Birth Defects Program

2006 Annual Report

MINNESOTA
MDH
DEPARTMENT OF HEALTH

Environmental Impacts Analysis Unit

May 2007

For more information about birth defects, contact the
Birth Defects Program at (651) 201-4610

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MINNESOTA MDH DEPARTMENT OF HEALTH

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Environmental Impacts Analysis Unit – Birth Defects
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Summary

The Birth Defects program began active surveillance on June 1, 2005. Due to the time lag in records being available for review after the birth of a child, site visits for abstraction began in August 2005. The data collected by the abstractors is entered into the Birth Defects Information System (BDIS) database. After review, a final birth defect code is assigned. The children are then referred to the Minnesota Children with Special Health Needs (MCSHN) program for referral to services such as Medical Assistance (MA), specialty clinics, local public health, etc. Specifics including: estimates of the number of birth defects in Minnesota from birth certificate data; actual numbers of validated birth defect cases at selected hospitals in Minnesota from active surveillance data; and the number of children referred for services are included in this document as well as background information on the Minnesota Birth Defects program.

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Introduction

Effective March of 2005, the State of Minnesota statutory language (MS144.2215-2219) authorized the Minnesota Department of Health (MDH) to collect birth defect information. This statute did not include financial support for Birth Defects program activities. MDH's Birth Defects program is primarily funded by a five-year non-competing grant from the Centers for Disease Control and Prevention (CDC) in the amount of $110,000 per year. In year two (June 2006 - May 2007), the MDH was awarded $120,000 for the year. In year two, the Birth Defects program also received in-kind contributions through collaborations with the following MDH programs:

- Fetal Alcohol Syndrome (FAS)
- Genomics Program
- Maternal and Child Health (MCH)
- Minnesota Children with Special Health Needs (MCSHN)
- Office of Minority and Multicultural Health (OMMH)

as well as the following Non-MDH collaborators:

- Birth Defects Work Group (an advisory work group)
- Specialty Physicians (for coding purposes)
- Folic Acid Council (FAC)
- Gillette Children's Specialty Healthcare
- Iowa Birth Defects Registry
- Local Public Health
- March of Dimes (MOD)
- Mayo Clinic of Rochester
- National Birth Defects Prevention Network (NBDPN)
- Shriners Hospitals for Children/Twin Cities
- University of Minnesota

As the program becomes more established, additional collaborating partners will be recruited and additional funding sources explored.

Data Collection

The Minnesota Department of Health's (MDH) Birth Defects program began active surveillance on June 1, 2005. Due to the time lag in records being available for review after the birth of a child, site visits for abstraction at a limited number of birthing hospitals began in August 2005. The Birth Defects program has gained access to records in a total of 13 locations. (Table 1). These facilities represent all birthing hospitals in Hennepin and Ramsey counties, with an estimated capture of approximately fifty percent of all births in Minnesota. As funding becomes available, the program plans to expand abstraction to all hospital Neonatal Intensive Care Units (NICUs) and birthing hospitals statewide.

Table 1: Current facilities for case finding as of 1/1/2007

Hennepin County	Ramsey County
Abbott Northwestern Hospital	Children's Hospital and Clinics (St. Paul)
Children's Hospital and Clinics (Mpls.)	Regions Hospital
Fairview Southdale	St. John's Hospital
Fairview University Medical Center	St. Joseph's Hospital
Hennepin County Medical Center	United Hospital
Methodist Hospital	Woodwinds Hospital
North Memorial Medical Center	

Participating hospitals regularly notify the Birth Defects program of children in their records with a potential birth defect. The potential cases are appended to a tracking table to check for any previous abstraction of the same defect. Currently, the two full-time abstractors work at all facilities, but an individual primary contact has been established for each location. Based on reporting hospital, new defects are assigned to an abstractor who reviews the medical records of potential cases at that hospital.

The Birth Defects program uses the Minnesota Birth Defects Coding List (Appendix A). Conditions include 44 nationally reported birth defects and a single ventricle defect. The list of nationally reported birth defects was developed collaboratively by the Centers for Disease Control and Prevention (CDC) program and the National Birth Defects Prevention Network (NBDPN); the single ventricle defect was included at the recommendation of a collaborating physician.

Confirmed cases are entered into a database on a laptop computer. At the completion of each abstraction an error checking program is run to alert abstractors of any missing or improper field entries. Completed abstractions are downloaded weekly to the main database where they are matched to any previous abstractions and assigned a unique identification number. The downloaded records are then reviewed and validated by the Public Health Nurse lead worker final codes are assigned to each birth defect.

Among abstracted cases born in 2005 and 2006 and reviewed by the MDH Public Health Nurse as of January 1, 2007, 1136 cases were validated and entered into BDIS. Because cases can have additional birth defects diagnosed up to their first birthday entered into BDIS, these 1136 cases incurred 1161 unique abstractions and a total of 1913 unique birth defects. Figure 1 shows the percentage of cases with one or multiple birth defects. Almost 40 percent of cases in BDIS have more than one birth defect. Figure 2 shows the breakdown of unique birth defects by groups of defect. The majority of validated birth defects were cardiovascular (48%), followed by genitourinary (18%) and gastrointestinal (11%) defects.

Figure 1: Number of birth defects per case among cases born in 2005 and 2006, reviewed by 1/1/2007

