



# Navigating Iowa's Resources

**A caregiver's guide to autism spectrum disorder**

Iowa Regional Autism Assistance Program (RAP)

University of Iowa Health Care Child Health Specialty Clinics administer the Regional Autism Assistance Program (RAP) with support provided by the Iowa Departments of Education, Health and Human Services and the State of Iowa.

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## A note about language:

In this guide, you may see different terms used for autism. These include "person with autism," "person with ASD," "autistic person," and "person on the autism spectrum." Some people in the autism community like one term more than another. We respect these differences and do not intend to support only one choice. We also use the words "autism" and "autism spectrum disorder (ASD)" to mean the same thing, unless stated otherwise.

## Introduction

After your child is diagnosed with autism spectrum disorder (ASD), you may be wondering what happens next for your child and your family. Everyone reacts in different ways. You might feel sad, worried, relieved, or have many emotions at the same time. All of these feelings are normal.

There may be challenges ahead, but you are not alone. There are many resources across the state of Iowa that help families of children with autism.

This guide outlines many of the services and supports available to you and your family as you move through this next stage.





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## Understanding Your Child's Diagnosis

### What is autism spectrum disorder?

Autism spectrum disorder (ASD) is a lifelong developmental condition. It can affect how a person behaves, communicates, and manages emotions and actions. Some people may need very little support, while others may need more help in daily life. You cannot tell if someone has autism just by looking at them. However, they may talk, act, and learn differently than people without autism. People with ASD have a wide range of strengths and challenges. Some may be gifted, while others may be severely affected.

### What causes autism?

There is no one known cause of autism. Some research shows that ASD may be linked to differences in how the brain grows and works. Other studies suggest that genetics or certain medical conditions may play a role.

Researchers believe that autism may be caused by a mix of factors that affect brain development. Research has also shown that there are proven therapies and supports that can help autistic people.



### What does it mean to have a medical diagnosis of ASD?

Your child may need a medical diagnosis of ASD to get certain services. Insurance often requires a diagnosis to cover services like Applied behavior analysis (ABA), or speech, physical, or occupational therapy. A medical diagnosis of ASD can also help your child qualify for more community programs, resources, and supports.

In Iowa, a medical diagnosis of autism can be made by a developmental pediatrician, clinical psychologist, child psychiatrist, or nurse practitioner. Sometimes, a team of professionals work together to make a diagnosis. This team may have neurologists, school psychologists, speech and language pathologists, behavior analysts, learning consultants, and other professionals trained to identify ASD. Families can reach out to the Iowa Regional Autism Assistance Program (RAP) or Autism Society of Iowa for help finding a provider who can diagnose ASD.



## Living with autism: In school and beyond

People with autism can learn ways to handle challenges and build on their strengths and talents. Everyone has their own journey, but some families may find it helpful to know:

- Many children with ASD go to regular school classrooms where they can learn from and teach their peers.
- Some autistic people continue their education after high school and graduate from college.
- Many people with challenging symptoms are able to work in their communities.
- Having access to services and supports can help people be more independent and have the highest quality of life.

## Notes

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## Resources and services

These are some of the most common resources and services for children with ASD and their families. See pages 20 and 21 to learn more about these resources.

### Evidence-based behavioral interventions

- Applied behavior analysis (ABA)
- Naturalistic developmental behavioral interventions
- Cognitive behavior therapy (CBT) and self-management therapy
- Social skills training

### Evidence-based medical referral interventions

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

### Education services

- Early ACCESS (birth to age 3)
- Early childhood special education (programming through Area Education Agencies or local school districts, age 3 and older)
- Special education up to age 21

### Family support and care coordination (family navigation)

- Iowa Regional Autism Assistance Program (RAP)
- Autism Society of Iowa
- Access for Special Kids (ASK) resource center

### Financial resources

- Autism Support Program (ASP)
- Medicaid for Kids with Special Needs
- Medicaid Waivers
- Children at Home

### Medicine management

- Medicine (sometimes prescribed to reduce certain symptoms including self-injury, mood disorders, aggression, hyperactivity, and more)

### Other interventions, therapies, and services

- Behavioral Health Intervention Services (BHIS)
- Nutrition services program through Early ACCESS and Child Health Specialty Clinics (CHSC)
- Visual supports and schedules
- Parent training or parent-mediated therapies
- Feeding therapy

## Education

### Your family's rights in an educational setting

The Individuals with Disabilities Education Act (IDEA) gives students with disabilities the right to a free and appropriate public education (FAPE). This education must be provided in the least restrictive environment (LRE).

