

Navigating Iowa's System of Care: A Caregiver's Guide to Autism Spectrum Disorder

First Steps After Diagnosis



THANK YOU

A special thank you to the following individuals and organizations for their contribution, dedication, and guidance in preparing this resource for Iowa families:

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INTRODUCTION



After receiving a diagnosis of Autism Spectrum Disorder (ASD), you may be wondering what will happen next for your child and your family.

Everyone experiences this process differently, with emotions ranging from grief to relief.

Although there will likely be challenges ahead, you are not alone in this journey.

There are many systems throughout the state of Iowa that specialize in supporting families of children with ASD.

This guide is intended to outline many of the services and supports available to you and your family as you progress through this transition period.



UNDERSTANDING YOUR CHILD'S DIAGNOSIS



WHAT IS AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder (ASD) is a developmental disability often affecting behavior and communication skills. ASD can impact a person's daily life at different levels, from mild to severe. There is no way to tell that a person has ASD by looking at them, but they may talk, act, and learn in different styles than those without an ASD diagnosis. The abilities of people with ASD may range from gifted to severely affected.¹

WHAT CAUSES ASD?

There is no single cause of ASD.² Some research shows that ASD originates from differences in the shape and function of the brain. Other studies show ASD may be caused by genetics, heredity, or medical conditions. While researchers continue to search for answers, it seems that ASD may be caused by a combination of ASD risk factors that may influence brain development.³ Research has also shown that there are several evidence-based interventions to help individuals with ASD that are detailed throughout the following pages.

WHAT DOES IT MEAN TO HAVE A MEDICAL DIAGNOSIS OF ASD?

Referrals to services like Applied Behavioral Analysis (ABA), or speech, physical, and occupational therapies may need a medical diagnosis in order to be covered by insurance when services are provided outside of school. A medical diagnosis of ASD can also increase your child's eligibility for additional community-based services, resources, and supports.

In the state of Iowa, a medical diagnosis of ASD can only be made by a developmental pediatrician, a clinical psychologist, or a child psychiatrist. A diagnostic team may be made up of several providers, including neurologists, school psychologists, speech and language pathologists, learning consultants, and other professionals who are trained to recognize the signs of ASD.

1. Autism Society (2016) <http://www.autism-society.org/what-is/>

2. Autism Society (2016) <http://www.autism-society.org/what-is/causes/>

3. Huquet G, Ey E, Bourgeron T. (2013) The genetic landscapes of autism spectrum disorders. *Annu Re Genomics Hum Genet.* 14:191-213.

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IOWA RESOURCES FOR YOUR FAMILY



Research has helped healthcare providers gain a better understanding of ASD and has led to the discovery of many effective resources and therapies. Individualized and appropriate interventions can lead to better results for children with ASD. Early intervention, or providing services to children as soon as possible, has been shown to improve the quality of life for individuals with autism. Individuals with ASD may continue to show symptoms over their lifespan and some will need care and supervision throughout their life.

Any intervention should be specific to the needs of an individual child and family. Many available resources are meant to be intensive. The plan for each child should be flexible and tailored to make the most of their strengths and improve on their weaknesses. A child's plan and interventions may need to be re-evaluated and changed over time by the family and care team, and not all resources will be appropriate for every family and child.

This guide provides information about these resources and other information.

NOTES

RESOURCES

This page lists some of the most common resources and services for children with ASD and their families. See Pages 11 and 12 for brief descriptions of some interventions listed below.

EVIDENCE-BASED BEHAVIORAL INTERVENTIONS

- * Applied Behavioral Analysis (ABA)
- * Naturalistic Developmental Behavioral Interventions, which may include Behavioral Health Intervention Services (BHIS; for Medicaid members only)
- * Visual Supports and Schedules
- * Cognitive Behavior Therapy (CBT) and Self-Management Therapy

EVIDENCE-BASED MEDICAL REFERRAL INTERVENTIONS

- * Occupational Therapy
- * Physical Therapy
- * Speech Therapy (including language therapy and augmentative communication interventions)

EDUCATION SERVICES

- * Early ACCESS (Birth to age 3)
- * Early Childhood Special Education (programming through Area Education Agencies/Local School Districts; Age 3 and older)

FAMILY SUPPORT AND CARE COORDINATION (FAMILY NAVIGATION)

- * Autism Society of Iowa
- * ASK (Access for Special Kids) Resource Center
- * Iowa Regional Autism Assistance Program (RAP)

FINANCIAL RESOURCES

- * Autism Support Program (ASP) - *see Page 15*
- * Medicaid for Kids with Special Needs
- * Medicaid Waivers

MEDICATION MANAGEMENT

- * Medication (sometimes prescribed to reduce certain symptoms including self-injury, mood disorders, aggression, hyperactivity, etc.)