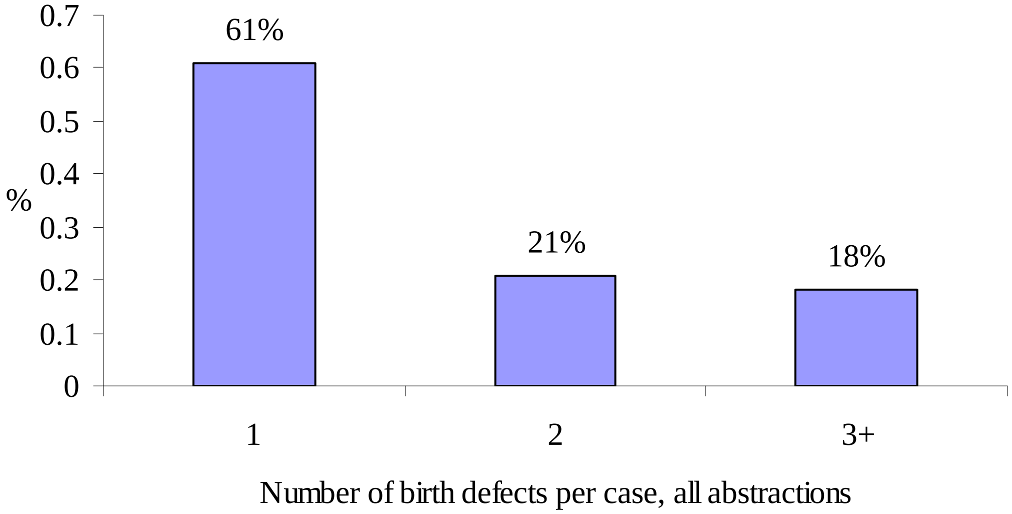
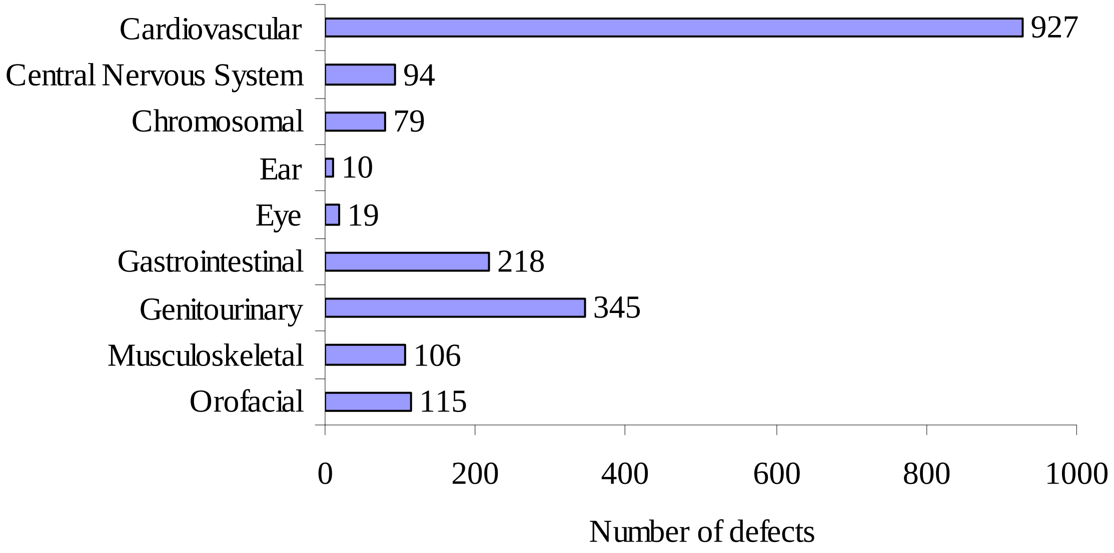


Figure 2: Number of birth defects by defect group among cases born in 2005 and 2006, reviewed by 1/1/2007



Because abstraction began in mid-year 2005 and abstraction facilities were phased in throughout the two years, the data does not include all possible cases born in 2005 or 2006 who received services at a hospital located in Hennepin or Ramsey counties. In addition, data presented are frequencies; it is not possible to analyze birth year cohort data until the close of the following year due to the inclusion into BDIS of birth defects diagnosed up to a child's first birthday. It is anticipated that estimates of 2006 prevalence rates for select birth defects in Hennepin and Ramsey counties will be available by 2008.

After entry into BDIS, each validated birth defect case is sent a parent letter (Appendix B) from the Birth Defects program which explains the opt-out option. Included with the letter are: the fact sheet, "Birth Defects – What is Being Done in Minnesota?" (Appendix C); a brochure provided by the MCSHN program which describes services available (Appendix D); and a Birth Defects Opt-Out Form (Appendix E). The Birth Defects Opt-Out Form can be filled out and returned to the Birth Defects program if parents do not want their child's information included in the BDIS database. Upon receipt of a completed opt-out form, the Birth Defects program removes an individual's personal identifying information from BDIS and sends the family a letter confirming this action. As of January 1, 2007, 45 parents or guardians have returned an opt-out form to MDH requesting that all identifying information pertaining to them and their child be removed from BDIS.

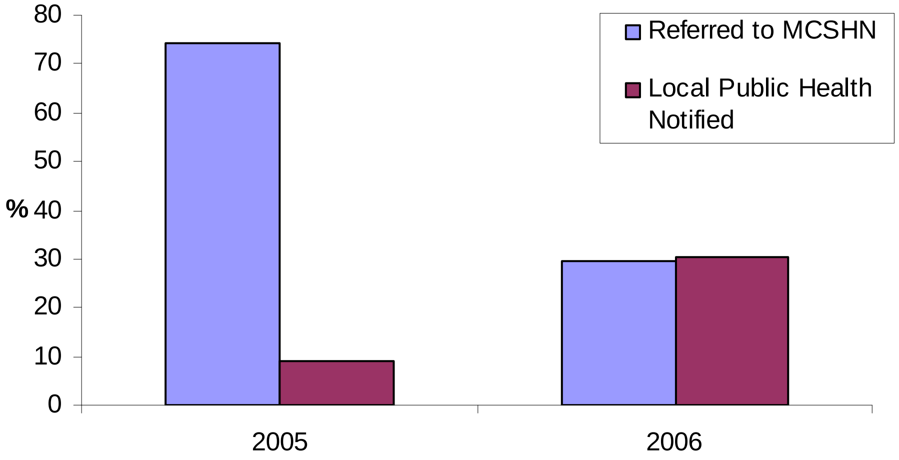
The Birth Defects Program collaborates with the Minnesota Fetal Alcohol Syndrome (FAS) program and receives some funding from their program. The FAS Prevention program case definition for FAS is broader than the NBDPN case definition used for Minnesota's Birth Defects Information System (BDIS) database. All FAS data collected by the abstractors are also validated using the CDC software "FASSLink" (Fetal Alcohol Syndrome Surveillance Link) to meet the FAS program's grant objectives. As of January 1, 2007, there were 32 confirmed cases of FAS identified using the FASSLink software. Case finding has not been initiated in all diagnostic centers in Minnesota. No rates are available, because the Birth Defects program is in the process of identifying county of residence for the mothers of the identified cases. This process is complicated by the fact that more than 70 percent of FAS children do not live with their biological parent.

Notification/Referral to Services

All validated cases receive information about MCSHN in the initial letter sent by the Birth Defects program. MCSHN is the state health department program accountable for the performance of core public health functions for children with special health needs. In addition, cases that have not opted-out of BDIS and meet certain medical criteria are followed-up on to ensure appropriate services are provided to the affected families. A flow chart illustrating the abstraction to follow-up process is shown in Appendix F.

Local public agencies, located in each of Minnesota's 87 counties, provide most of the actual case management and direct services for public health activities in the State of Minnesota. These agencies are encouraged to participate in MDH programs and projects within the limits of their resources. Certain local public health agencies have agreed to take notification of BDIS cases; they are informed by the Birth Defect program when a case in their county is diagnosed with a birth defect. As of January 1, 2007, 53 local public health agencies were receiving notification of children with select birth defects in their counties. The remaining cases are referred to MCSHN, who connects children and families with necessary public health services. During 2007, staff from the Birth Defects program will meet with the counties who are not currently receiving notices of cases entered into the BDIS to encourage their participation. Figure 3 shows the increasing participation of local public health agencies in the follow-up of cases born in 2005 and 2006 and reviewed as of January 1, 2007.

