

Michigan Children with Birth Defects

Statewide Observations of Referral Practices & Presentation of Best Practice Guidelines



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Outline

- Overview of the Michigan Birth Defects Registry (MBDR)
- MBDR Hospital Based Referral Study
- Suggested Best Practice Guidelines
- Next Steps

MBDR Follow-Up Program 1999-2002, 2002-2005

- CDC Cooperative Agreements to improve birth defects surveillance and promote integration of surveillance data in public health prevention and intervention programs
 - MDCH Genetics and Newborn Screening Program
 - Vital Records and Health Data Development Section

Birth Defects

- 1 in 33 babies is born with a birth defect
- 150,000 babies in the United States are born each year with birth defects



Michigan Birth Defects Registry (MBDR)

- Established in 1988 with statewide reporting since 1992
- Cases reported by inpatient hospital medical record departments and cytogenetic labs (*passive surveillance*)
- 861 reportable diagnostic codes (ICD-9)
- Birth to age 2 years

Michigan Birth Defects Registry (MBDR)

- MBDR report + birth record + death record = *MBDR CASE*
- *Supplemental* MBDR reports from
 - Pediatric genetics clinics
 - Early Hearing Detection and Intervention (EHDI) Program
 - Newborn Screening (NBS) Program

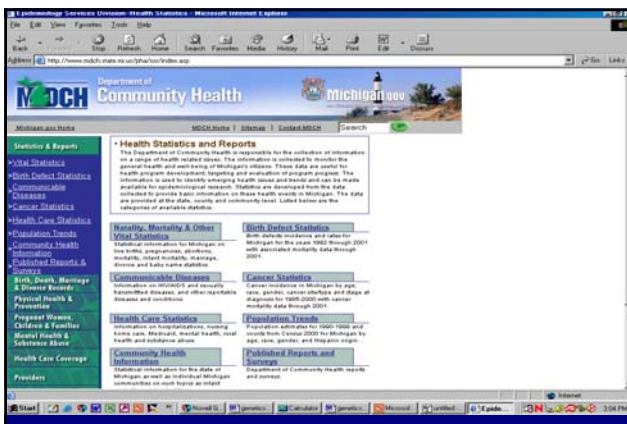
Michigan Birth Defects Registry (MBDR)

- ~ 8,000 new cases per year
(80 liveborn NTD cases/year)
- ~ 115,000 children registered (1992—2001)
(832 NTD cases during this period)



Michigan Birth Defects Registry (MBDR)

- Approximately 10,500 babies were born with birth defects in 2001 among 133,247 liveborns
- Heart and limb defects are the most common
- Birth defects are the leading cause of death in children under 12 months of age—causing 1 in 5 deaths



MBDR Purpose

- Collect statistical data on the incidence of birth defects and monitor trends
- Facilitate research studies on etiology of various birth defects
- Provide data for prevention efforts, program planning and evaluation
- Assure referral to needed services



Surveillance: Reportable Conditions

- Congenital anomalies
 - excludes only minor conditions
- Disease processes
 - immunological / metabolic / endocrine disorders
- Infectious disease exposures during the perinatal period
 - syphilis / rubella / cytomegalovirus
- Other maternal exposures during pregnancy
 - alcohol / illicit drugs / toxic substances



MBDR Follow-up Program: Guiding Framework

- The MBDR is ultimately aware of EVERY Michigan child from birth through age two years who is diagnosed with a birth defect or special health care need

MBDR Follow-up Program: Guiding Framework

- *The MBDR is a statewide safety net for ensuring that children with special needs are linked with services for which they may be eligible*

MBDR Follow-up Program: Guiding Framework

- *The CDC has encouraged (.....required) its cooperative agreement recipients to USE registry data to link families with services through integration of surveillance data in public health prevention and intervention programs*

Methods of Linking Families with Services



- Inform professionals
- Provide information directly to families
- Link MBDR data with service providers