Parents can ask the school to evaluate their child to see if they need special instruction or special education services. This evaluation looks at how a child's challenges may affect learning. It is **not** used to make a medical diagnosis.

The educational evaluation team must have a specialist who has experience with autism. Even if a child already has a medical diagnosis, an evaluation must be done for the child to get services in the public schools.

For children ages 3 and older, this evaluation helps decide whether the child needs an Individualized Education Plan (IEP).

### What is an individualized family service plan (IFSP)?

It is a written plan for children under age 3. The plan lists the Early ACCESS services that a child will receive. Most services under an IFSP are focused on the family and are often given in the home.

Families play a very important role in creating the IFSP. The plan is designed to support the whole family. This is based on the idea that when families are well supported, they are better able to support their child.

### What is an individualized education program (IEP)?

It is a written plan for children and youth ages 3 to 21. An IEP is focused on each child's unique learning needs.

By law, an IEP must include:

- Learning goals for the child
- Information about how the child is currently doing in school
- Services, supports, and modifications the school will provide
- Ways to measure the child's progress toward their goals

For teenagers, the IEP also includes transition planning to help get them ready for life after high school.

## Early ACCESS and early childhood programs in Iowa

### Early ACCESS: Birth to age 3

Early ACCESS is Iowa's Part C of IDEA for babies and toddlers who are not developing as expected or who have a medical condition that may slow their development. Families and providers work together to understand a child's development, growth concerns, and family goals. Families do **not** need a medical diagnosis to ask for Early ACCESS services in Iowa.

Early ACCESS services are provided through an IFSP.

Services may include:

- Early educational programming
- Occupational therapy
- Speech therapy
- Family training

#### For more information, visit:

[educate.iowa.gov/pk-12/early-childhood/early-access](https://educate.iowa.gov/pk-12/early-childhood/early-access)

#### To apply, visit:

[iafamilysupportnetwork.org/families/make-a-referral](https://iafamilysupportnetwork.org/families/make-a-referral)

There is no cost for evaluation, assessment, service coordination, or creating the IFSP.

An Early ACCESS service coordinator helps families understand any costs for extra services. Some services may be free, and others may be offered with a sliding fee scale (based on family income).

### Early childhood programs

For children 3 years and older, public schools and Area Education Agencies (AEAs) help find and evaluate children who may need special education services. Children can be eligible for services even if they do not go to school yet.

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

### Special education programs

A student may be eligible for special education until they:

- Graduate with a regular high school diploma
- Reach age of 21
- Are determined to no longer be eligible

Families should call their local school.

More information can be found at:  
[educate.iowa.gov/pk-12/special-education](https://educate.iowa.gov/pk-12/special-education).



## Common Medical Interventions

### Speech-language therapy

Speech-language therapy teaches children how to talk with and understand others. It can support autistic children who have trouble speaking, understanding language, or using social skills during conversations. It can help children:

- Improve speech
- Learn to use gestures, pictures, or other non-verbal ways to communicate
- Better understand social cues, like taking turns or reading facial expressions

### Occupational therapy

Occupational therapy helps people with ASD take part in daily activities. Therapy is based on each person's needs and strengths.

Occupational therapy can support:

- Sensory regulation, emotional control, and mental well-being
- Daily living skills, such as dressing, eating, and self-care
- Use of tools or equipment to increase independence
- Planning, organizing, and problem-solving skills
- Social interaction, play, and leisure activities
- Changes to the environment to support learning and participation
- Advocacy skills for the person, their family, and their community
- Caregiver education to support success at home, school, and in the community

Occupational therapy can support people across the lifespan. It focuses on helping people engage in activities that are meaningful to them.



