



IOWA AUTISM COUNCIL

2018 Priorities

Moving Iowa Forward
Summary of accomplishments in 2017 and Priorities and
Recommendations for 2018

Iowa Autism Council

December 2017

To the Governor and Iowa Legislature:

The Iowa Autism Council (Council) was formed in 2008 through legislation (Iowa Code §256.35A). The Council was formed to act “in an advisory capacity to the state in developing and implementing a comprehensive, coordinated system to provide appropriate diagnostic, intervention, and support services for children with autism and to meet the unique needs of adults with autism.”

The Council is pleased to report that in 2017 Iowa has made significant strides in supporting individuals with autism spectrum disorder (ASD) through the following activities and legislative acts:

- House File 215 was signed into law on March 30, 2017 and received broad bi-partisan support. This law requires insurance providers to cover applied behavior analysis (ABA) for children with ASD in state regulated group coverage plans exceeding 50 employees.
- Fall of 2017 marked the beginning of Drake University’s Master of Science in Applied Behavior Analysis, which will provide the training and credentials needed to serve children with ASD through ABA therapy. This program should benefit from legislation that provides grant funding for students pursuing board certification in the practice of behavior analysis once those funds are released.
- The Autism Support Program (ASP) reached new highs in 2017 in the number of enrollees served (30) and the number of approved providers (12) offering services.
- Continued work on the “Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism spectrum disorder and their Families.” This strategic plan was formally adopted by the Council in 2015 and the Council has been monitoring statewide progress. The following activities demonstrate progress made on focus areas within the plan:
 - The Regional Autism Assistance Program (RAP) continued to provide support to individuals and families of individuals with ASD in obtaining assessments and care coordination, as well as assisting with autism surveillance for at-risk children.
 - Spring of 2017, the Iowa Department of Education completed year 2 of the multi-year, statewide ASD professional development initiative utilizing the Autism Navigator® for Early Intervention Providers online professional development courses. These courses are designed to help early interventionists (Iowa’s Early ACCESS providers) to better recognize the early warning signs of ASD and to use the evidence-based practice of coaching caregivers to embed intervention strategies in everyday routines and activities.
 - Innovative collaboration between the Child Health Specialty Clinics (CHSC) and Green Hills Area Education Agency to provide autism diagnostic evaluations using personnel from both agencies has increased access to diagnostic evaluations in an area of Iowa with few options.

Although Iowa continues to make great strides in the goal to improve the lives of individuals with ASD and their families, there continues to be many areas where our state falls short. The following areas have been identified by the Council as areas of priority for 2018:

- With funding cuts to the RAP program, the services they provided will be an area of need. These services include early screening for identification of children at risk for ASD, care coordination and family-to-family support, and connecting families with diagnostic and treatment resources.
- Many areas of the state continue to lack qualified diagnosticians to provide early screening and comprehensive assessment for ASD.
- Families continue to struggle to access medically necessary, evidence-based interventions due to lack of qualified providers in their region, or prohibitive costs of said treatments.

For the Council,

Matthew O’Brien
Co-Chairperson

Brandon Arkland
Co-Chairperson

Iowa Autism Council

2018 Priorities and Recommendations

General

The purpose of the Iowa Autism Council (Council) is to act in an advisory capacity to the Governor and General Assembly to develop and implement a comprehensive, coordinated system of care to provide appropriate diagnostic, intervention, and support services for children with autism spectrum disorders (ASD) and to meet the unique needs of adults with ASD.

The prevalence of autism spectrum disorder remains high at 1 in 68 (or 1.5%) of 8-year-old children according to Center for Disease Control and Prevention's [Community Report from the Autism and Developmental Disabilities Monitoring \(ADDM\) Network: A Snapshot of Autism Spectrum Disorder among 8-year-old Children in Multiple Communities across the United States in 2012](#). These findings indicate that there continue to be many children living with ASD who need services and support now, and as they grow into adolescence and adulthood.

2018 Priorities and Recommendations

Iowa has made some significant progress in supporting Iowans with ASD throughout their lifespan. However, there is still more to be done to ensure all Iowans affected by ASD have the opportunity to lead meaningful and successful lives in their community. The following are the 2018 priorities of the Iowa Autism Council:

➤ Filling the Gap Left by Funding Cut to Regional Autism Assistance Program (RAP)

The Regional Autism Assistance Program (RAP) was created by the legislature to “coordinate educational, medical, and other human services for persons with autism, their parents, and providers of services to persons with autism” (Iowa Code §256.35). This program, coordinated by the Child Health Specialty Clinics (CHSC) and the University of Iowa Hospitals and Clinics, has provided statewide services that include:

- Coordination of services, including diagnostic assessments and therapies
- Facilitation of family-to-family support
- Efforts for early identification of children at risk for ASD
- Assistance for families in accessing community-based services and supports
- Provision of technical assistance and training on evidence-based screening and assessment tools to medical home providers, Area Education Agencies, and other early intervention community providers.