Hospital Based Referral Study Objectives

- Assess suitability of birth defects data as a basis for family contact or other follow-up (confirm accuracy of reported diagnoses)
- Document referrals to intervention services
- Estimate family needs for additional resource information
- Identify types of health personnel involved in information and referral process

Hospital Based Referral Study

- Seek medical research project designation
- Representative MBDR diagnostic categories

Congenital Anomalies of the Central Nervous System
Congenital Anomalies of the Heart and Circulatory System
Congenital Anomalies of the Respiratory System
Cleft Palate and Cleft Lip
Congenital Anomalies of the Upper Alimentary Canal/Digestive System
Congenital Anomalies of the Genital and Urinary Systems
Congenital Anomalies of the Musculoskeletal System
Chromosomal Anomalies
Endocrine Disorders

Hospital Based Referral Study

- Select a sample of geographic regions
 - urban / rural
 - racial / socioeconomic diversity
 - good birth defects reporting
 - representative reporting facilities: regional NICU, major obstetrical, minor obstetrical facilities
- Design a database to record results
- Contact hospitals to arrange visits

Counties Visited

- Bay
- Chippewa
- Delta
- Genesee
- Grand Traverse
- Kalamazoo
- Kent
- Marquette
- Midland
- Oakland
- Saginaw
- Washtenaw
- Wayne

Study Results

- Reviewed inpatient hospital health records of 825 MBDR cases
- 699 of 825 (84.7%) children had one or more referrals documented
- Most documented referrals were to:
 - inpatient specialty care (cardiology, endocrinology, orthopedic surgery)
 - outpatient specialty care (genetics, peds specialty clinics)
 - public health systems or services (*Early On*® or CSHCS, public health nursing)

Types of Referrals

Source of Referral

Physician

Social work / discharge planning

Types of Services

- Medical / surgical inpatient consults
- Genetics
- Specialty outpatient clinics
- Public health
- *Early On*®
- WIC
- CSHCS

Regional Pilot Study- Results

- Referral to *Early On*® documented in 139/699 records (19.9%)
- Referral to CSHCS documented in 141/699 records (20.2%)
- Referral to WIC documented in 139/699 records (10.3%)

Comparison of MBDR Cases with CSHCS Enrollees

- Search CSHCS enrollment database for a subset of 138 cases
 - manual links by last name, first name, birth date, parent's name
 - 36/138 cases (26.1%) found in CSHCS database
 - ~ 7/36 case matches were not enrolled, 29 were enrolled
 - ~ of the 29 enrolled cases, 19 were not referred, 10 were referred
 - ~ of the 12 cases referred by the hospital, 10 were enrolled, 2 were not
 - mean times from birth to enrollment vary
 - ~ 248 days when referral present in health record
 - ~ 370 days when referral absent

		CSHCS Referral in Health Record	
		+	—
Enrollment in CSHCS	+	10 cases	19 cases
	—	2 cases	5 cases

Suggested Best Practice Guidelines

The purpose of these guidelines is to offer a handful of suggestions to professionals caring for neonatal and pediatric populations affected by special health care needs.

The guidelines are offered as action steps to facilitate entry of children with special needs into services.

Suggested Best Practice Guidelines

Of special consideration are children with birth defects whose referral needs escape attention because of the non life threatening nature of their condition--such as an otherwise healthy baby born with Down syndrome... discharged on a Saturday afternoon... from a smaller, rural Michigan facility.



Suggested Best Practice Guidelines



Referral opportunities may be missed when critically ill babies require acute and sophisticated medical care. Preserving the child's life is paramount but consideration of long-term medical and educational needs as well as the family's financial health are often not addressed during hospitalization.

Suggested Best Practice Guidelines

What role can a hospital play in helping a family receive referral to services for which they may be eligible?

- Hospital staff can provide referrals to families of children **EARLIER** than waiting until after discharge
- Earlier referral may lead to **earlier enrollment** in services and more timely establishment of a medical home
- Earlier enrollment may decrease morbidity and mortality and improve outcomes

Suggested Best Practice Guidelines

What difference can one individual make?