OTHER INTERVENTIONS & THERAPIES

- * Nutrition Services Program through Early ACCESS and Child Health Specialty Clinics
- * Social Skills Training

YOUR FAMILY'S RIGHTS IN AN EDUCATIONAL SETTING



The Individuals with Disabilities Education Act (IDEA) guarantees students with disabilities the right to a free and appropriate public education (FAPE), provided within the least restrictive environment (LRE). Parents can request an assessment for their child to determine if specially designed instruction, special education services, are needed. This educational evaluation determines if an educational disability exists (does the child have challenges that can impact their learning), not to make a medical diagnosis. The educational evaluation team must include a specialist with experience in autism when children are evaluated. Even if children already have a medical diagnosis, an educational evaluation must be completed for children to receive services in the public schools. The educational evaluation for children ages 3 and over will determine if an Individualized Education Plan, or IEP, is needed.¹

WHAT IS AN...

Individualized Family Service Plan (IFSP)?

A personalized, written treatment plan for children under age 3 years old. An IFSP outlines the Early ACCESS services that a child will receive. Most services under an IFSP are family-centered and provided in the home. This means that the family's participation is very important in the development of an IFSP, as it is designed to support the entire family. This comes from the belief that if a family is better supported, they will be better equipped to support their child.²

Individualized Education Program (IEP)?

A written plan that focuses on the unique learning needs of individual children and youth who are 3 to 21 years of age. An IEP is required by law to include: individual educational goals, documentation of current school performance, supports, services, and modifications the school is required to provide to help children meet their goals, and measures to assess progress toward those goals. Transition planning is also included in an IEP to prepare teens for life after high school.³

1. Special Education (2016) <http://www.specialeducationguide.com/pre-k-12/what-is-special-education/legal-rights-to-services/>
2. Special Education Guide (2016) <http://www.specialeducationguide.com/early-intervention/the-who-what-why-of-an-individual-family-services-plan-ifsp>
3. Understood (2016) <https://www.understood.org/en/school-learning/special-services/ieps/understanding-individualized-education-programs>

EARLY INTERVENTION CAN SIGNIFICANTLY IMPROVE THE QUALITY OF LIFE FOR INDIVIDUALS WITH ASD

EARLY ACCESS IN IOWA: BIRTH TO AGE 3

Early Intervention in Iowa is called Early ACCESS. Families and providers work together to understand and address developmental and growth concerns and family priorities for their child. Families do not need a medical diagnosis to seek Early ACCESS services in Iowa.

Early ACCESS provides services through an Individualized Family Service Plan, or IFSP, and may include early educational programming, occupational therapy, speech therapy, and family training. There is no cost to families for evaluation, assessment, service coordination, and the creation of an IFSP.

Early ACCESS Service Coordinators work with families to identify costs and payment methods for any additional services that a child may need. Depending on the intervention or service, there may be no cost or a sliding fee scale.¹

FOR MORE INFORMATION VISIT:

www.educateiowa.gov/pk-12/early-childhood/early-access

TO APPLY VISIT:

www.iafamilysupportnetwork.org/early-access-iowa/what-is-ea

or call toll-free 1-888-425-4371

EARLY CHILDHOOD PROGRAMS IN IOWA

For children 3 years and older, public schools and Area Education Agencies (AEAs) help identify and evaluate children for special education school-based services. Even if children are not attending school, they may be eligible for services.

Families should call their local elementary school and ask to speak with someone who can help get their child evaluated for school-based services or the principal.