Recently, the Iowa Department of Public Health cut 70% of the RAP program budget, eliminating numerous services, programs, and opportunities including:

- Elimination of the RAP Coordinator position who provided statewide support to RAP teams.
- Family Navigator positions from the Des Moines metro area and Creston were cut. The Des Moines position provided services to more than 70 families in the area. Additional caseloads for other locations absorbing these cases will decrease the timely response for support and will result in decreased contacts to families.
- Reduction of FTE for Child Health Specialty Clinic RNs from 4 hours to 2 hours weekly in all of the CHSC regional centers.
- Professional development opportunities for staff are no longer available.
- Outreach efforts to increase awareness of and assist with applications to the Autism Support Program (ASP) have been eliminated, reducing the likelihood that funds dedicated to ASP can be accessed by all who need it.
- Social media outlets (e.g., Facebook, Twitter, Pinterest), which the RAP depended on to provide information on autism-related programs throughout the state, will no longer be maintained.

Without these highly valued services, the needs of many children and families dealing with ASD will go unmet. The Council urges legislators to consider funding options that will return these services to individuals with ASD and their families.

➤ Continued Funding of the Autism Support Program: Modification Considerations due to Insurance Reform

The Autism Support Program (ASP) was created to fund applied behavior analysis (ABA) services for children with ASD who are “determined ineligible for coverage of applied behavioral analysis services under the medical assistance program, Iowa Code § 514C.28, or private insurance coverage.” Since its inception, ASP has provided funding for 42 children. While this is a relatively small number of children statewide, parents report that the services their children receive help them make significant gains in communication and socialization that will positively impact the rest of their lives. The Council recommends continued support for this valuable program.

With the passage of House File 215, requiring more group insurance carriers to cover ABA for children with ASD, there is hope that many families previously denied coverage will benefit. There may, however, be an unintended negative consequence to this law. For some individuals currently served through the ASP program, with a modest out-of-pocket cost share, a new ABA benefit through their private insurance would make them no longer eligible for ASP. As these individuals access ABA services through their private insurance instead, they may be required to meet a high deductible, co-pay or co-insurance that pushes their out-of-pocket cost for an intensive service such as ABA beyond their ability to pay. This additional expense could make accessing ABA services at the recommended therapeutic level cost prohibitive for families. The Council recommends that legislators consider a flexible funding option for ASP eligibility that would allow ASP funds to be used to help “fill the gap” between cost and insurance coverage by reimbursing families for high co-pays, co-insurance and/or deductibles that are spent for ABA services.

➤ Increasing Access to Treatment through Telehealth Models

In large and rural states, such as Iowa, there are barriers to treatment for individuals with ASD due to the limited number of trained professionals who provide ABA services and also due to the extreme distance some must drive to access services. In fact, Iowa has one of the lowest ratios of credentialed behavior analysts (Board Certified Behavior Analysts - BCBAs) to individuals with ASD in the United States and recent studies published at the University of Iowa have reported that families often must travel over 200 miles to access face-to-face services. These factors have led to excessive delays to treatment services and in many cases they have prohibited services altogether. The lack of trained professionals has recently been addressed through legislative funding efforts to establish a training program in ABA at Drake University and through state education grants to support students who choose to train in ABA. However, there likely will continue to be an insufficient number of treatment providers for many years and it is unlikely that those living in rural areas will ever find treatment close to home.

A possible solution to these barriers may be in the use of telehealth. Telehealth involves the provision of health care remotely by means of technology, including telecommunications, such as Skype®, Vido® (a HIPAA compliant telecommunications option), and many others. A telehealth model of ABA services allows a child with ASD to connect from home or a nearby clinic to a therapist who is stationed at a clinic that may be far from the patient's home. This model requires minimal technology equipment on the part of the patient, other than a laptop, tablet, or smartphone. There are numerous benefits to this model of service provision, including:

- substantial savings in terms of the time and money needed for travel to distant clinics
- increased generalization in home and community settings (outside of a clinic setting)
- training for parents/caregivers in ABA techniques so they can better help their family member

Recently, a number of studies have shown telehealth to be just as effective for ABA services for children with ASD as in-vivo service provision. In fact, researchers at the University of Iowa used telehealth to treat severe and challenging behavior in young children with ASD at a fraction of the cost as in-vivo therapy. This study was published in the prestigious journal *Pediatrics*¹.

The Council recommends legislative efforts that increase the options of reimbursable service provision to include telehealth models, including clinic to home services.

