

IOWA'S AUTISM STRATEGIC PLAN

2022-2027

To Improve Services and Supports for Individuals with Autism Spectrum Disorder and Their Families



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INTRODUCTION

The prevalence of autism spectrum disorder (ASD) continues to rise. According to a report released by the Centers for Disease Control and Prevention (CDC) on December 3, 2021, 1 in 44 children have ASD. This new estimate is significant and supports the urgent need for Iowans to have access to effective interventions and additional programs to support individuals with ASD and their families.

Iowa's current infrastructure and system of care for individuals with ASD and their families have several strong areas upon which to build. This initiative was implemented to establish a structure for collaboration, resource leveraging, and service coordination with the goal being a unified and efficient support structure for individuals with ASD and their families.

In the spring of 2015, a strategic planning committee was created with the goal of developing a statewide strategic plan. Members of the planning committee represent a broad group of individuals, including family members as well as educational, medical, and community service providers.

The committee convened in April 2015 and was led by a facilitator from the Division of Child and Community Health, Center for Child Health Improvement and Innovation, at the University of Iowa to assist with the strategic planning process. The group met regularly to develop the strategic plan for 2016-2021.

In November 2015, a draft of the state strategic planning document was presented to the Iowa Autism Council. In December 2015, the Iowa Autism Council included the state strategic plan in their annual recommendations made to the Governor and the Iowa Legislature.

In the fall of 2021, the Iowa Regional Autism Assistance Program Expert Panel and Iowa Autism Council conducted a survey on the progress of the strategic plan. Individuals with autism, parents or primary caregivers, family members, and providers (including educational, medical, and community service providers) were invited to complete the survey on how Iowa can improve services and supports for individuals with autism spectrum disorder (ASD) and their families.

According to the survey results and based on the wording in the original plan, the areas that continue to need the most improvement include:

- Ensure equal access to high quality and timely services across the state regardless of geographic location.
- Increase coordination between oral, physical, and mental health, and educational services for all individuals with ASD.
- Ensure a range of safe, high-quality living options are available in Iowa for people with ASD.
- Increase access to high quality services through the lifespan.

An Autism Strategic Planning Update Committee was formed to revise the strategic plan, incorporating the feedback received. The updated document was reviewed by the RAP Expert Panel and the Iowa Autism Council for additional input.

CONTRIBUTING MEMBERS

Members of the 2021 Strategic Planning Update Committee included:

Erika Hertel*	Family Member/Regional Autism Assistance Program
Evelyn Horton	Balance Autism
Leslie Rogers	ChildServe
Wendy Trotter	Iowa Department of Education
Brad Zelinger	Stride Autism Centers

*Chair

Contributing members of the 2015 Strategic Planning Committee:

Marilyn Althoff	Hills & Dales
Susan Askeland	Grant Wood Area Education Agency (AEA)
Alyson Beytien	Family Member/Hills & Dales
Josh Cobbs	Family Member
Gretchen Conway	Keystone AEA
Pam Fields	Keystone AEA
Erika Hertel	Family Member/Regional Autism Assistance Program
Katie Hepfer	University of Iowa, College of Nursing
Leann Hotchkiss	Regional Autism Assistance Program
Vicki Hunting	University of Iowa – Center for Child Health Improvement & Innovation
Scott Lindgren	University of Iowa Children’s Hospital – Autism Center
Steve Muller	The Homestead (now Balance Autism)
Mary Roberts	Family Member/University of Iowa Children’s Hospital – Autism Center
Allison Schroeder	Family Member
Renee Speh	Family Member
Kris Steinmetz	Family Member/Autism Society of Iowa
Rachell Swanson-Holm	Regional Autism Assistance Program
Peggy Swails*	Regional Autism Assistance Program
Wendy Trotter*	Iowa Department of Education
Tara Underwood-Levin	Regional Autism Assistance Program
Maria Valdovinos	Drake University
Carrie Van Quathem	ChildServe

*Co-Chairs

Note: Members are listed along with their role on the committee and employer in 2015. This may not reflect their current position.