Figure 3: Case follow-up patterns among cases born in 2005 and 2006, reviewed by 1/1/2007



Timeliness of Abstraction and Referrals

As previously mentioned, potential cases are appended to a tracking table in order to check for previous abstractions of the same defect. The records-tracking spreadsheet includes information on dates, hospitals, and other medical record information for each case (see Appendix G). In addition to ensuring that all medical records are reviewed and completely abstracted, the records-tracking database is used to determine the average times between birth, abstraction activities, and notification or referral. This data allows the Birth Defects program to build upon areas of strength and understand sources of delay in providing referral to services for affected families.

Average times between events for BDIS cases born in 2005 and 2006 reviewed as of January 1, 2007 are reported in Table 2. The time between a case's date of birth and date of medical record request by MDH abstractors is an estimate of the average time before MDH is made aware by the hospitals of a child to with a potential birth defect. The average child in BDIS born in 2005 was over 4 months old before MDH requested their medical record; the average child in BDIS born in 2006 was less than 3 months old before MDH abstractors requested their medical record. Since the start of Minnesota's Birth Defects program, several of the participating hospitals have switched from paper to electronic medical records. This, and the more streamlined notification process that comes with experience, has shortened the time it takes for MDH to become aware of potential cases at participating hospitals.

The time between the date of abstraction of a case's medical record and the date the Birth Defects program sends the affected family a letter with information about the system and services available is an estimate of the average turn-around time for MDH to process each case. This time has remained steady over the two years of operation, at just under a month. Overall, the time from the birth of a case to the time affected families received information from the Birth Defects program about available services was over 5 months for cases born in 2005, and less than 4 months for cases born in 2006.

Table 2: Average time between events completed by the Birth Defects program among cases born in 2005 and 2006, reviewed by 1/1/2007

	Birth Year 2005		Birth Year 2006	
BDIS Case Events	**Number of Cases**	**Time (days)**	**Number of Cases**	**Time (days)**
Birth to medical record request by MDH	398	127	592	82
Abstraction to letter sent by MDH	423	26	630	27
Birth to letter sent by MDH	407	166	594	117

Starting in September of 2006, the Birth Defects program began a new system of referring cases to MCSHN. Birth Defects program staff analyzed the number of cases referred between September 18, 2006 and December 31, 2006 in order to evaluate the timeliness and helpfulness of the new system of referral of cases to MCSHN. During the fifteen weeks of referral used in the analysis, 151 cases were referred to MCSHN. Of these, MCSHN made phone calls to 24 cases, sent letters on services available to 96 cases, and did not make any known contact with 33 cases. The average time between MDH referral of cases to MCSHN and phone contact by MCSHN was over a month. The average time between MDH referral of cases to MCSHN and a letter sent by MCSHN is also about a month. These results are shown in Table 3. In order to evaluate the helpfulness of the phone call made by MCSHN, Birth Defects staff made phone calls to families reported as having received a phone call. Very few families could be reached; many of those reached did not remember having received a phone call, possibly due to the stressful period in which these calls were made. As a result, phone survey data were not used to analyze the usefulness of the MCSHN phone call.

Table 3: Average time between events completed by MCSHN among cases born in 2005 and 2006, reviewed by 1/1/2007

BDIS Case Events	Number of Cases	Time (days)
MDH referral to MCSHN to MCSHN phone contact with family	24	41
MDH referral to MCSHN to MCSHN letter sent to family	96	32

Completeness of Case Finding

Case finding is an important aspect of any surveillance system. Therefore, it is important to have multiple sources of data. Currently, the Birth Defects program uses the following sources for case finding in addition to medical records:

- Birth Certificates
- Hospital Discharge Summaries
- Medical Records

Many studies have shown that birth defects are severely under-reported on birth certificates. Appendix H lists the total number of each birth defect in Minnesota for 2000 - 2006 as listed on Minnesota birth certificates. Appendix I provides the rate of birth defects per 10,000 births in Minnesota based on birth certificate data. Because birth certificates are not a very accurate source for birth defect data, high confidence should not be placed in these figures to represent the actual rates of birth defects in the state of Minnesota. However, birth certificates can be matched to BDIS records to determine completeness of our active surveillance system and will be a means of case finding.

The Minnesota Hospital Discharge Database (MnHDD) for years 2005 and 2006 will be examined as another passive data source for case finding. The MnHDD will be searched for all occurrences of an ICD-9 code corresponding to a birth defect and analyzed to identify possible duplicates in the de-identified data. Duplicates result from a child being seen multiple times and a new discharge record is generated for each visit. An entry will be identified as a duplicate if it has the same date of birth, gender, zip code and diagnosis. In 2005, the de-duplicated data at one facility was compared to the known cases at that facility; 93% of potential duplicates were determined to be real duplicates and not unique cases. Likely duplicate entries for the same child were eliminated to estimate a case count. An analysis to be completed this year will check de-duplicated cases seen in any of the participating hospitals against BDIS data for each defect to determine potential missing cases. The MnHDD is useful for case finding and will also be used to determine how many cases are seen in facilities outside of the Minneapolis-St. Paul metropolitan area. Although complete, MnHDD cannot be used for patient referrals because the data is de-identified and greater than one year old. As the system grows, other data sets such as fetal death records, death certificates for infants and medical assistance data will be used for quality control and case finding.

Data Accuracy

Of the 500 records abstracted on paper from 2005 – 2006, five percent (25) were randomly selected and reabstracted for quality control purposes. A review of the re-abstracted charts indicated that overall the data collection is of high quality. The data did indicate that not all “not found” check boxes were always documented when information was abstracted. It is important to have each of those boxes verified to be able to confidently determine whether the data is not found or that the item was not assessed. Accuracy is determined using a process to evaluate the major or minor discrepancies entered by each abstractor for each required field that is abstracted from the medical record (see Appendix J for the Birth Defects Validation Study Form). After the birth defect epidemiologist reviewed the major and minor discrepancies, the public health nurse and abstractors met to discuss ways in which to help eliminate errors in the abstracting process. Policies and procedures were developed to help eliminate future errors in data collection. During 2006, the Birth Defects program switched from paper to laptop data collection by the abstractors. A five percent sample of selected medical records will be completed using the new collection process in 2007.

Data Cleaning and Retention

The BDIS database, a relational database consisting of multiple tables, is cleaned using a multi-step process on a duplicate of the database. Each table within the database is compared to the main table to identify any unmatched records. Matched records in each table are checked for appropriate and logical entries. Finally, logical checks between the tables are made to ensure all necessary entries are included in the database. In addition to periodic cleaning of tables within the database, Birth Defects program staff has developed a retention schedule for all of the BDIS records.