➤ Increasing Access to Diagnostic Assessment through Innovative Models

As noted previously, delays to treatment can be highly detrimental to the development of young children with ASD. For many children suspected of having ASD, the wait time for a diagnostic evaluation may be as long as or longer than the wait to access treatment services. At the University of Iowa Hospitals and Clinics, families of children suspected of having autism wait, on average, six months for a diagnostic evaluation. In some parts of Iowa, the same concern that exists for accessing treatment (i.e., lack of trained professionals and long distances to travel) exists for accessing diagnostic evaluations.

To decrease wait times for evaluations and improve access to services, some organizations in Iowa have partnered with other agencies to provide an innovative approach to diagnostic evaluations. An example of one such model is the Regional Autism Clinic of Iowa (RAC-I), which is a collaboration between the Child Health Specialty Clinics (CHSC) and Green Hills Area Education Agency. These two agencies teamed up to provide screening, evaluation, diagnosis and intervention recommendations for children that may have ASD or other developmental delays. The RAC-I team (which is comprised of personnel from both agencies) conducts a complete assessment using evidence-based screening and diagnostic tools. The team uses these tools, along with the American Psychiatric Association diagnostic manual (DSM-5) and the Autism Diagnostic Observation Schedule (ADOS-2), to assist in making a diagnosis. RAC-I partners with families to diagnose ASD and recommends interventions that will help children and youth in Southwest Iowa reach their full potential. Although the number of diagnostic evaluations is limited, it is the first time that this part of the state has had a diagnostic option for children at risk of ASD.

The Council recommends continued exploration and consideration of innovative models of diagnostic assessment to decrease wait times for diagnostic evaluations and access to services.

➤ Continued implementation of the Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families:

In November 2015, the Council adopted the *Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families* (see attachment). This document charts a course for Iowa to systematically and comprehensively improve its response to ASD and create opportunities for individuals with ASD to have meaningful and successful lives in their communities. The Council continues to see this document as the principal guide for developing and maintaining optimal services and supports for individuals with ASD and the families of those living with ASD.

Conclusion:

The State of Iowa continues to make progress toward improving the lives of individuals and families touched by ASD. The accomplishments noted at the outset of this report are an example of how hard work, dedication, and compassion contribute to this progress; however, the people of Iowa, including the Office of the Governor and the Iowa Legislature, should not be satisfied with the current status of our state. There continues to be many individuals with ASD and their families who have unmet needs, some of which have obvious solutions and others which will require additional hard work, dedication, and compassion.

¹Lindgren S., Wacker, D., Suess, A., Schieltz, K., Pelzel, K., Kopelman, T., Lee, J., Romani, P., and Waldron, D. Telehealth and autism: Treating challenging behavior at lower cost. *Pediatrics*. 2016; 137 (S2) e201528510.

Iowa Autism Council Members

2017 Voting Members

<u>Name:</u>	<u>Position/Representation:</u>
Arkland, Brandon (<i>co-chairperson</i>)	Person with ASD
Bowker, Christine	Family Member of person with ASD
Croonquist, Theresa	Insurance Industry Representative
Curry, James	Family member of person with ASD
Hertel, Erika	Family member of person with ASD
Kerkhoff, Jeanne	Family member of person with ASD
Logsdon, Angela	Family member of person with ASD
Muller, Steve	Residential Service Provider
Nopoulos, Nicholas	Insurance Industry Representative
O'Brien, Matthew (<i>co-chairperson</i>)	Service Provider
Peterson, Sean	Research
Phan, Jenny	Family member of person with ASD
<i>Vacant</i>	Mental Health Professional

2017 Ex-Officio Members

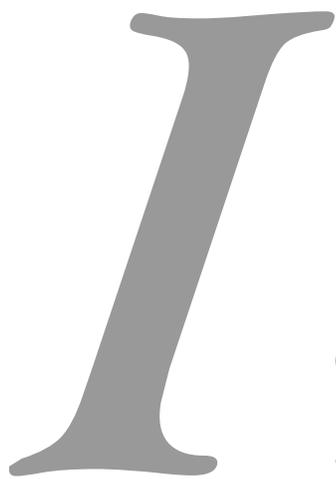
<u>Name:</u>	<u>Position/Representation:</u>
Boston, Angela	Iowa Insurance Division
Buehler-Sapp, Beth	Iowa Department of Education
Etscheidt, Susan / Kliewer, Chris	Board of Regents
Fanselow, Connie	Iowa Department of Human Services
Keith, Andrea	Iowa Vocational Rehabilitation
Shannon, Rik	Iowa Developmental Disabilities Council
Swails, Peggy	Child Health Specialty Clinics
Trotter, Wendy	Iowa Department of Education

Further findings are available with previous year's recommendations located at:

Iowa Department of Education website – www.educateiowa.gov
(located under the Iowa Autism Council)