### Physical therapy

Physical therapy helps with movement skills like sitting, walking, running, and jumping. It can improve strength, balance, coordination, and muscle tone. These skills help children move more easily and safely in daily activities.

## Applied behavior analysis

Applied behavior analysis (ABA) is an evidence-based therapy commonly used to support people with ASD. It uses learning and behavior strategies to teach useful skills and reduce behaviors that interfere with daily life.

In ABA therapy:

- Licensed behavior analysts create goals based on assessments, child strengths, and family priorities.
- Skills are taught in small, clear steps.
- Positive behaviors are encouraged to help learning.

ABA can support skills such as:

- Communication and social interaction
- Daily living skills
- Academic skills
- Emotional regulation
- Play and leisure skills
- Behavior management

Parent education is an important part of ABA, helping families support learning in daily routines.

## Mental health

Mental health services, such as cognitive behavioral therapy (CBT) may be provided by psychologists, social workers, or other licensed providers. Behavioral health therapy can be done with a child or their whole family. These services can help children learn new skills, strengthen existing skills, or address behaviors that interfere with daily life.



## Other interventions, therapies, and services

### Behavioral Health Intervention Services (BHIS)

BHIS is only for people with Medicaid who have a qualifying diagnosis. They help the person and their family learn age-appropriate skills to manage their behavior and improve self-control. BHIS services usually take place in the home, school, and community, as well as foster family and group care settings.

### Nutrition Services Program through Early ACCESS and Child Health Specialty Clinics

Registered dietitians provide nutrition assessments when requested by a provider. They also help families with follow-up support and care coordination when needed. CHSC offers training and education about nutrition for children and youth with special health care needs.

### Visual supports and schedules

Visual supports and schedules use pictures, objects, or words to share information in a clear and predictable way. These tools help autistic people understand routines, get ready for transitions, and communicate more easily.

### Parent training or parent-mediated therapies

This type of therapy teaches parents skills they can use with their own child.

### Feeding therapy

Feeding therapy helps children who have trouble eating. This may include food aversions, picky eating, sensory sensitivities, trouble chewing or swallowing, or refusing certain textures, tastes, or food groups. Feeding therapy is often provided by occupational therapists, speech-language pathologists, or behavior analysts.

### Iowa Vocational Rehabilitation Services

Iowa Vocational Rehabilitation (VR) Services is part of Iowa Workforce Development. VR helps people with disabilities get ready to work, find and keep a job, and grow in their careers.

VR also offers Pre-Employment Transition Services (Pre-ETS) for high school students with disabilities. These services help them learn about careers and training options, build work and self-advocacy skills, and make personalized plans based on their job goals.

For more information, visit: [workforce.iowa.gov/vr](http://workforce.iowa.gov/vr)

## Common Types of Assistance in Iowa

### Medical assistance

Some families of children with ASD may qualify for Medicaid, or Medicaid for Kids with Special Needs (MKSN). These programs can help pay for medical care.

Health coverage is provided through a Managed Care Organization (MCO). The Iowa Department of Health and Human Services (HHS) decides who qualifies and manages applications. Eligibility is based on income, age, or disability.

Families with children **under age 18** may qualify for Medicaid, even if they already have private or employer-based insurance. Medicaid may help pay for services such as speech, occupational, and physical therapy, ABA, or behavioral health services.

For more information, visit: [hhs.iowa.gov/medicaid](https://hhs.iowa.gov/medicaid)

### Respite care

Respite provides short-term care for a child or an adult with special needs. This allows caregivers to take short, planned breaks. Respite care can be provided in the home, in the community, or at a licensed facility. Respite may be paid for by an agency, private funds, or the Home and Community Services Waiver (HCBS).

### Home and Community Services Waiver

Families who qualify for an HCBS waiver can get Medicaid covered services, respite care, and other supports in their community. A case manager helps families find and coordinate services.