- A LOT!
- Asking a question to the family may plant a seed of interest and awareness
- One individual may also initiate the chain reaction of having a social worker or care coordinator stop by to see the family which leads to resource referral
- Do not underestimate the important role you can play in helping to link families with services

How does all of this start?

- Make it a daily habit to read the documentation of others in the child's health record with the intent of seeking out information on referrals
- If referral to services is indicated and not yet documented, ask yourself WHY?
- Initiate a referral, if appropriate
- If you cannot initiate a referral in your facility but provide direct care to the child and family, introduce information on CSHCS or *Early On*®
- Empower the family to ask questions about services their child may require after discharge such as CSHCS or *Early On*®
- **DOCUMENT** what information you have provided in the progress notes or on the appropriate form in the health record

Suggestions for Nurses

- Find out how the referral system works in your hospital
- Learn more about statewide systems such as CSHCS and *Early On*®
- Consider every encounter with parents an opportunity to link their child and family with services
- Distribute educational resources to families that are available on your unit
- Remind medical colleagues about offering referrals to CSHCS and *Early On*® if your facility requires referrals be physician-initiated

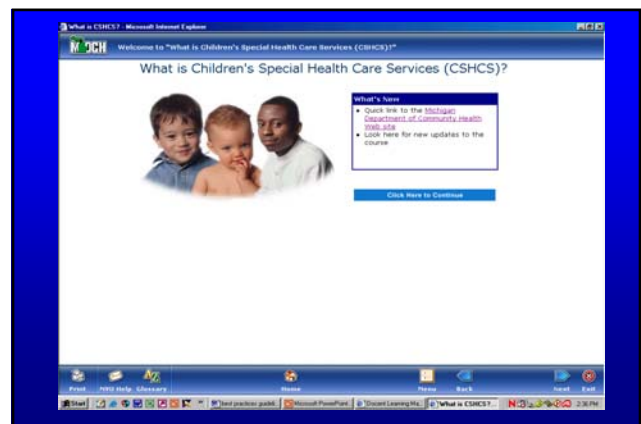
Suggestions for Nurses

Do not assume that the system of supports and services available to families is beyond your understanding

Empowering Professionals with Information



- *Resources for Families of Infants and Toddlers with Special Health Care Needs* pamphlet from MDCH
- Children with Special Health Care Needs Listserv digest
- In-services on the *Early On*® system provided by local intermediate school districts (ISD) or through the Clinton County Regional Educational Service Agency (RESA)
- Free CSHCS web-based educational module



Resources for Linking Families with Services



- *'Special Care for Special Kids'* parent handbook
- Genetics Program parent consultants
- Michigan Support Group Directory
- Genetics Program website
- Presentations, exhibits, mailings

What can hospitals do to help?

- ALL staff need to document in the health record any referral information shared with the family
- Maintain and distribute educational materials for families—make resources easy to access!!
- Find out more about CSHCS, *Early On*®, MBDR, NBS Program and the Michigan Early Hearing Detection and Intervention Program at MDCH
 - All of these state resources have personnel in place to offer in-services as well as pamphlets, fact sheets, etc.
 - Increasing public and professional awareness of these programs and systems is a common objective

What can hospitals do to help?

- Have in-services available to nursing and medical staff on how the referral system operates in your facility
- Make this information available during employee orientation
- Involve social work and care coordination staff members
- Become familiar with the key players across disciplines so that anyone involved in caring for a child with special health needs knows *WHO* to ask and *HOW* to help that family become linked with services after discharge

What can hospitals do to help?

- Become involved in the Local Interagency Coordinating Council (LICC) in your area to learn more about the larger system of care and community supports available to children and families in need
- Learn more about the importance of establishing a medical home for babies with special needs

Acknowledgements

- Michigan birth defects data available from <http://www.mdch.state.mi.us/pha/osr/index.asp>
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Southeast MI Association of Neonatal Nurses



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