

After the birth or adoption of a child with special needs, parents sometimes have questions. Families may wonder where to get help. There are many programs in Michigan. Most are free. Many are run by parents who want to share information. This pamphlet explains some of the resources available to families who have children with special needs. Your family might benefit from these services now or in the future.



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 1-866-852-1247, e-mail BDRFollowup@michigan.gov or visit www.migeneticsconnection.org.

The **Family Center for Children and Youth with Special Health Care Needs** provides information and support to families of children with all types of special needs. The center coordinates Michigan's Family Support Network as well as the Michigan Family-to-Family Health Information & Education Center (F2FHIEC). To contact the center, call the Children's Special Health Care Services (CSHCS) Family Phone Line at 1-800-359-3722 or visit www.bridges4kids.org/f2f/.

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 or call toll-free 1-877-553-5437.

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 or go to www.michigan.gov and search for local mental health services.

Parent HELPLine is a service of Gryphon Place, 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 1-800-942-HELP.

Michigan Alliance for Families 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 1-800-552-4821. For information see the website www.wash.k12.mi.us/perform.

Special Health Care

Your local health department can 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 1-800-359-3722.

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 or go to www.michigan.gov and search for local mental health services.

Hospice/Palliative Care

For information on Michigan hospice programs serving children with life-limiting conditions and their families please request a fact sheet from the MDCH **Birth Defects Follow-up Program**. Call toll-free 1-866-852-1247, e-mail BDRFollowup@michigan.gov or visit www.mihospice.org and click on the "Children with Illness" section. Some pediatric hospice programs also offer care and support *during pregnancy* when a life-limiting condition has been diagnosed prenatally in a family's unborn child.

Special Products

Advances in technology and new products help many children with special needs. **Michigan's Integrative 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 1-800-274-7426, or see www.cenmi.org/matr.

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. The services may include:

- family training (skill building)
- counseling (family, group or individual)
- home visits
- special instruction (teaching)
- speech pathology
- audiology
- occupational therapy
- physical therapy
- psychological services
- service coordination
- diagnostic medical services
- early identification
- screening
- assessment services
- health services
- nursing services
- social work services
- vision services
- assistive technology devices and services
- nutritional counseling
- transportation

For more information, call 1-800-Early-On (1-800-327-5966) voice, (517) 668-2505 (TTY) 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 1-800-252-0052 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 1-800-593-9146.

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 1-800-772-1213 or visit www.ssa.gov and search for SSI.

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 or visit www.michigan.gov and search for Family Support Subsidy Program.

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 1-800-359-3722 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 Michigan Department of Community Health (MDCH) **Genetics Program** coordinates a network of genetics clinics in the state. Call toll-free 1-866-852-1247 or visit www.migeneticsconnection.org 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 your 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 1-877-336-5333, 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 1-800-695-0285, 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 1-800-999-6673, 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) 747-4004 (x4286), or see www.fathersnetwork.org.

Facts about Michigan's Birth Defects Registry (MBDR)

- Between 9,000-11,000 infants and toddlers with birth defects, chronic illnesses and developmental disabilities are identified each year.
- Michigan law requires hospitals and medical labs to report certain health conditions to the MBDR.
- The MBDR is statewide and designed to help Michigan families obtain information, services and support.
- Information in the MBDR is confidential and regulated by Michigan law. It can be used only to offer appropriate services to families, for prevention education, and for research on the causes of birth defects.
- Registry data may be used to track the rate of birth defects, measure public health efforts to reduce the number of birth defects, and help communities improve services.

For more information, or to order additional copies of this pamphlet, please contact:

The Birth Defects Follow-up Program
Michigan Department of Community Health
201 Townsend Street, Fourth Floor
Lansing, MI 48913
1-866-852-1247 Toll-Free
1-517-335-8887
1-517-335-9790 FAX
1-517-335-8246 TTY
E-mail: BDRFollowup@michigan.gov

The Michigan Department of Community Health is an equal opportunity employer, services and programs provider. 25,000 printed at 0.071 cents each with a total cost of \$1,763.50. This publication was supported by Cooperative Agreement Number U50/CCU516053 from Centers for Disease Control and Prevention.

DCH-0951 printed 05/07
www.michigan.gov/mdch

Resources for Families of Infants and Toddlers with Special Health Needs



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Birth Defects Follow-up Program**