Folic Acid Prevention Activities

The Birth Defects program continues to work with the Minnesota Folic Acid Council (FAC) to recruit collaborating partners and pursue educational opportunities. A folic acid media campaign, developed by Birth Defect program staff and endorsed by FAC, was designed for the 2006 Minnesota State Fair. The poster (Appendix K) promoted daily folic acid use at 400 mcg for all women, regardless of pregnancy status, in order to prevent birth defects of the spine and brain. Program staff, along with other MDH staff (many who are also FAC members), performed an on-location survey evaluation of the poster. The information obtained from the evaluation was analyzed and presented as a poster by MDH at the National Birth Defects Prevention Network’s (NBDPN) Annual Meeting. The MDH poster was voted best in the Prevention, Intervention, and Public Policy category of the meeting’s poster session.

In April of 2006, MDH, local public health organizations and providers in Minneapolis and St. Paul, and a coalition of Catholic parishes that serve primarily Hispanic populations planned and produced a Latina Mother-Baby Group workshop to address health concerns in the Hispanic community. The workshop, conducted entirely in Spanish, trained key individuals in the Hispanic community about access to health care and awareness of public health risks. The Birth Defects program and the FAC were interested in reaching out to this population because Hispanic women have significantly higher rates of neural tube defects in their newborns. These trained community leaders now have skills to better communicate and implement effective methods for preventing birth defects in their community. MDH has long struggled to reach out to communities with significant health disparities, and this conference was an important step in bridging the communication gap between public health information and local community leaders. Collaborating partners included MDH Office of Minority and Multicultural Health, the MDH Community and Family Health Division, and a range of public and private organizations.

The Birth Defects program is collaborating with the MDH Maternal and Child Health (MCH) program to fund and create English and Spanish versions of a display on folic acid consumption and birth defects prevention. A display board in each language will be available for the Birth Defects program and the Minority Health program for use at community events. This project is expected to be completed by Spring of 2007.

2004 and 2006 (BRFSS) Folic Acid Survey

The (BRFSS) Behavioral Risk Factor Surveillance System is the world’s largest on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Conducted by the 50 state health departments as well as those in the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands with support from the CDC, BRFSS provides state-specific information about issues such as asthma, diabetes, health care access, alcohol use, hypertension, obesity, cancer screening, nutrition and physical activity, tobacco use, and more. During 2004 and 2005 the BRFSS survey in Minnesota included questions about Folic Acid. These questions were designed and tested by the Centers for Disease Control and are used nation wide.

In Minnesota as indicated by the following table, about 68 – 65 percent of women in Minnesota took a vitamin in 2004 and 2006 respectively, about 85 percent of the women indicated that they were multivitamins. When asked whether any of the vitamins contained Folic Acid only 33 percent in 2004 and 22 percent in 2006 indicated that they knew there vitamins contain Folic Acid while about 34 and 23 percent did not know if there vitamins contained folic acid. Only about 50 percent of the women in both years of the survey knew that Folic Acid was needed to prevent birth defects. See Table 4 below.

Table 4: Folic acid questions answered by women in 2004 and 2006 from the BRFSS survey

Question	2004	2006
Currently taking Vitamin (yes)	68.3	65.0
Are they Multivitamins (yes)	85.0	84.7
Do they contain Folic Acid (Don't Know)	33.5	23.2
Folic Acid prevents birth defects (yes)	47.6	51.4

The results of the BRFSS survey indicate that MDH needs to continue to develop educational messages about the benefits of folic acid for the general population.

Appendices

Appendix A – Minnesota Birth Defects Coding List

Appendix B – Birth Defects Parent Letters

Appendix C – Birth Defects Program Fact Sheet

Appendix D – MCSHN Program Brochure

Appendix E – Minnesota Birth Defects Information System Opt-Out Form

Appendix F – Abstraction to Follow-Up Flow Chart

Appendix G – Records-Tracking Spreadsheet Variables

Appendix H – Number of Birth Defects from MN Birth Certificates

Appendix I – Rates of Birth Defects from Minnesota Birth Certificates

Appendix J – Birth Defects Validation Study Form

Appendix K – Poster Used for the 2006 Minnesota State Fair

Appendix A – Minnesota Birth Defects Coding List

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ICD-9 Codes of the 44 Nationally Reported Birth Defects Collected in Minnesota

Central Nervous System	
Anencephalus	740.0-740.1
Spina Bifida Without Anencephalus	741.0-741.9, w/o 740.0-740.10
Hydrocephalus Without Spina Bifida	742.3 w/o 741.0,741.9
Encephalocele	742.0
Microcephalus	742.1
Eye	
Anophthalmia/Microphthalmia	743.03,743.1
Congenital Cataract	743.30-743.34
Aniridia	743.45
Ear	
Anotia/Microtia	744.01, 744.23
Cardiovascular	
Common Truncus	745.0
Transposition of Great Arteries	745.10,.11,.12,.19
Tetralogy of Fallot	745.2
Ventricular Septal Defect	745.4
Atrial Septal Defect (Include only if estimated gestational age is greater than or equal to 36 weeks)	745.5
Endocardial Cushion Defect	745.60,.61,.69
Pulmonary Valve Atresia and Stenosis	746.01,746.02
Tricuspid Valve Atresia and Stenosis	746.1
Ebstein's Anomaly	746.2
Aortic Valve Stenosis	746.3
Hypoplastic Left Heart Syndrome	746.7
Patent Ductus Arteriosus (Include only if estimated gestational age is greater than or equal to 36 weeks)	747.0
Coarctation of Aorta	747.10

Orofacial	
Cleft Palate Without Cleft Lip	749.0
Cleft Lip With and Without Cleft Palate	749.1,749.2
Choanal Atresia	748.0
Gastrointestinal	
Esophageal Atresia/Tracheoesophageal Fistula	750.3
Rectal and Large Intestinal Atresia/Stenosis	751.2
Pyloric Stenosis	750.5
Hirshsprung's Disease (Congenital Megacolon)	751.3
Biliary Atresia	751.61
Genitourinary	
Renal Agenesis/Hypoplasia	753.0
Bladder Exstrophy	753.5
Obstructive Genitourinary Defect	753.2,753.6
Hypospadias and Epispadias	752.61,752.62
Musculoskeletal	
Reduction Deformity, Upper Limbs	755.20-755.29
Reduction Deformity, Lower Limbs	755.30-755.39
Gastroschisis	756.79
Omphalocele	756.79
Congenital Hip Dislocation	754.30,.31,.35
Diaphragmatic Hernia	756.6
Chromosomal	
Trisomy 13	758.1
Down Syndrome	758.0
Trisomy 18	758.2
Other *	
Fetal Alcohol Syndrome	760.71

Non-Nationally Reported Birth Defect to Collect:

Single Ventricle 745.3

Appendix B – Birth Defects Parent Letters

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This letter is sent to the parents
of all abstracted children, except
deceased children and those with
Fetal Alcohol Syndrome (FAS).

