _____		
24. Name of Person Completing Form _____		
(Last) _____ (First) _____		
Telephone Number _____		

Appendix D

MICHIGAN BIRTH DEFECTS REGISTRY “CYTOGENETICS” REPORT

1. NAME OF CHILD			
(Last)	(First)	(Middle initial)	
2. IF THE CHILD HAS BEEN IDENTIFIED BY ANOTHER NAME (AKA - also known as)			
3. CHILD'S CURRENT STREET ADDRESS _____ CITY _____		APARTMENT No. _____ STATE _____	P.O. BOX No. _____ ZIP CODE _____
4. CHILD'S SOCIAL SECURITY No. (if known)	6. MEDICAL RECORD No.	8. SEX <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Undesignated	10. PLURALITY <input type="checkbox"/> Single <input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third or More
5. CHILD'S MEDICAID No. (if known)	7. DATE OF BIRTH (Month) (Day) (Year) _____-_____-_____-	9. DECEASED <input type="checkbox"/> Yes <input type="checkbox"/> No	
11. HOSPITAL - PLACE OF BIRTH _____			
12. MOTHER'S LAST NAME	FIRST NAME	M.I.	SOCIAL SECURITY No.
_____	_____	_____	_____
13. HOSPITAL - PLACE OF DIAGNOSIS	CITY	STATE	
_____	_____	_____	
14. <u>CYTOGENETICS</u> - DESCRIBE FINDINGS		ICD - 9 - CM CODE	
_____		_____	
_____		_____	
_____		_____	
15. NAME OF LABORATORY	CITY		
_____	_____		
16. <u>LAST NAME</u> OF PERSON COMPLETING THIS FORM (LAST)	<u>FIRST NAME</u> OF PERSON COMPLETING THIS FORM (FIRST)		
_____	_____		
TELEPHONE NUMBER	DATE COMPLETED		
_____	(Month) _____ (Day) _____ (Year) _____		

Appendix E

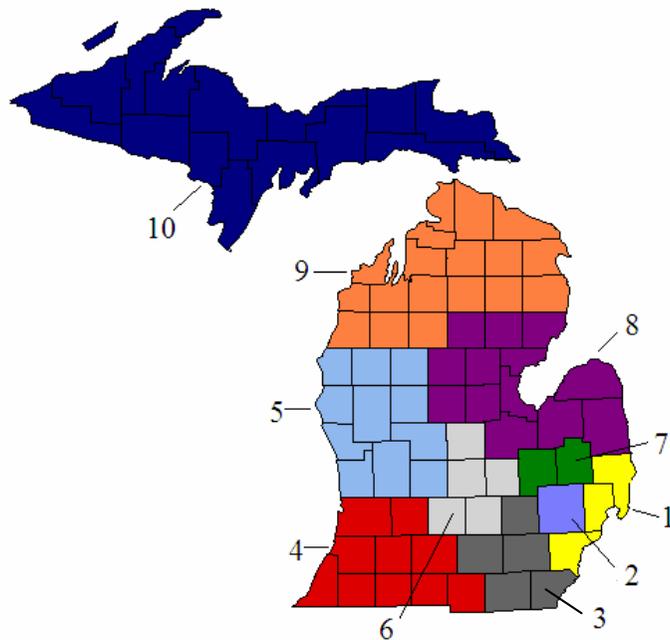


Figure 1: Geographic regions approximate pediatric specialty care service areas.

Region 1	Region 5	Region 8	Manistee
Macomb	Ionia	Arenac	Missaukee
Wayne	Kent	Bay	Montmorency
St. Clair	Lake	Clare	Oscoda
	Mason	Gladwin	Otsego
Region 2	Mecosta	Huron	Presque Isle
Oakland	Montcalm	Iosco	Wexford
	Muskegon	Isabella	
Region 3	Newaygo	Midland	Region 10
Jackson	Oceana	Ogemaw	Alger
Lenawee	Osceola	Roscommon	Baraga
Livingston	Ottawa	Saginaw	Chippewa
Monroe		Sanilac	Delta
Washtenaw	Region 6	Tuscola	Dickinson
	Clinton		Gogebic
Region 4	Eaton	Region 9	Houghton
Allegan	Gratiot	Alcona	Iron
Barry	Ingham	Alpena	Keweenaw
Berrien	Shiawassee	Antrim	Luce
Branch		Benzie	Mackinac
Calhoun	Region 7	Cheboygan	Marquette
Cass	Genesee	Charlevoix	Menominee
Hillsdale	Lapeer	Crawford	Ontonagon
Kalamazoo		Emmet	Schoolcraft
St. Joseph		Grand Traverse	
Van Buren		Kalkaska	
		Leelanau	

Table 1: Prevalence of selected birth defects diagnosed by 1 year of age by region approximating pediatric specialty care service areas: MBDR 1992-2006.

