



PARENTS RESOURCE GUIDE

After talking with your child’s health care provider, you may feel overwhelmed. You are not alone! **This flyer is a resource guide for families with infants with specific healthcare needs.** Connect with parents in similar circumstances who can give support and empower your family.

This is not a comprehensive guide to all the local, private and public services available in your community

Special Education Services

Early Childhood and Special Education 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.

- educateiowa.gov/pk-12/special-education
- educateiowa.gov/pk-12/early-childhood
- ☎ Your local AEA



Early Childhood



Special Education

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 programs. Families and providers work together to identify, coordinate, and provide services that help the child grow and develop.

- educateiowa.gov/pk-12/early-childhood/early-access
- ✉ iafamilysupportnetwork@everystep.org
- ☎ 1-888-425-4371



Early Access

Health Care and Family Support

Child Health Specialty Clinics (CHSC) and CHSC Parent Consultation Network



CHSC Iowa

A public health program that provides services to children with special health care needs birth to age 21. CHSC operates under a System of Care approach to services for children and youth with special health care needs that recognizes the importance of family, school, and community, and seeks to promote the full potential of all children and youth. CHSC also helps families find other local health care services that their child may need.

- chsciowa.org
- ☎ 66-219-9119

Parent Educator Connection

A statewide group that encourages and promotes active partnerships between parents and educators of children with special needs.



Iowa AEA

- iowaaea.org/find-my-aea
- ☎ Your local AEA



Information and Referral

Iowa COMPASS

A free, confidential information and referral service for people with all types of disabilities, their families, providers, and other community members. They can help access thousands of local, state and national programs for people with complex health-related conditions and disabilities.

➔ iowacompass.org

☎ 800-779-2001

Supplemental Security Income

A federal program that provides monthly payments and state Medicaid coverage for children with severe mental, emotional, and physical disabilities.

➔ ssa.gov/benefits/ssi/

☎ 800-772-1213

Iowa HHS Home and Community-based Waiver Services (HCBS)

Designed to return or maintain a child in his or her home or community. Specific waivers available are Health and Disability (HD), AIDS/HIV (AH), Intellectual Disability (ID), Brain Injury (BI), Physical Disability (PD), and Children's Mental Health Waiver (CMH).

➔ hhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers

☎ 800-338-8366



Iowa Compass



Security Income



HCBS

Genetic Counseling

The University of Iowa Hospitals and Clinics Regional Genetic Consultation Service

A program that provides statewide 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.

☎ 800-260-2065

The University of Iowa Hospitals and Clinics Neuromuscular and Related Genetic Disease Program

A program that provides health care services statewide including diagnosis and management of care for people with problems of the nerve and muscle systems.

☎ 319-353-6200

Developmental Center at Blank Children's Hospital

The Developmental Center follows babies who experience certain complications before birth, or shortly after. The babies can occasionally experience problems with vision, hearing, communication, behavior, or delays in mental or motor development. Most at-risk infants develop and grow normally, suffering no lasting effects from the early complications.

☎ 515-241-5437



National Organizations

In addition to Iowa-based resources, there are national organizations that provide services to families of children with specific needs.

National Organization for Rare Disorders (NORD)

Dedicated to helping people with rare diseases that affect only a small number of people.

- rarediseases.org
- ☎ 800-999-6673



Rare Diseases

National Center on Birth Defects and Developmental Disabilities

Provides information on birth defects and developmental disabilities for families, children, and health professionals.

- cdc.gov/ncbddd/index.html



CDC

Genetic Alliance

An international group of families, health professionals and genetic organizations dedicated to enhancing the lives of everyone living with a genetic condition

- geneticalliance.org
- ☎ 800-336-4363



Genetic Alliance

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

Iowa HHS, Division of Public Health
Center for Congenital and Inherited Disorders
321 E. 12th Street
Des Moines, Iowa 50319-0075

- hhs.iowa.gov/genetics/iowa-registry
- ☎ 833-496-8040

US Department of HHS Child Welfare Family Support Services

Family support services are community-based services that assist and support parents in their role as caregivers. Such services can take many different forms depending on the strengths and needs of the family, but their overarching goal is to help parents enhance skills and resolve problems to promote optimal child development. All families can benefit from support in some way.

- childwelfare.gov/topics/supporting/support-services/



Child Welfare

Just In Time Parenting

Cooperative Extension System provides research-based information to families in factsheets and newsletters and connects parents to age-appropriate resources and expert advice.

- jitp.info/



Just In Time

National Parent Helpline®

Parents Anonymous® Inc. offers a call center and resources to provide parents and caregivers with emotional support.

- nationalparenthelpline.org



Parent Helpline