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

The Minnesota Department of Health would like to congratulate you on the birth of your baby!

Our goal is to help all children thrive, grow, and be as healthy as possible. We understand that your baby may have special health needs. Finding help for your baby can be overwhelming. We have enclosed information from MDH's Minnesota Children With Special Health Needs program that may be useful to you and your family.

We gather data about babies born each year with certain health conditions (some minor, others serious) diagnosed in the first year of life. This helps us look for causes of these conditions. It may also help us prevent them in the future. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us.

Having your identifying information allows us to contact you about services that may be helpful to you. If you remove your identifying information, state law requires we inform you that our program can no longer contact you about services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

JLS:BB:rlk
Enclosures

This letter is sent to the parents of all
abstracted children who are deceased.

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

We understand that you have recently lost a child and extend our sympathies to you and your family. The Minnesota Department of Health gathers data about babies born each year with certain health conditions diagnosed in the first year of life. This helps us look for causes of these conditions. It may also help us prevent them in the future.

Your child had one of the conditions on which we collect data. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us. If you choose to have your identifying information remain, we will continue to offer you services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

JLS:BB:rlk
Enclosures

This letter is sent to the parents
of all abstracted children with
Fetal Alcohol Syndrome (FAS).

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

The Minnesota Department of Health's (MDH) goal is to help all children thrive, grow, and be as healthy as possible.

We understand that your child was born with special health needs. Finding help for your child can be overwhelming. We have enclosed information from MDH's Minnesota Children With Special Health Needs program that may be useful to you and your family.

We gather data about children born each year with certain health conditions. This helps us look for causes of these conditions. It may also help us prevent them in the future. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us.

Having your identifying information allows us to contact you about services that may be helpful to you. If you remove your identifying information, state law requires we inform you that our program can no longer contact you about services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

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Enclosures

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Appendix C – Birth Defects Program Fact Sheet

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Minnesota Department of Health Fact Sheet

Birth Defects – What is Being Done in Minnesota?

What causes birth defects?

Little is known about the actual causes of birth defects. Approximately twenty percent of birth defects may be attributed to genetic factors. Ten percent are attributed to environmental factors, including drug or alcohol abuse, infections, or exposure to certain medications or other chemicals. The causes of the remaining seventy percent are currently unknown.

What is the Minnesota Birth Defects Program and what are its goals?

The Birth Defects Program is a new activity at the Minnesota Department of Health (MDH). This program gathers data about babies born each year with certain health conditions diagnosed within the first year of life. The mission of the program is to help children thrive, grow, and be as healthy as possible. The primary goals of the Birth Defects Program are to:

- Monitor incidence trends of birth defects to detect emerging health concerns and identify affected populations,
- Ensure appropriate services are provided to affected families,
- Prevent birth defects through targeted education,
- Educate physicians and the public regarding birth defects, and
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

How does the Birth Defects Program benefit Minnesota?

There are many programs in our state that may benefit children with birth defects and their families. Knowledge of the occurrence of birth defects will help the MDH link families to the services they need. Better tracking of when and where birth defects occur and potential links to environmental factors will provide critical information that may help prevent birth defects in the future. This information will help all children have the best possible start in life.

What if parents don't want MDH to have their personal identifying information?

Data privacy laws strictly protect the information that the Birth Defects Program gathers. If, for any reason, parents want to exclude their child from the system, they can fill out a form and the personal identifying information on that child will be removed. The Birth Defects Program will no longer contact you regarding services for that child. This does not eliminate the possibility that another program within MDH will contact you. They may have your information from another source.

Where can I get additional information?

The MDH maintains a website for birth defects information at the state level. It contains background information on current and past activities, an overview of the current advisory work group, fact sheets on medications that are known to cause birth defects, links to Minnesota statutes and other helpful websites. The web page is at:

http://www.health.state.mn.us/divs/eh/birthdefects

For more information about birth defects, or if you require this document in another format such as large print, Braille, or cassette tape, contact the Birth Defects Program at:

651-201-5000 or 1-800-657-3908

MDH TDD/TTY at: 651-201-5797
MN Relay Service at: 1-800-627-3529

MINNESOTA MDH DEPARTMENT OF HEALTH
Environmental Health Division
Environmental Surveillance and Assessment Section
Environmental Impact Analysis Unit – Birth Defects Program
625 Robert Street North, P.O. Box 64975
St. Paul, MN 55164-0975

08/30/2006
IC #141-1718
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Appendix D – MCSHN Program Brochure

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Team Clinics:

Children who have chronic health conditions, including birth defects, can benefit from being in contact with specialists who work together in developing care plans. There are Team Clinics at the major medical centers in Minnesota as well as some that are located outside the cities of St. Paul and Minneapolis. MCSHN can assist in identifying a team clinic for you to consider for your child.

Dental Law for Cleft Lip and/or Palate:

In Minnesota there are two laws that cover children born with cleft lips and/or palates. If the cleft has caused problems with the child's dental development, and the family has both private medical and dental insurance, the medical insurance can be billed once the dental insurance has paid what it will.

The second law states that children with clefts can be covered by their parent's insurance until age 25 if they are enrolled as a full-time student in a post-secondary program such as college or a technical school.

To locate services in your community go to: http://www.health.state.mn.us/mcshn and click on "Early Childhood Intervention" or call
toll free: 1-800-728-5420
Metro: 651-215-8956

Don't Speak English?

People who speak little or no English can reach someone who speaks their language (live or voice mail) to help them access early childhood programs and services.

There is no cost to use these lines.

Multilingual Human Services Referrals:

Arabic	(800) 358-0377
Hmong	(888) 486-8377
Khmer (Cambodian)	(888) 468-3787
Lao	(888) 487-8251
Oromo	(888) 234-3798
Russian	(888) 562-5877
Serbo-Croatian (Bosnian)	(888) 234-3785
Somali	(888) 547-8829
Spanish	(888) 428-3438
Vietnamese	(888) 554-8759

MCSHN
85 East Seventh Place
P.O. Box 64882
St. Paul, MN 55164-0882

Upon request, this publication can be made available in alternate forms, such as large print, or audiotape.

♻ *Printed on recycled paper.*

5/05

MCSHN

Health Resources for Your Child

The information in this brochure briefly describes some of the services that might be helpful to you and your new baby.

The Minnesota Children with Special Health Needs (MCSHN) Information and Assistance Line

Toll free: 1-800-728-5420
Metro area: 651-215-8956

MINNESOTA
MDH
DEPARTMENT OF HEALTH

This brochure is sent to the parents of all abstracted children, except deceased children and those with Fetal Alcohol Syndrome (FAS).

How Can MCSHN Help You?