MBDR (1992-2006)	Live Births	NTD		Orofacial Clefts		Down Syndrome		CHD	
		Number	Prevalence ^{1,2}	Number	Prevalence ^{1,2}	Number	Prevalence ^{1,2}	Number	Prevalence ^{1,2}
State of Michigan	2,003,686	1,268	6.3	3,125	15.6	2,283	11.4	33,166	165.5
Region 1	650,015	371	5.7	881	13.6	724	11.1	11,977	184.3
Region 2	235,857	123	5.2	317	13.4	273	11.6	4,748	201.3
Region 3	165,086	109	6.6	234	14.2	190	11.5	2,780	168.4
Region 4	195,198	123	6.3	335	17.2	212	10.9	2,378	121.8
Region 5	281,909	222	7.9	516	18.3	346	12.3	4,340	154.0
Region 6	108,901	71	6.5	186	17.1	136	12.5	1,329	122.0
Region 7	112,428	68	6.0	182	16.2	114	10.1	1,456	129.5
Region 8	135,463	99	7.3	234	17.3	162	12.0	2,592	191.3
Region 9	70,184	57	8.1	152	21.7	81	11.5	1,044	148.8
Region 10	48,375	24	5.0	84	17.4	45	9.3	521	107.7

¹ Prevalence rates are based on resident occurrences. Data are current through August 2009.

² Prevalence rate expressed as cases per 10,000 live births.

Appendix F

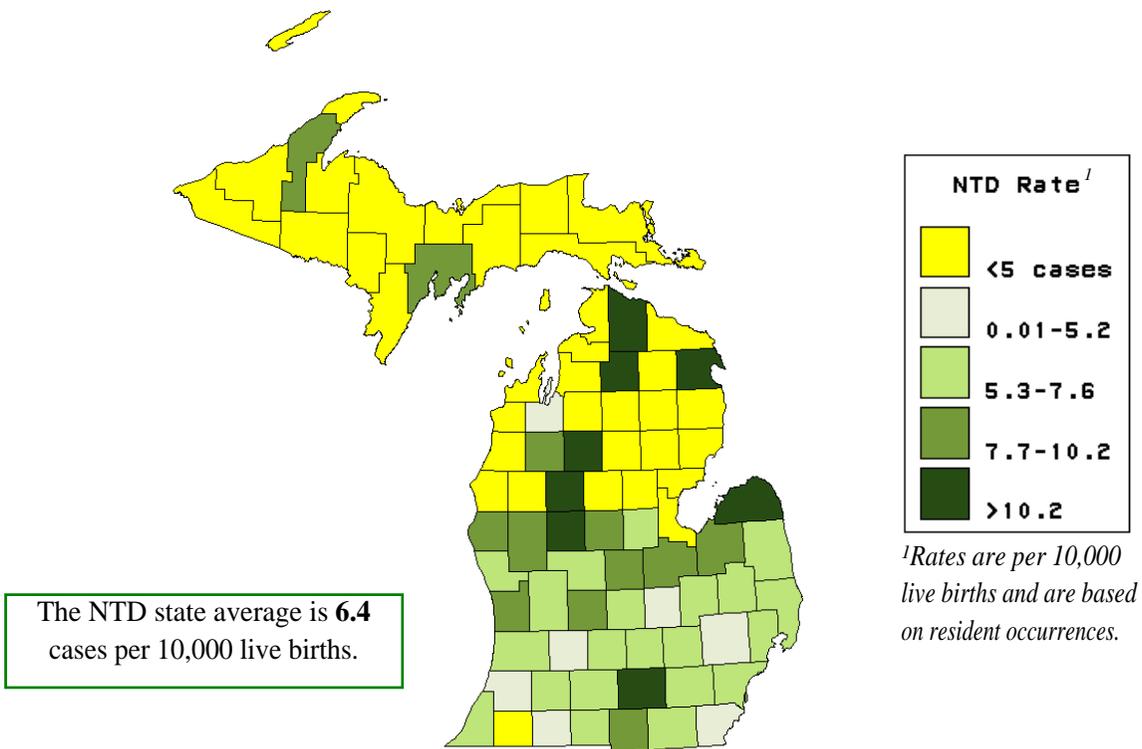


Figure 1: Prevalence of neural tube defect (NTDs) by county: MBDR, 1992-2006.