For more information, visit: [hhs.iowa.gov/medicaid/services-care/home-and-community-based-services](https://hhs.iowa.gov/medicaid/services-care/home-and-community-based-services)



## The Autism Support Program

The Autism Support Program (ASP) was created by Iowa law in 2013. This program helps pay for ABA therapy for some children and youth with ASD.

Eligible children may get up to \$36,000 per year for ABA services for up to 24 months (2 years).

A child may qualify if:

- They are under age 14 at the time of application.
- They have an ASD diagnosis from a child psychiatrist, developmental pediatrician, or clinical psychologist.
- The diagnosis was made within the last 24 months.
- They do **not** qualify for Medicaid or private insurance coverage.
- Family income meets guidelines (under 500% of the Federal Poverty Level).
- The family fills out an application.

For more information, visit: [hhs.iowa.gov/health-prevention/child-adolescent-health/autism-support](https://hhs.iowa.gov/health-prevention/child-adolescent-health/autism-support)

## Children at Home program

The Children at Home program helps families pay for supports and services for a child with a disability when other programs do not cover those needs.

For more information and to see if your family qualifies, visit: [iafamilysupportnetwork.org/families/children-at-home/](https://iafamilysupportnetwork.org/families/children-at-home/).



## Iowa Regional Autism Assistance Program (RAP)

### What is RAP?

RAP connects families to services for their child with ASD.

### RAP team members

The RAP team includes:

- Advanced registered nurse practitioners
- Registered nurses
- Family navigators

RAP teams use screening tools to identify children at risk for ASD and help families find services. They are committed to making sure all Iowans ages 0 to 21 years with ASD have access to care coordination and family-to-family support in their community.

### Care coordination

RAP teams help Iowa families find ASD services in their area. They coordinate care based on each family's needs and goals.