Early Childhood Programs

Early Intervention Services (Part C):

Early intervention services are available in every community to children with disabilities or other health conditions that hinder a child's development. Parents and professionals decide together which services the child and family needs.

Follow Along Program:

The Follow Along Program is a free program that helps families understand and learn about their child's health and development. It is an easy way to find out about other services available for your child.

Financial Assistance

Medical Assistance (MA/Medicaid):

Medical Assistance is Minnesota's program to help people who have a low income with the cost of medical care. Eligibility is decided based upon family size and income.

Pregnant women and babies and toddlers under the age of two years are eligible at a higher income level than children ages two to eighteen years of age. Minnesota Children with Special Health Needs can help you decide whether or not you may qualify for MA.

It is important that applications be completed and returned as soon as possible so that you get the most coverage for any medical costs.

TEFRA Option:

The TEFRA option gives MA to certain children with disabilities or long-term health conditions who live at home with their families, but whose families are above-income for MA.

The State Medical Review Team (SMRT) determines medical eligibility for TEFRA .

MinnesotaCare:

MinnesotaCare is a subsidized health care program for people who live in Minnesota and do not have access to health insurance. There are no health condition barriers, but applicants must meet income and program guidelines to qualify. There are either annual or monthly premiums to pay depending on the family's income. There also may be co-pays.

Home and Community Based Waivered Services:

There are seven different types of waivered services that may be available for children and adults in Minnesota who have a chronic illness or disability. The waivers are designed to assist families in caring for their ill or disabled family member at home.

Access to waivered services is through the local county family or human services department.

Supplemental Security Income (SSI):

SSI may be an additional source of money to assist with a child's special needs. There are both income and medical eligibility criteria that must be met. Children who are eligible both financially and medically for SSI are also eligible to apply for MA and food stamps.

Minnesota Comprehensive Association (MCHA):

This is health insurance for Minnesota residents who have been turned down for health insurance by the private market, due to pre-existing health conditions.

Miscellaneous Financial Help:

It is possible that your child might receive help with prescription drug coverage, glasses, and eye examinations.

Specialized Care

Public Health Home Visiting:

Home visiting goals include promoting family self-sufficiency and improving the health and well-being of Minnesota children and families.

Primary Care/Medical Home: Do You Have One?

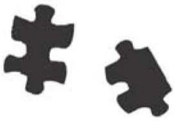
A "medical home" is a way to provide high quality primary health care for children with special health needs. It is health care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally competent.

This fact sheet is sent to the parents of all abstracted children with Fetal Alcohol Syndrome (FAS).

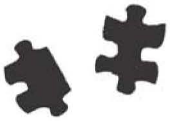
Minnesota Department of Health

Minnesota Children with Special Health Needs (MCSHN)

www.health.state.mn.us/mcshn



Need Help Piecing Together Services for a Child with Special Health Needs?



Call: 651-215-8956 or 1-800-728-5420

The Minnesota Children with Special Health Needs (MCSHN) Information and Referral Line can link you with agencies in your area that provide the services you need.

Finding necessary services for children with special health needs can be a puzzling job. The **MCSHN Information and Referral Line** can help you find the right resources to meet special needs. The service is free and confidential. Call weekdays from 8:00 a.m. to 4:30 p.m.

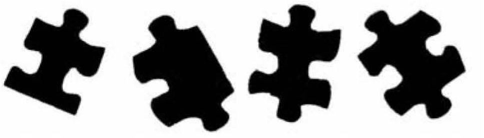
The Information and Referral Line is for families, health care providers, public health nurses, teachers, social workers and anyone who needs help identifying and locating resources for children with special health needs. It offers a listing of services and resources provided by public and private agencies. Both national and state information is available.

We can provide you with information about:
- educational services
- financial assistance resources
- home health care
- legal resources
- protection and advocacy
- service coordination
- specialized equipment
- summer camps
- support groups
- transportation

When You Call 651-215-8956 or 1-800-728-5420

A MCSHN information specialist will:
- Ask questions regarding the type of assistance you are seeking, the child's condition and where the child and/or family lives.

- Provide information about resources and services to meet your needs. Contact names, addresses and phone numbers will also be provided.



This project is funded in part through federal funding from Part C – Infants and Toddlers Program, IDEA. Upon request, this material can be made available in alternative formats, such as large print or audiotape. Printed on recycled paper.

Division of Family Health
85 East Seventh Place, Suite 400
P.O. Box 64882
St. Paul, MN 55164-0882
651-215-8956
1-800-728-5420

IC #141-1411 12/03 Rev.

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Appendix E – Minnesota Birth Defects Information System Opt-Out Form

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Birth Defects Opt-Out

Birth Defects Information System

Data privacy laws strictly protect the information in the Birth Defects Information System. The data is used to monitor the rates of birth defects in Minnesota. This helps discover if there are unusual patterns. Also, the data is useful for finding out how to prevent birth defects in the future.

Every measure is taken to keep this data secure and make it impossible to identify you or your child. However, you may choose to have the personal identifying information removed from the system.

Please fill out the form on the back of this sheet if you would like your personal identifying information removed.

If you have any questions, please call Myron Falken at (651) 201-4898.

MINNESOTA MDH DEPARTMENT OF HEALTH

Birth Defects Opt-Out Form

Birth Defects Information System

1. Please remove the personal identifying information as listed below.

2. **PRINT** the information below:

Name of Infant	Parent(s) Full Name
Birth Date	Street Address
	City/State/Zip

3. **SIGN** this form below.

By signing below, you acknowledge:

- I have received and read the Minnesota Department of Health's fact sheet concerning birth defects.
- I have been notified of Minnesota Statute 144.2215 concerning my right to have my child's and my personal identifying information removed from the birth defects database.
- I have been informed that more information on birth defects, including the statute, is available at: www.health.state.mn.us/divs/eh/birthdefects/index.html .
- I understand that by removing personal identifying information, the Minnesota Department of Health will not be able to inform me of information related to the prevention, treatment, or cause of a particular birth defect.

Signature	____/____/____ Date	Witness
Relationship to Infant		Witness (print name)

4. **MAIL** this form to:

Minnesota Department of Health
Attn: EH Birth Defects Program
Freeman Building – Pod C
P.O. Box 64975
St. Paul, MN 55164-0975

For more information about the Birth Defects Program please call:
(651) 201-4892; or 1 (800) 657-3908; or TTD (651) 201-5797.

Division of Environmental Health
Environmental Surveillance and Assessment Section
Environmental Impacts Analysis Unit

Printed on Recycled Paper
April 2006

If you require this document in another format, such as large print, Braille or cassette tape, call (651) 201-5000.