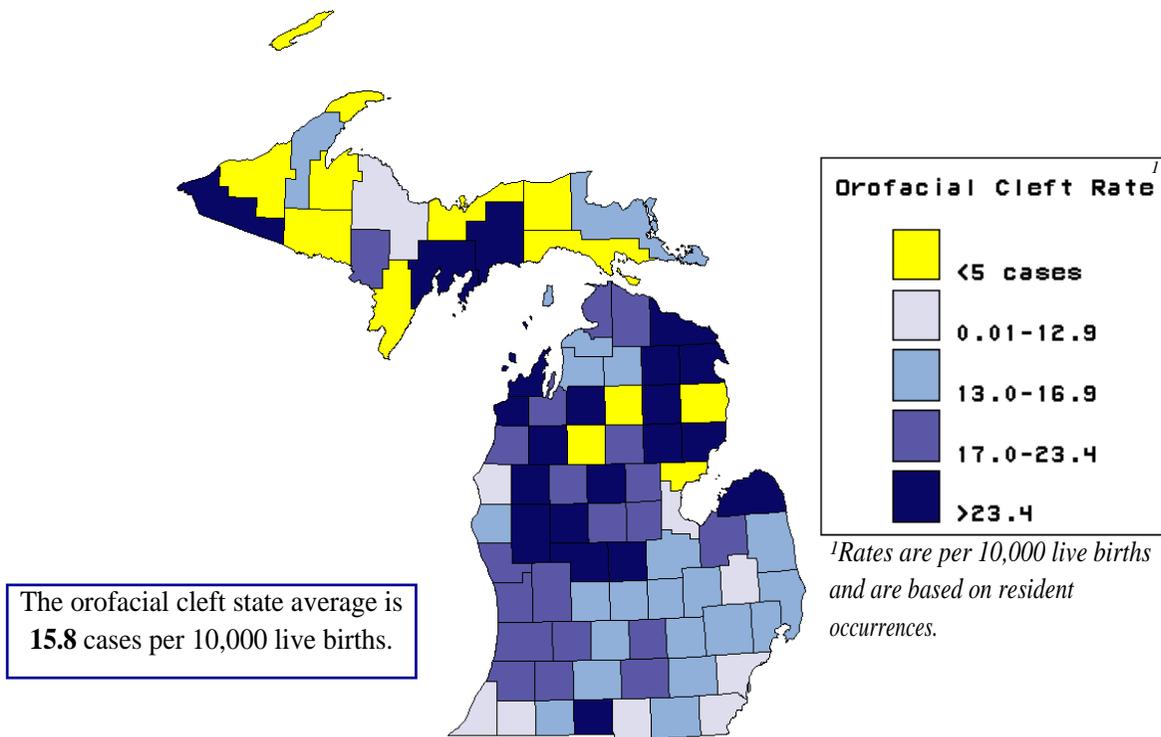


Figure 2: Prevalence of orofacial clefts (lip and palate) by county: MBDR, 1992-2006.