#### RAP teams can help families:



Find autism information



Find an advocacy or family support group



Explore insurance coverage and payment options for ABA and other needs



Communicate with diagnostic facilities and health care providers



Navigate the education system

### Follow RAP on social media



@IowaRegionalAutismAssistance Program



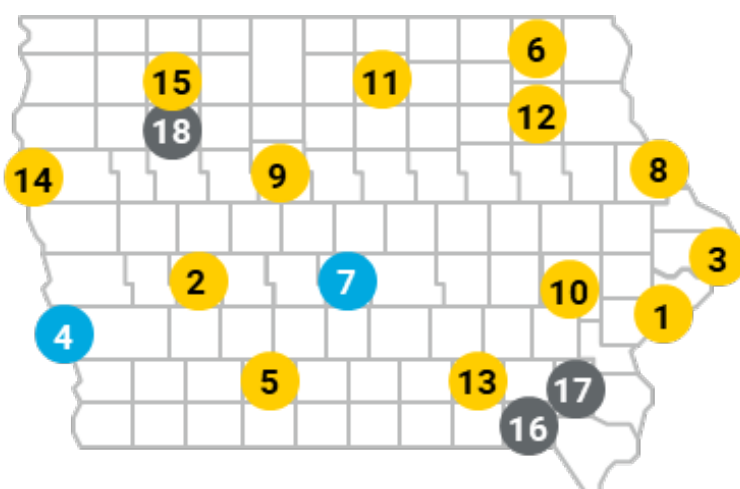
@rap\_iowa



@rap\_iowa

## RAP teams serve all Iowa counties

- Regional center
- Family navigation
- Satellite location



|                                                      |              |                                                     |              |                                                       |
|------------------------------------------------------|--------------|-----------------------------------------------------|--------------|-------------------------------------------------------|
| <span style="color: yellow;">●</span> 1 Bettendorf   | 563-344-2250 | <span style="color: yellow;">●</span> 8 Dubuque     | 563-556-3700 | <span style="color: gray;">●</span> 16 Keosauqua      |
| <span style="color: yellow;">●</span> 2 Carroll      | 712-792-5530 | <span style="color: yellow;">●</span> 9 Fort Dodge  | 515-955-8326 | <span style="color: gray;">●</span> 17 Mount Pleasant |
| <span style="color: yellow;">●</span> 3 Clinton      | 563-243-0292 | <span style="color: yellow;">●</span> 10 Iowa City  | 866-219-9119 | <span style="color: gray;">●</span> 18 Storm Lake     |
| <span style="color: cyan;">●</span> 4 Council Bluffs | 319-353-7203 | <span style="color: yellow;">●</span> 11 Mason City | 641-424-0030 |                                                       |
| <span style="color: yellow;">●</span> 5 Creston      | 614-782-9500 | <span style="color: yellow;">●</span> 12 Oelwein    | 319-283-4135 |                                                       |
| <span style="color: yellow;">●</span> 6 Decorah      | 563-382-1277 | <span style="color: yellow;">●</span> 13 Ottumwa    | 641-682-8145 |                                                       |
| <span style="color: cyan;">●</span> 7 Des Moines     | 319-678-3747 | <span style="color: yellow;">●</span> 14 Sioux City | 712-224-5437 |                                                       |
|                                                      | 319-678-4143 | <span style="color: yellow;">●</span> 15 Spencer    | 712-264-8517 |                                                       |

### Family-to-family support

Families raising a child with autism often have unique needs and may benefit from extra support.

RAP family navigators are team members who are also parents or primary caregivers of a child with special health care needs. Because of their personal experience, they understand many of the challenges families may face. Family navigators listen to your concerns and offer emotional support.

The RAP team is committed to helping each family connect to the level of support they want.

**To learn more about RAP, call 866-219-9119 or email [Iowa-RAP@uiowa.edu](mailto:Iowa-RAP@uiowa.edu).**

Visit [uihc.org/childrens/services/child-health-specialty-clinics](http://uihc.org/childrens/services/child-health-specialty-clinics) for CHSC Regional Center specific information, as well as other programs and services for children and youth with special health care needs and their families.

## More Resources

**IOWA**  
**HEALTH CARE**

Stead Family Pediatrics

### Iowa Regional Autism Assistance Program (RAP)

[uihc.org/childrens/RAP](http://uihc.org/childrens/RAP)

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



### Autism Society of Iowa

[autismia.com](http://autismia.com)

Provides information about Iowa-specific ASD services, supports, programs, and advocacy efforts. Offers a monthly e-newsletter with information on upcoming events throughout Iowa, as well as information on autism and special needs.

**IOWA**  
**HEALTH CARE**

Stead Family Pediatrics

### Stead Family Children's Hospital Center for Disabilities and Development

[uihc.org/childrens/services/autism](http://uihc.org/childrens/services/autism)

Works with patients and families to diagnose, treat, and address the many aspects of life touched by autism.



### Iowa Vocational Rehabilitation Services (VR)

[workforce.iowa.gov/vr](http://workforce.iowa.gov/vr)

Helps Iowans with disabilities find successful employment.



### ASK Resource Center

[askresource.org](http://askresource.org)

A parent training, information, and advocacy center for Iowa families of children with special needs.

## More Resources



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

[autismspeaks.org/family-services/tool-kits/100-day-kit](https://autismspeaks.org/family-services/tool-kits/100-day-kit)

Created specifically for families of children ages 4 and under to make the best possible use of the 100 days after their child's diagnosis of autism.



### **Mayo Clinic**

[mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/definition/con-20021148](https://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)**

[nami.org](https://nami.org)

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



### **Autism Society**

[autism-society.org](https://autism-society.org)

Connects people to the resources they need through education, advocacy, resources, and community programming. Provides reliable information about a broad range of topics.



### **American Academy of Pediatrics – HealthyChildren.org**

[HealthyChildren.org/English/health-issues/conditions/autism](https://HealthyChildren.org/English/health-issues/conditions/autism)

Source for autism information.



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- RAP Family Advisory Committee members

**Note:** People are listed along with their employer in 2016. This may not reflect their current position

# Iowa Regional Autism Assistance Program

## Contact us:

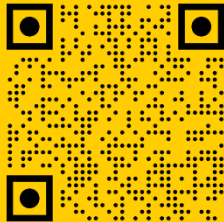
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