1. Iowa Department of Education (2016) <https://www.educateiowa.gov/pk-12/early-childhood/early-access>
2. Early Childhood Iowa (2016) <http://www.earlychildhoodiowa.org>

NOTES

COMMON MEDICAL INTERVENTIONS



SPEECH– LANGUAGE THERAPY

Speech-language therapy is used to help children understand speech processes and language use in social situations. This type of therapy can be beneficial for children with ASD who may struggle with communication, or those who have difficulty understanding social cues when talking to others.¹

OCCUPATIONAL THERAPY

Occupational therapy involves physical, and motor skills and can be important for some children with ASD. The goal of occupational therapy is to develop age-appropriate independence and self-care skills.¹

PHYSICAL THERAPY

Physical therapy focuses on problems with movement that cause limitations in daily life including challenges with sitting, walking, running, and jumping. Physical therapy can also improve coordination, poor muscle tone, and balance leading to better overall movement.¹

1. Autism Speaks (2016) <https://www.autismspeaks.org/what-autism/treatment/what-treatments-are-available-speech-language-and-motor-impairments>
2. Autism Speaks (2016) http://www.autismspeaks.org/docs/sciencedocs/atn/atn_air-p_applied_behavior_analysis.pdf
3. CDC (2016) <http://www.cdc.gov/ncbddd/adhd/treatment.html>

APPLIED BEHAVIORAL ANALYSIS

Depending on a child's needs, Applied Behavior Analysis, or ABA therapy, may focus on teaching self-help skills, social skills, academic skills, communication, or appropriate behavior.

An ABA therapist determines how a child's surroundings, including the people around them, may influence their behavior. ABA therapy focuses on positive reinforcement; teaches children how to increase their useful behaviors and decrease behaviors that may cause harm or interfere with learning. ABA uses rewards for positive behaviors rather than recognition of negative behaviors.²

BEHAVIORAL HEALTH

There are many types of behavioral health services for children typically provided by social workers, psychologists, and mental health counselors. This type of therapy may be helpful for children with difficult behaviors or co-occurring disorders, such as ADHD, disruptive behavioral disorders, depression, or anxiety. Behavioral health therapy can be provided to an individual child, or to their entire family, and can help new skills and behaviors or strengthen existing skills to address problematic behaviors.³

COMMON TYPES OF ASSISTANCE AVAILABLE IN IOWA

MEDICAL ASSISTANCE

Some families of children with ASD are eligible for Title 19 funding, or Medicaid for Kids with Special Needs (MКСN) that can help pay for the costs of medical care.

Title 19 funding is administered by Managed Care Organizations; however, the Iowa Department of Human Services determines eligibility and manages applications. Eligibility is based on income, age, or disability.

Families with children under the age of 18 may be eligible for Title 19, even if they already have commercial or private insurance coverage. Title 19 may cover specific services including speech, occupational, and physical therapy, ABA, or behavioral health services.¹

For more information, please visit:

<https://dhs.iowa.gov/ime/members/medicaid-a-to-z/MКСN>

RESPITE AND HOME AND COMMUNITY SERVICES WAIVER

Respite is temporary care provided to a child or an adult with special needs, which allows short, planned breaks for the child's primary caregiver. Respite supports the needs of families so they can better care for their child and can be provided in the community, at home, or at a licensed facility. Funding for respite can come from an agency, private pay, or the Home and Community Services Waiver (HСBS).

Families eligible for an HСBS waiver can receive respite and other community based services through a through a case manager.²

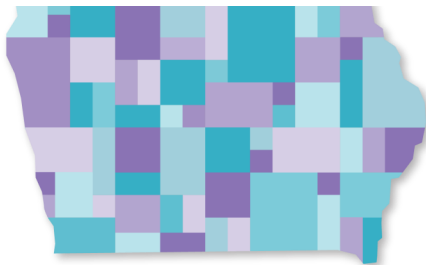
For more information, please visit:

<http://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs>

Financial support may also be available for ABA through the Autism Support Program (ASP).

Please see Page 15 for more information on the eligibility guidelines and how to apply for this funding.

1. Iowa Department of Human Services (2016) <https://dhs.iowa.gov/ime/members/medicaid-a-to-z/MКСN>
2. Iowa Department of Human Services (2016) <http://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers>



RAP

Iowa Regional
Autism Assistance
Program



CONNECTING IOWA'S CHILDREN AND FAMILIES TO COMMUNITY RESOURCES

WHAT IS RAP?

The Iowa Regional Autism Assistance Program (RAP) provides community-based clinical consultation, multidisciplinary care planning recommendations, and family to family support for children with ASD and their families.

RAP team members who work with families may include advanced registered nurse practitioners (ARNPs), registered nurses (RNs), and family navigators. The ARNPs and RNs use standardized tools to identify children at risk for ASD and help families find diagnostic services.

