

After the birth or adoption of a baby with special needs, families may wonder where to get help or how to connect with other parents who have children with similar needs. There are many programs in Iowa.

This flyer is a guide to some of the resources available to families who have infants with special needs. Some resources can connect you with families in similar circumstances who have navigated the "system of services." Your family may benefit from these services now or in the future. This flyer does not reflect all the local, private, and public services available in your community, but rather is a beginning point to start you on your way to receiving support you need.

Family Support

Child Health Specialty Clinics Parent Consultation Network is a statewide network of parents of children with special health care needs. To find a parent consultant nearest you, call toll-free 1-866-219-9119 or visit www.uihealthcare.com/depts/state/chsc and click on regional centers.

Parent Educator Connection is a statewide group that encourages and promotes active partnerships between parents and educators of children with special needs. To find a parent educator coordinator near you, call your local Area Education Agency or visit www.aea11.k12.ia.us/pareduc.

Health Care

Child Health Specialty Clinics (CHSC) is a public health program that provides services to children birth to age 21 with special health care needs working with families, service providers, and communities. CHSC provides clinical services to children who have long-term physical and mental health problems. CHSC also helps families find other local health care services that their child may need. Call toll-free 866-219-9119 or www.uihealthcare.com/depts/state/chsc.

Special Education Services

Early Childhood and Special Education Services. Early childhood professionals in the Area Education Agencies (AEA) and local schools provide many services and resources for families and young children up to five years of age. Services include health services, therapy, social work, transportation services, and more. For more information, call your local AEA or visit the Web site at www.iowa.gov/educate and click on special education under the PK-12 section.

National Organizations

Genetic Alliance is an international group of families, health professionals and genetic organizations dedicated to enhancing the lives of everyone living with a genetic condition. Their Web site has information, resources and support group connections. Call 800-336-4363, or visit www.geneticalliance.org.

Family Village is a Web site that has links and supports for children with disabilities. The site includes a library with general disability subject links, message boards, chat groups, and a shopping mall. Visit www.familyvillage.org.

National Center on Birth Defects and Developmental Disabilities provides information on birth defects and developmental disabilities for families, children, and health professionals. Visit www.cdc.gov/ncbddd/default.htm.

National Organization for Rare Disorders (NORD) is dedicated to helping people with rare diseases that affect only a small number of people. Call 800-999-6673, or visit www.rarediseases.org.

Genetic Counseling

Neuromuscular and Related Genetic Disease Program is a program that provides health care services including diagnosis and management of care for people with problems of the nerve and muscle systems. To find out more, call 319-356-4071.

Regional Genetic Consultation Service is a program that provides diagnosis, testing, information, support management of care, and counseling to people and families with history of an inherited problem, delays of growth or development, or genetic syndromes. To find out more, call toll-free 800-260-2065.

Early Intervention

Early ACCESS is a partnership between families with children ages birth to three and providers from local health, human services, education and Child Health Specialty Clinics programs. Families and providers work together to identify, coordinate, and provide services that help the child grow and develop. To find out more, contact the area provider closest to you by calling 800-779-2001, or visit the Web site www.iowacompass.org.

Information and Referral

Iowa COMPASS is a free, confidential information and referral service for people with all types of disabilities, families, providers, and other community members. They will help locate statewide programs that provide services. Examples of these services are recreation activities, respite care, special foods, parent training, transportation counseling, special equipment and many more. Call 800-779-2001, or visit the Web site at www.iowacompass.org.

INFO TECH provides information and referral for families about assistive technology (AT) devices and payment options. AT devices may help you care for your child or allow your child to do what they need to do at home, school, work or play. INFO TECH also has a used equipment referral service. Call 800-331-3027 or visit www.uiowa.edu/infotech/ATDevice.htm for more information.

Supplemental Security Income (SSI) is a federal program that provides monthly payments and state Medicaid coverage for children with severe mental, emotional, and physical disabilities. To find out more, call the Social Security Administration at 800-772-1213.

Waiver Services are designed to return or maintain a child in his or her home or community. If you would like to learn more, please call the following: for AIDS/HIV Waiver: 515-281-7266. Brain Injury Waiver: 515-281-7266. Ill and Handicapped Waiver: 800-338-8366. Mental Retardation Waiver: 515-256-4641. Physical Disability Waiver: 515-281-7266.

Parents of children born with a physician-diagnosed birth defect will receive information through the mail about the Iowa Registry for Congenital and Inherited Disorders and resources within six months of being identified by the Registry.



For more information or to obtain additional copies of this flyer, please contact:

Iowa Department of Public Health, Center for Congenital and Inherited Disorders, 321 E. 12th Street, Des Moines, Iowa 50319-0075
Phone 800-383-3826 Web site: www.idph.state.ia.us/genetics