For office use only: ____________________

Original: Birth Defects Information System **Copy:** MCSHN

Appendix F – Abstraction to Follow-Up Flow Chart

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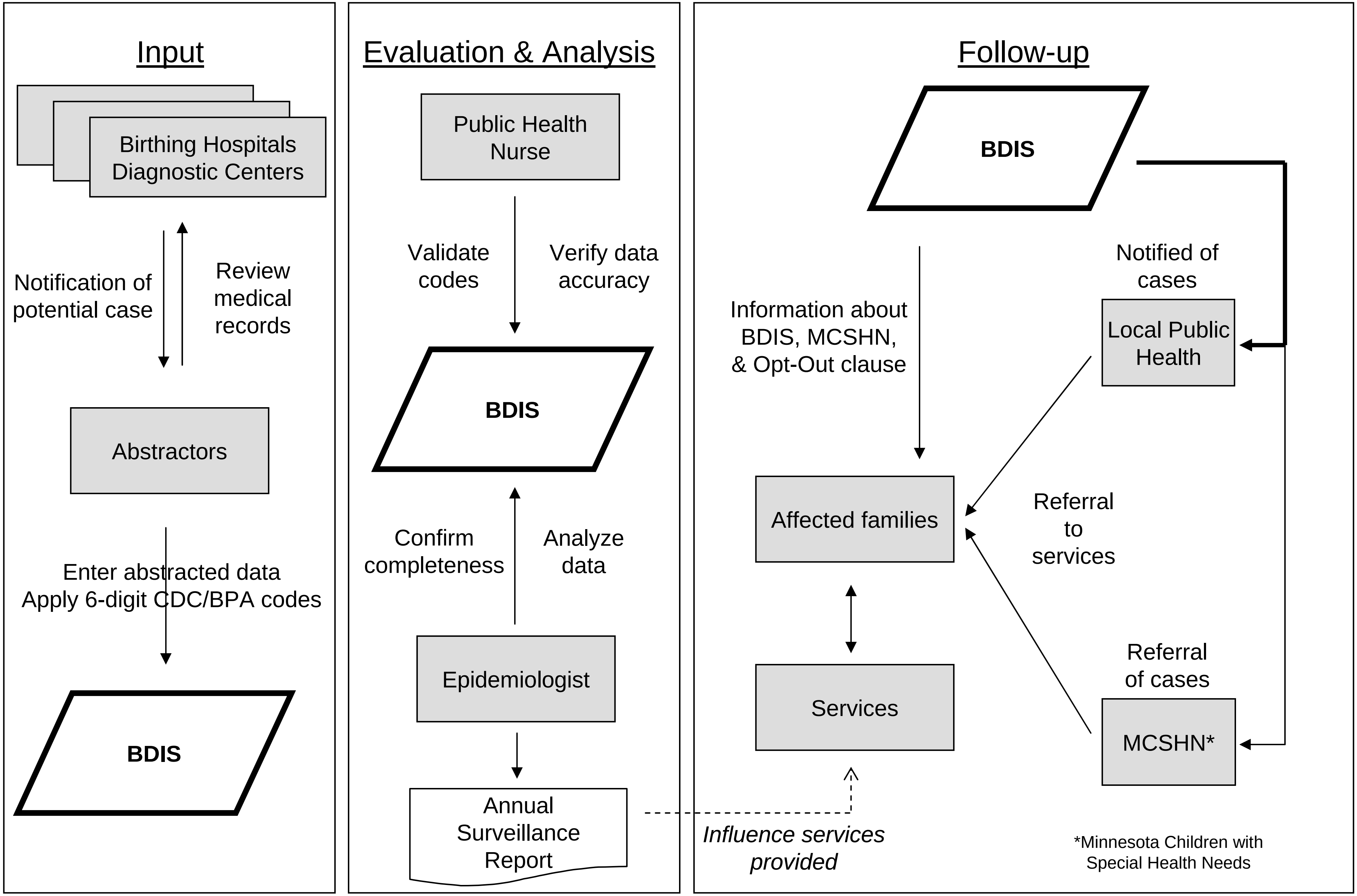
Minnesota's Birth Defects Information System (BDIS)



Input

Birthing Hospitals
Diagnostic Centers

Notification of potential case

Review medical records

Abstractors

Enter abstracted data
Apply 6-digit CDC/BPA codes

BDIS

Evaluation & Analysis

Public Health Nurse

Validate codes

Verify data accuracy

BDIS

Confirm completeness

Analyze data

Epidemiologist

Annual Surveillance Report

Follow-up

BDIS

Notified of cases

Local Public Health

Information about BDIS, MCSHN, & Opt-Out clause

Affected families

Referral to services

Services

Referral of cases

MCSHN*

Influence services provided

*Minnesota Children with Special Health Needs

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Appendix G – Records-Tracking Spreadsheet Variables

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Records-Tracking Spreadsheet Variables

- Medical Record Number
- Patient Name
- Child’s Date of Birth
- Facility
- Case Finding Source
- ICD-9 Codes/Potential Birth Defect
- Date MR was last requested
- Status of Abstract
- Comments
- Date Abstracted
- Date Referred to MCSHN

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Appendix H – Number of Birth Defects from MN Birth Certificates

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Number of Birth Defects by Specific Defect from MN Birth Certificates, 1998-2006

	Number of Birth Defects								
	1998	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**
Anencephalus	8	9	11	7	6	10	7	10	9
Spina Bifida	9	16	14	10	10	13	5	6	14
Hydrocephalus	16	24	10	12	12	21	7	12	10
Microcephalus	5	5	5	3	3	5	2	6	1
Central Nervous System	20	17	19	21	21	25	24	20	20
Heart Malformations	49	62	70	56	58	73	73	68	69
Circulatory/Respiratory	52	48	54	47	42	57	65	44	35
Rectal Atresia/Stenosis	4	4	9	2	6	5	5	4	10
Tracheo-Esophageal	13	11	21	7	9	5	7	5	3
Omphalocele/Gastroschisis	14	18	20	20	16	13	12	23	20
Gastrointestinal	20	34	21	16	24	21	24	25	24
Malformed Genitalia	23	21	29	24	26	24	23	27	24
Renal Agenesis	6	4	7	11	6	15	9	8	5
Urogenital	101	93	93	88	74	97	93	85	80
Cleft-Lip/Palate	61	56	60	63	66	45	53	57	67
Polydactyly	40	37	44	32	26	27	37	35	48
Club Foot	27	34	43	39	44	36	51	40	45
Diaphragmatic Hernia	9	10	9	6	7	8	6	9	9
Musculoskeletal	97	112	100	80	74	65	73	65	69
Down Syndrome	34	34	30	33	28	29	40	46	30
Chromosome	26	52	41	20	27	26	26	26	30
Other	249	231	252	234	269	258	237	294	241
Total Number of Defects	883	932	962	831	854	878	879	915	863
Total Births	65,207	65,953	67,451	66,617	68,178	70,191	70,728	70,920	73,189

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Appendix I – Rates of Birth Defects from Minnesota Birth Certificates