RAP teams also help families access community-based services and supports to help meet their specific needs and goals.

CONNECT WITH RAP ON SOCIAL MEDIA



Like us on Facebook
[www.facebook.com/
IowaRegionalAutismAssistanceProgram](http://www.facebook.com/IowaRegionalAutismAssistanceProgram)



Follow us on Twitter
[@IowaRAP](https://twitter.com/IowaRAP)



Follow us on Pinterest
<https://www.pinterest.com/iowarap/>

CARE COORDINATION

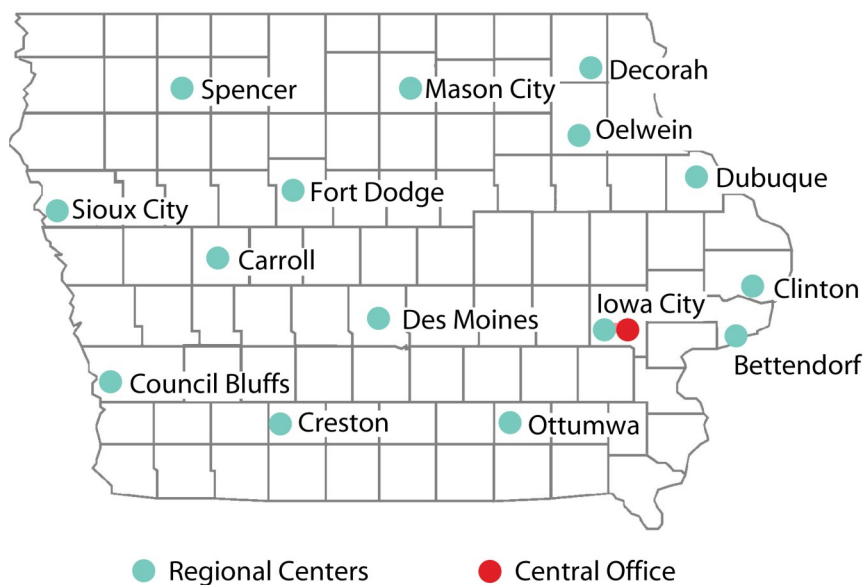
RAP teams help Iowa families access local and community-based ASD services based on each family's needs and goals. RAP teams can help families:

- * Navigate the education system
- * Find insurance coverage and payment options for Applied Behavioral Analysis
- * Communicate with diagnostic facilities and health care providers
- * Connect with an advocacy or family support group

FAMILY-TO-FAMILY SUPPORT

Families of children with ASD often have unique needs and may benefit from extra supports. One of the most meaningful sources of support is someone who has shared the same experience. All RAP Family Navigators are the parent or caregiver of a child or youth with special health care needs. Family Navigators listen to the concerns of families, share their own experiences, and provide systems navigation for families.

RAP TEAMS SERVE ALL IOWA COUNTIES



Bettendorf
563-344-2250

Carroll
712-792-5530

Clinton
563-243-0292

Council Bluffs
319-353-7203

Creston
641-782-9500

Decorah
563-382-1277

Des Moines
515-528-2571

Dubuque
563-556-3700

Fort Dodge
515-955-8326

Mason City
641-424-0030

Oelwein
319-283-4135

Ottumwa
641-682-8145

Sioux City
712-224-5437

Spencer
712-264-6362

CENTRAL OFFICE

Iowa City
Toll-free: 866-219-9119
Extension 1

Please visit www.chsciowa.org for CHSC Regional Center specific information, as well as other programs and services available for children and youth with special health care needs and their families.



THE AUTISM SUPPORT PROGRAM



In 2013, Iowa Legislation created the statewide Autism Support Program, or ASP. This program provides funding for children and youth to access Applied Behavior Analysis (ABA) therapy for some Iowa children with an ASD diagnosis.

Eligible children may receive up to \$36,000 per year for ABA therapy services over a 24-month period of time, not to exceed \$72,000 total.

