To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families
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 March 27, 2014, 1 in 68 children have an 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 ultimate goal being a unified and efficient system of care for individuals with ASD and their families.

In Spring 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 through the University of Iowa’s Division of Child and Community Health, Center for Child Health Improvement and Innovation, to assist with the strategic planning process. The group met regularly to develop the strategic plan.

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.
## Contributing members of the Strategic Planning Committee:

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Our Vision

The vision of the Strategic 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 the 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
IOWA STRATEGIC PLAN, 2016-2021

A. 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.
  - Ensure 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 ASD.
  - Promote recommendations consistent with the American Academy of Pediatrics (AAP) guidelines that all children should receive developmental screenings at ages 9, 18, and 24 or 30 months to identify developmental delays.
  - Increase screening efforts for ASD at 18 and 24 months as recommended by the Centers for Disease Control and Prevention (CDC) within the healthcare system.
  - Promote consistency in referrals for comprehensive diagnostic evaluation following identification of red flags or a positive screening.
IOWA STRATEGIC PLAN, 2016-2021

- Increase the knowledge of healthcare and educational professionals of the 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.

B. Have Access to and Obtain Needed Services

- **Strategy 3**: Increase access to high quality services throughout the lifespan.
  - Ensure community stakeholders and families are aware of ASD services and resources available in their regions.
  - Provide professional development on evidence-based practices, and how to individualize them to the specific needs of each individual with ASD, to educators, healthcare providers and community service providers.
  - Develop a standard of practice that recognizes the importance of individuals with ASD 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.).
IOWA STRATEGIC PLAN, 2016-2021

- **Strategy 4:** Ensure equal access to high quality and timely services across the state regardless of geographic location.
  - 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.
  - Promote health insurance coverage for quality, evidence-based services throughout the lifespan.

**C. Have Well-Informed, Empowered, and Supported Individuals, Families and Caregivers**

- **Strategy 5:** Empower individuals and families to advocate for the services and supports they or their family member needs as soon as ASD 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.
  - Develop a central location to provide support, resources, and advocacy information for individuals with ASD and their families (e.g., web-based resource directory).
• **Strategy 6**: Create options for crisis prevention and intervention that ensure the health, safety, and stabilization of individuals with ASD and their families across the lifespan.

  - Conduct statewide mapping of programs that serve individuals with ASD 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.

**D. Successful Transition to Adult Life**

• **Strategy 7**: Ensure all youth and individuals with ASD 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.
  
  - Ensure families and the individual with ASD are included 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.
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- Provide parents information on transition and adult services (roadmap for transition to adulthood).

- **Strategy 8**: Ensure there is 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 with ASD have and the supports that can help ensure successful employment.
  - 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 individuals with ASD 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.

- **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.
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- Link adult individuals with ASD to advocacy networks for increased community opportunities and support.
- Teach individuals with ASD how to navigate the system in order to obtain maximum financial help and still maintain their services.

- **Strategy 10:** Ensure a range of safe, high-quality living options are available in Iowa for people with ASD.
  - 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.

**E. Ongoing Coordination of Systems of Care and Support**

- **Strategy 11:** Increase coordination between oral, physical and mental health, and education services for all individuals with ASD.
  - Continue collaborative workgroups and advisory panels (such as the Iowa Autism Council and the Regional Autism Assistance Program Expert Panel Advisory Committee) to inform legislators and policy makers of best practices and to continue to monitor the progress of the strategic plan for Iowa.
  - Encourage families to participate in task forces and program development.
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♦ 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.

- **Strategy 13**: Develop methods for state-level agency coordinated data sharing.
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