OUR VALUES

Our Vision

The vision of this plan is to ensure that all Iowans with Autism Spectrum Disorder (ASD) have the opportunity to develop the skills and knowledge necessary to live independent and interdependent lives within their community and to reach their full potential.

Our Mission

The mission is to build a state infrastructure for comprehensive, lifespan supports to individuals with ASD and their families through access to information and resources, coordination of services, and implementation of evidence-based practices.

Summary of Recommendations

The following areas of focus were identified so that all Iowans with ASD will:

- A. Get a Good Start
- B. Have Access to and Obtain Needed Services
- C. Have Well-Informed, Empowered, and Supported Families and Caregivers
- D. Successfully Transition to Adult Life
- E. Be Assured of Ongoing Coordination of Systems of Care and Support





A Note about Language:

The terms “person with autism,” “person with ASD,” “autistic person,” and “person on the autism spectrum” are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. We respect the different opinions within the community on the use of this language and do not intend to endorse any particular preference. In addition, the terms “autism” and “autism spectrum disorder (ASD)” are used interchangeably throughout this document unless otherwise noted.



GET A GOOD START

Strategy 1

Expand and intensify public awareness of the early signs of ASD and educate the public on the benefits of early identification.

- Increase family awareness of early childhood developmental milestones and recognition of early warning signs for ASD.
- Make certain that health care professionals and early childhood providers (teachers, childcare providers, and other community service providers) recognize early warning signs of ASD and know of screening, diagnostic, and family support resources available in their community.



Strategy 2

Ensure that Iowans are receiving timely screenings and comprehensive diagnostic evaluations at the first suspected signs of autism.

- Promote recommendations consistent with the American Academy of Pediatrics (AAP) guidelines that all children should receive developmental screenings at ages 9, 18, and 30 months, along with autism screenings at 18 and 24 months.
- Promote consistency in referrals for comprehensive diagnostic evaluations following identification of early warning signs or a positive screening.
- Increase the knowledge of healthcare and educational professionals of resources available in their region for quality comprehensive diagnostic evaluations.
- Explore options for increasing capacity to provide quality, comprehensive diagnostic evaluations in a timely manner across the state.



HAVE ACCESS TO AND OBTAIN NEEDED SERVICES

Strategy 3

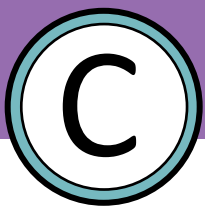
Increase access to high quality services throughout the lifespan.

- Make sure community stakeholders and families are aware of autism services and resources available in their regions.
- Build workforce capacity through more awareness of available job roles related to ASD services.
- Provide professional development on evidence-based practices and how to individualize them to the specific needs of each autistic individual, to educators, healthcare providers, and community service providers.
- Develop a standard of practice that recognizes the importance of individuals with autism developing skills in social interaction, self-regulation, and communication to succeed in each stage of life.
- Create a plan to allow all Area Education Agencies (AEAs) and Local Education Agencies (LEAs) to be able to offer the same full array of current, evidence-based practices and models of service delivery regardless of student's placement (e.g., within district, special school, etc.).
- Explore and define services and supports to assist youth with autism who are transitioning into adulthood and facing the "autism cliff," the loss of services that many autistics and their families experience as they age out of pediatric and school-based services.

Strategy 4

Provide equal access to high quality and timely services across the state regardless of age, race, ethnicity, zip code, or insurance.

- Increase use of and access to quality services by exploring collaborative partnerships between agencies/entities.
- Expand use of telehealth to allow families in rural areas to access quality services.
- Increase access to interpreters to reduce language barriers.
- Increase transportation options to allow improved access to services.
- Expand health insurance coverage for quality, evidence-based services throughout the lifespan by eliminating age, dollar, and length of service caps.



HAVE WELL-INFORMED, EMPOWERED, & SUPPORTED INDIVIDUALS, FAMILIES, & CAREGIVERS

Strategy 5

Empower individuals and families to advocate for the services and supports they or their family member needs as soon as autism is suspected, as well as throughout their lifespan.

- Provide training opportunities to individuals, families, and caregivers on evidence-based practices, education rights, and disability rights.
- Support the collaboration of agencies and service providers across Iowa to develop and maintain comprehensive lists of resources that can be accessed through the Autism Society of Iowa and the Iowa Regional Autism Assistance Program (RAP).