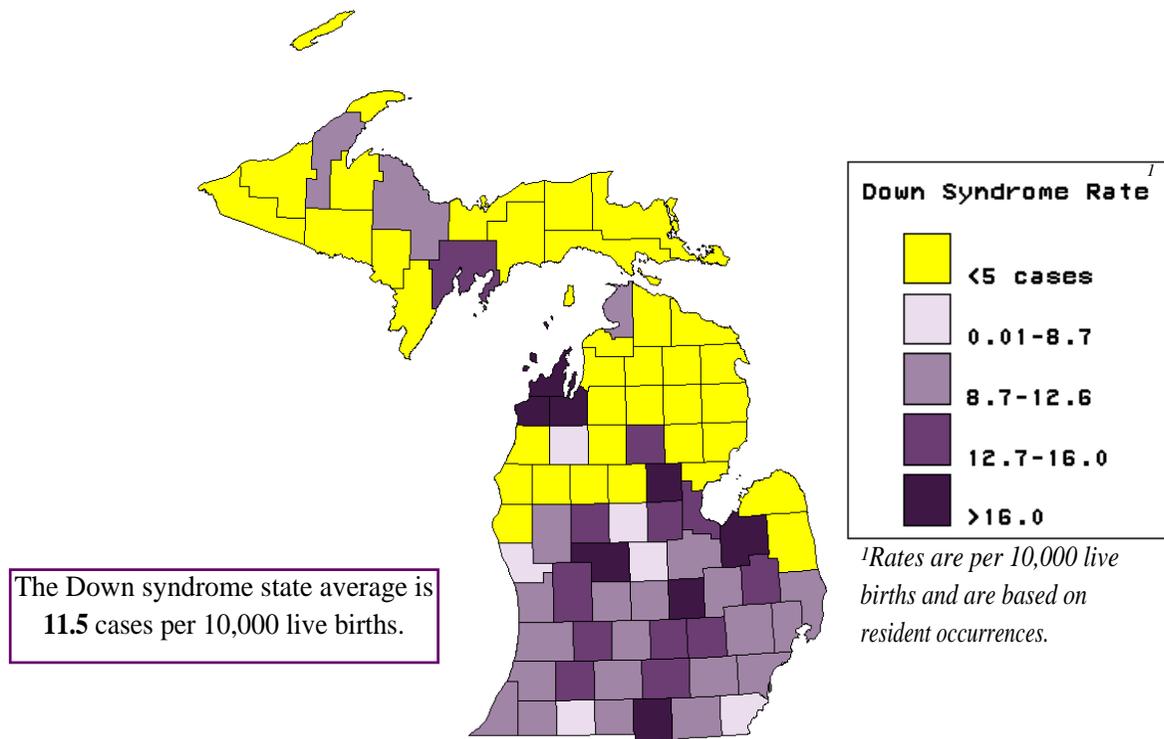


Figure 3: Prevalence of Down syndrome (trisomy 21) by county: MBDR, 1992-2006.

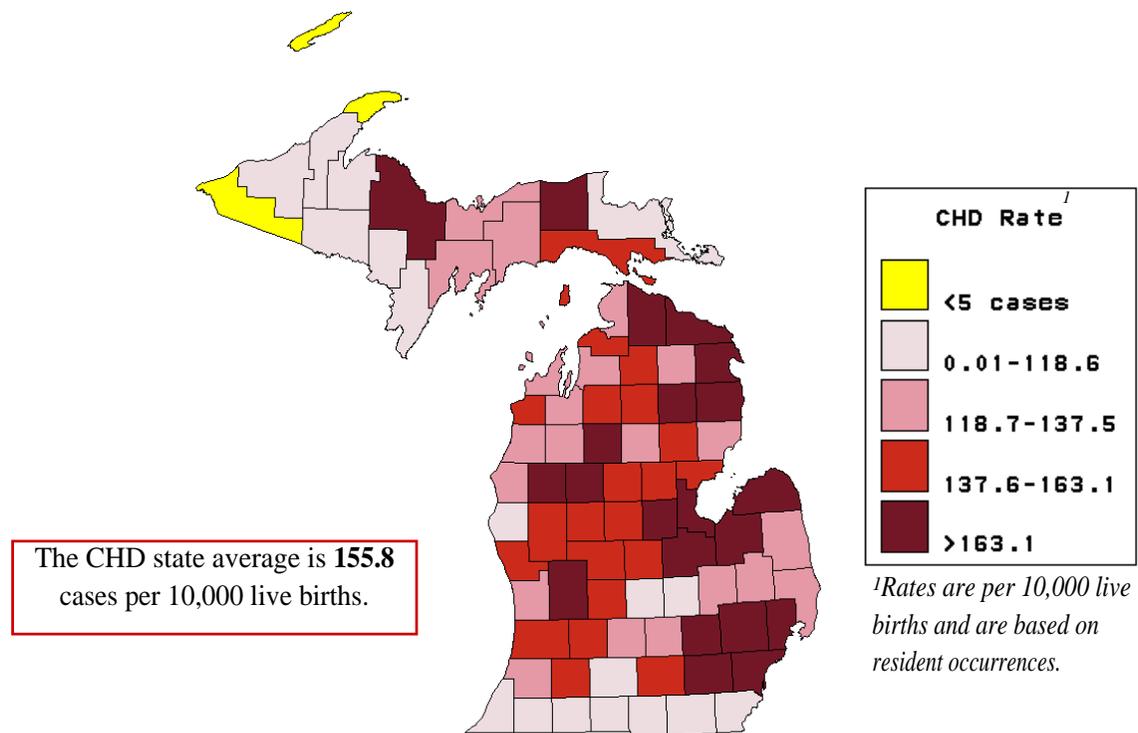


Figure 4: Prevalence of congenital heart defects (CHD) by county: MBDR, 1992-2006.