GENERAL ELIGIBILITY GUIDELINES FOR THE AUTISM SUPPORT PROGRAM

- * Child is under the age of 14 years at the time of application
- * A diagnosis of ASD has been provided by a child psychiatrist, developmental pediatrician or clinical psychologist
- * Diagnosis was provided within 24 months of the date of application
- * The child does not qualify for Medicaid coverage or coverage under a commercial insurance plan.
 - Individual and group insurance policies vary. RAP teams are available to help families apply for the Autism Support Program and to explore their insurance coverage options
- * The family meets specified Federal Poverty Level (FPL) income guidelines (income must be under 500% FPL)
- * Complete an application

**CONTACT A RAP TEAM MEMBER FOR ADDITIONAL
INFORMATION AND FOR ASSISTANCE ON
COMPLETING AN APPLICATION**

Iowa-RAP@uiowa.edu

Toll Free 1-866-219-9119, Ext. 1

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ADDITIONAL RESOURCES

Autism Society

www.autism-society.org/

The Autism Society is an advocacy group that works to increase public awareness about the everyday issues faced by individuals with ASD. This website provides reliable information about a broad range of topics including legal resources and future planning for families of children with ASD.



Autism Society of Iowa

<http://autismia.com/>

Provides information about Iowa-specific ASD services, supports, programs, and advocacy efforts.



Iowa Regional Autism Assistance Program (RAP)

www.chsciowa.org/rap

Provides community-based clinical consultation, multidisciplinary care planning recommendations, and family to family support for children with ASD and their families.

Pediatric Integrated Health Home Program

<http://dhs.iowa.gov/ime/providers/integrated-home-health>

Provides care coordination services and family to family supports for Medicaid-eligible children and youth with serious mental health needs and their families.



Autism Speaks First 100 Days Kit (available in English and Spanish)

www.autismspeaks.org/family-services/tool-kits/100-day-kit

The *Autism Speaks 100 Day Kit for Newly Diagnosed Families of Young Children* was created specifically for families of children ages 4 and under to make the best possible use of the 100 days following their child's diagnosis of autism.



ADDITIONAL RESOURCES



Sesame Street and Autism: Seeing the Amazing in All Children - <http://autism.sesamestreet.org/>
Offers families ways to overcome common challenges and simplify everyday activities and fosters an affirming narrative around autism for all children and families.



**University of Iowa
Stead Family
Children's Hospital**

University of Iowa Hospitals Stead Family Children's Hospital Autism Center

<https://uichildrens.org/medical-services/autism>

Provides assessments, treatment recommendations, and ongoing follow-up care for children with ASD and their families.

Mayo Clinic

www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/definition/con-20021148

Information about ASD diagnoses, treatments, outcomes and support.



National Alliance on Mental Illness (NAMI) - www.nami.org

Provides education and advocacy resources to improve the lives of individuals with mental illnesses.

ASK Resource Center - <http://askresource.org/>

ASK (Access for Special Kids) Resource Center is a parent training, information, and advocacy center for Iowa families of children and youth with special needs.



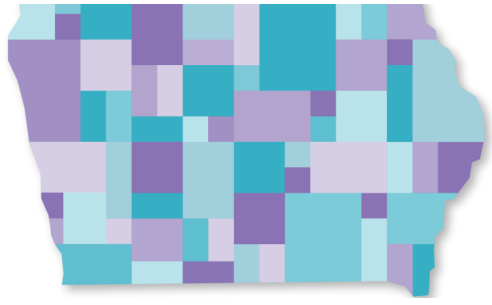
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FUNDING RECOGNITION

This project was supported in part by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), under grant award number H6MMC27438-01-01, *State Implementation Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities*. Total project award amount for period 9/1/2014-3/31/2017 was \$591,436.

This information or content should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.



RAP

Iowa Regional
Autism Assistance
Program



CHILD HEALTH SPECIALTY CLINICS

**Assuring a System of Care for Iowa's Children
and Youth with Special Health Care Needs**

For more information, please contact:

Central Office

Iowa Regional Autism Assistance Program
Division of Child and Community Health
Child Health Specialty Clinics
Stead Family Department of Pediatrics
100 Hawkins Drive, 247 CDD
Iowa City, IA 52242

Toll-free: 1-866-219-9119, Extension 1
Email: Iowa-RAP@uiowa.edu
Website: www.chsciowa.org/rap



The Iowa Regional Autism Assistance Program (RAP) is administered by the University of Iowa, Stead Family Department of Pediatrics, Division of Child and Community Health and Child Health Specialty Clinics. Support is provided by the Iowa Department of Education, the Iowa Department of Public Health, and the State of Iowa.

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Updated January 2022