Strategy 6

Create options for crisis prevention and intervention that ensure the health, safety, and stabilization of individuals with autism and their families across the lifespan.

- Conduct statewide mapping of programs that serve autistic individuals in crisis for both pre-planned and emergency situations.
- Identify best-practice crisis intervention/stabilization models and their potential for being implemented in Iowa for individuals with varying needs across the spectrum.
- Provide training in crisis intervention and crisis management to parents, school personnel, emergency first responders, law enforcement officials, etc.
- Increase access to education and resources for comorbid conditions (e.g., seizures, feeding disorders, and mental health).





SUCCESSFULLY TRANSITION TO ADULT LIFE

Strategy 7

Make sure all autistic youth and individuals are provided appropriate and outcome-driven transition planning and associated services.

- Teach social skills and work skills needed to keep a job long before graduation from high school.
- Include families and the autistic individual in transition planning and program development so that plans and programs developed match the skills, interests, abilities, passions and supports of the individual with ASD.
- Provide information on transition and adult services, including the transition to adult health care, to autistic youth and individuals, and their families.
- Be sure people with autism, or their caregivers, have the skills to manage and access health care.
- Confirm that people with autism, or their caregivers, have the skills they need to stay well, such as nutrition, sleep, hygiene, self-care, etc.
- Provide opportunities for autistic people to develop skills and hobbies, participate in activities, and build relationships around shared interests.

Strategy 8

Provide a range of appropriate post-secondary program options in Iowa for youth with ASD (including employment opportunities, college and/or post-secondary education).

- Educate community employers of the potential individuals on the autism spectrum have and the supports that can help ensure successful employment.
- Make certain employers and co-workers have accurate, reliable information about autism, and available resources and supports.
- Ensure all Iowa higher education systems provide support services for students with ASD.
- Enhance the accessibility and services of Iowa Vocational Rehabilitation Services (IVRS) for individuals with ASD across the spectrum.
- Develop and provide training for adult service providers and employers on working with autistic individuals in community-based settings.
- Educate and encourage collaborative groups within the community to provide social skills training via social groups for young adults and/or adults with ASD.



SUCCESSFULLY TRANSITION TO ADULT LIFE (cont'd)

Strategy 9

Empower individuals across the spectrum to advocate for their rights and to take responsibility for their life choices as they transition to adulthood.

- Promote opportunities for training on self-advocacy (e.g., life skills, financial, personal and sexual safety, security, and awareness), including how and where to seek help.
- Link adult individuals with ASD to advocacy networks for increased community opportunities and support.
- Teach individuals with autism how to navigate the system to obtain maximum financial help and still maintain their services.

Strategy 10

Provide a range of safe, high-quality living options are available in Iowa for people on the autism spectrum.

- Explore and develop best practice guidelines that include housing options, varying level of supports needed for independent living, and incorporation of individuals' and families' preferences.





BE ASSURED OF ONGOING COORDINATION OF SYSTEMS OF CARE AND SUPPORT

Strategy 11

Increase coordination between service providers, which may include, but is not limited to any of the following: medical (physical, behavioral, and mental health), dental, social services, education, and vocational services for all individuals with autism.

- Continue collaborative workgroups and advisory panels, such as the Iowa Autism Council and the Iowa Regional Autism Assistance Program Expert Panel, to inform legislators and policy makers of best practices and to continue to monitor the progress of the strategic plan for Iowa.
- Encourage people with autism and families to participate in task forces and program development.
- Ensure both public and private agencies are aware of available resources and services in their communities and are collaborating in the dissemination of resources to individuals with ASD and their families.

Strategy 12

Promote shared service models and public-private partnerships to increase cost-effectiveness and efficiency.

- Investigate shared service models that demonstrate quality, cost-efficiency, consistency, accountability, and sustainability.
- Explore how other states coordinate data sharing across agencies.





This document, along with a one-page summary, can be found on the Regional Autism Assistance Program, Child Health Specialty Clinics website: <https://chsciowa.org/RAP>.

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