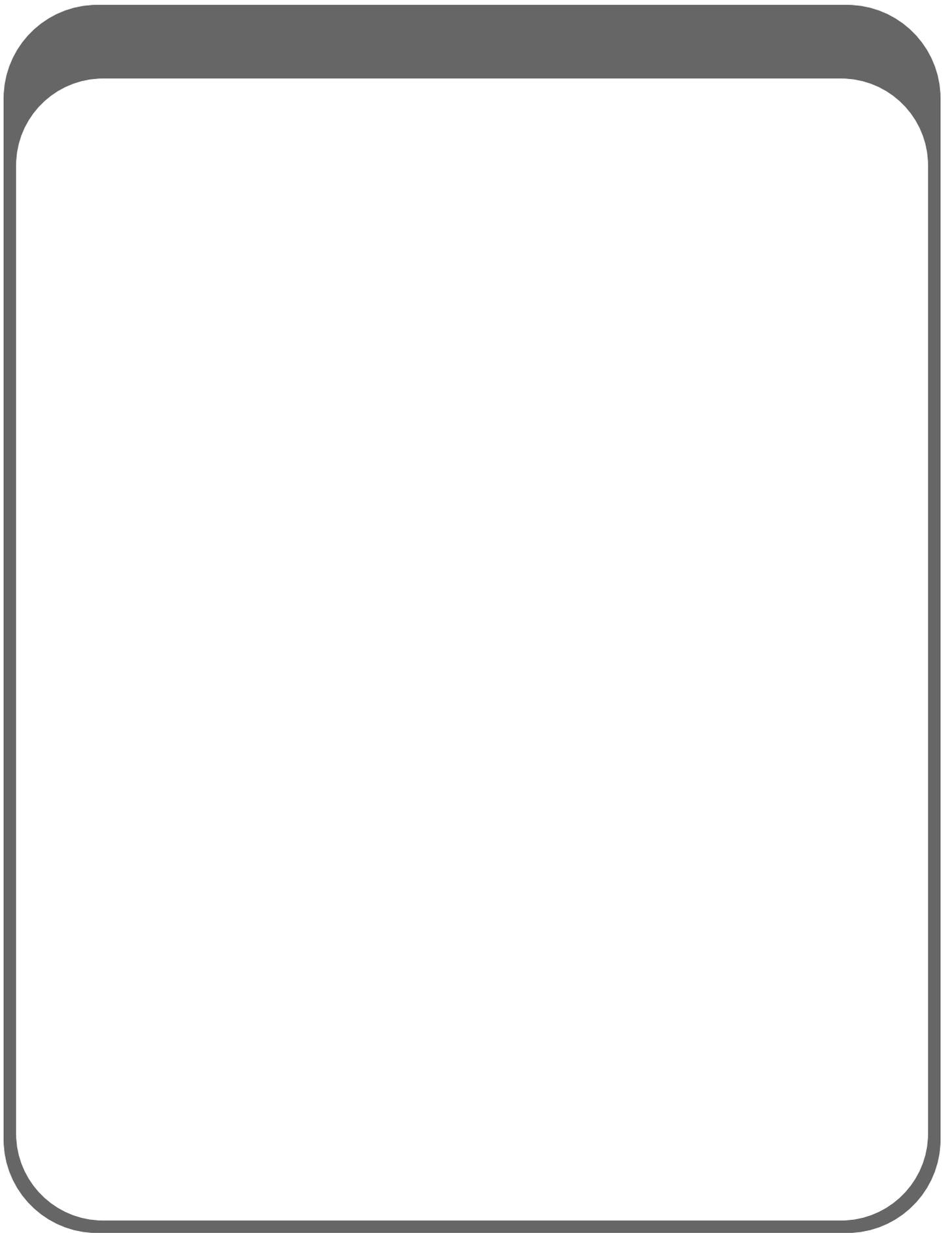
You may also contact:

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A large, bold, grey serif letter 'I' is positioned on the left side of the page. It is the first letter of the word 'Iowa'.

**owa's
Strategic Plan
2016-2021**

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



IOWA STRATEGIC PLAN, 2016-2021***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.

IOWA STRATEGIC PLAN, 2016-2021

Contributing members of the 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
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

IOWA STRATEGIC PLAN, 2016-2021***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.).**

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- **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 Families and Caregivers

- **Strategy 5: Empower families to advocate for the services and supports their family member needs as soon as ASD is suspected, as well as throughout their lifespan.**
 - ♦ Provide training opportunities to 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.**

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- ◆ **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.**
 - ◆ **Provide parents information on transition and adult services (roadmap for transition to adulthood).**

IOWA STRATEGIC PLAN, 2016-2021

- **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.
 - ♦ Link adult individuals with ASD to advocacy networks for increased community opportunities and support.

IOWA STRATEGIC PLAN, 2016-2021

- ♦ **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.**
 - ♦ **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.**

IOWA STRATEGIC PLAN, 2016-2021

- **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.**

IOWA STRATEGIC PLAN, 2016-2021

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