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Birth Defect Rates* (per 10,000) from Birth Certificates 2000 - 2006

Birth Defect	**Minnesota Birth Certificates**						
	2000	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**
Anencephalus[1]	1.6	1.1	.88	1.4	1.0	1.4	1.2
Spina Bifida	2.1	1.5	1.5	1.9	.70	.84	1.9
Hydrocephalus	1.5	1.8	1.8	3.0	1.0	1.7	1.4
Microcephalus	.74	.45	.44	.70	.30	.84	.14
Central Nervous System	2.8	3.2	3.1	3.6	3.4	2.8	2.7
Heart Malformations	10.4	8.4	8.5	10.4	10.3	9.6	9.5
Circulatory/Respiratory	8.0	7.1	6.2	8.1	9.2	6.2	4.8
Rectal Atresia/Stenosis	1.3	.30	.88	.70	.70	.56	1.4
Tracheo-Esophageal	3.1	1.1	1.3	.70	1.0	.70	.41
Omphalocele/Gastroschisis	2.9	3.0	2.3	1.9	1.7	3.2	2.7
Gastrointestinal[2]	3.1	2.4	3.5	3.0	3.4	3.5	3.3
Malformed Genitalia[3]	4.3	3.6	3.8	3.4	3.3	3.8	3.3
Renal Agenesis	1.0	1.6	.88	2.1	1.3	1.1	.68
Urogenital[4]	13.8	13.2	10.9	13.8	13.2	12	10.9
Cleft-Lip/Palate	8.9	9.5	9.8	6.4	7.5	8.0	9.2
Polydactyly	6.5	4.8	3.8	3.8	5.2	4.9	6.6
Club Foot	6.4	5.8	6.5	5.1	7.2	5.6	6.2
Diaphragmatic Hernia	1.3	.90	1.0	1.1	.80	1.3	1.2
Musculoskeletal[5]	14.8	12.0	10.9	9.3	10.3	9.1	9.5
Down Syndrome	4.4	4.9	4.1	4.1	5.7	6.5	4.1
Chromosome[6]	6.1	3.0	4.0	3.7	3.7	3.7	4.1
Other[7]	37.4	35.1	39.5	36.8	33.5	41.4	33.0

* *Birth defect reporting on birth certificates is known to greatly underestimate the actual number of birth defects. Rates of birth defects based on birth certificate data should be used with extreme caution. The rates listed on this table are useful for comparing Minnesota's reporting with national reporting from birth certificates, but they are not necessarily representative of the true rate of birth defects in Minnesota.*

1=Encephalocele
2=Hirshsprung's Disease
3=Hypospadias and Epispadias
4=Obstructive Genitourinary Defect
5=Reduction Deformity, Upper Limbs; Congenital Hip Dislocation
6=Trisomy 13 and 18
7=Anophthalmia, Congenital Cataract, Anidridia, Anotia Microtia, Choanal Atresia, Fetal Alcohol Syndrome

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Appendix J – Birth Defects Validation Study Form

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Birth Defects
Validation Study Form 2006

Abstractors Name ___________________________________

Reviewer's Name ___________________________________

Date ____________________

Medical Record/Case _______________________

Circle discrepancy for each variable

Variable Name	Major Discrepancy	Minor Discrepancy
Infant First Name	Incorrect Spelling	
Infant Middle Name		Incorrect Spelling
Infant Last Name	Incorrect Spelling	
Infant Suffix		Missing
Infant Date of Birth	Incorrect/Not Found	
Mother's First Name	Incorrect Spelling	
Mother's Middle Name		Incorrect Spelling
Mother's Last Name	Incorrect Spelling	
Mother Suffix		Incorrect/Not Found
Also Known As		Not Required
Mother's Address	Not Found	Incorrect
Mother's County	Not Found/Incorrect	
Mother's City	Not Found	Incorrect
Mother's State	Not Found/Incorrect	

Mother’s Zipcode		Incorrect/Not Found
Mother’s Date of Birth	Incorrect Month or Year	Incorrect Day
Mother’s Telephone Number		Not Found/Incorrect
Father’s Last Name		Not Found/Incorrect
Father’s First Name		Not Found/Incorrect
Father’s Middle Name		Not Found/Incorrect
Father’s Birth Date		Not Found/Incorrect
Father’s Telephone		Not Required
Adoptive/Foster Care		Incorrect/Not Found
CLW Relationship		Not Found/Incorrect
CLW County		Not Found/Incorrect
CLW Last Name		Not Found/Incorrect
CLW First Name		Not Found/Incorrect
CLW Middle Name		Not Found/Incorrect
CLW Address		Not Found/Incorrect
CLW County		Not Found/Incorrect
CLW City		Not Found/Incorrect
CLW State		Not Found/Incorrect
CLW Zipcode		Incorrect/Not Found
CLW Telephone		Not Found/Incorrect
Address of Guardian	Incorrect County or City	Incorrect Residence
Birthing Hospital	Incorrect Facility	Incorrect Spelling
Birth Weight	Incorrect Weight or Not Listed	

Head Circumference	Incorrect/Not Found	
Gender	Incorrect Gender or Not Listed	
Hospital Transferred To		Not Found
Apgar Score	Incorrect/Not Found	
Admission/Discharge	Incorrect Dates	Not Found
Plurality	Not Found	Incorrect
Co-Twins LB/SB	Not Found	Incorrect
Did Infant Die	Not Found	
Ethnicity		Incorrect/Not Found
Race		Incorrect/Not Found
Case Finding Number		Incorrect
Medical Record #		Incorrect
Facility Name		Incorrect
Did Mom Receive Prenatal Care		Incorrect/Not Found
Pregnancy Record		Incorrect/Not Found
Family History of BD	Not Found	
LMP	Not Found/Incorrect Month Year	Incorrect Day
Ultra Sound	Not Found/Incorrect Month Year	Incorrect Day
Clinical Exam	Not Found/Incorrect Month Year	Incorrect Day
Prenatal Proc & Tests	Not Found/Incorrect Month Year Incorrect Results of Diagnosis	Incorrect Day
ICD-9 Coding	Incorrect First 3 Digits	Incorrect Last 2 Digits
Diagnosis Date	Incorrect Month Year/Not Found	
Verbatim	Incorrect/Not Found	

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Appendix K – Poster Used for the 2006 Minnesota State Fair

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For You, For Them

Take folic acid EVERY DAY...

...even if you're not planning to have a baby.

Half of all pregnancies are not planned.

Taking folic acid ***BEFORE*** getting pregnant

and early in your pregnancy, can protect your child from birth defects of the spine and brain.

Take 400 mcg of folic acid daily —almost every multi-vitamin has all the folic acid that you need.

MINNESOTA MDH DEPARTMENT OF HEALTH

1-800-657-3908 ● www.health.state.mn.us/divs/eh/birthdefects