



IOWA AUTISM COUNCIL

2016 Priorities

Moving Iowa Forward

Summary of accomplishments in 2015 and Priorities and
Recommendations for 2016

Iowa Autism Council

December 2015

To the Governor and Legislators of Iowa:

The Iowa Autism Council (Council) was formed in 2008 as a result of authorizing legislation 256.35A Section 126. The Council was “created 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 2015, Iowa has made progress in supporting children and adults with Autism Spectrum Disorders (ASD) through the following initiatives:

- A. The Summary of Findings from the 2013 Statewide Needs Assessment report was completed and shared with various stakeholders.
- B. The Legislature has continued to fund the Autism Support Program helping to provide needed evidence-based services to children with ASD and their families.
- C. Legislation was also passed to create a board-certified behavior analyst (BCBA) and board-certified assistant behavior analyst (BCaBA) grants program to help address the shortage of BCBA/BCaBA providers in Iowa.
- D. In the Dubuque area, additional facilities staffed to handle individuals with ASD who also exhibit challenging behaviors have opened.

However, to ensure Iowans affected by 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, there is still more we can do. The following are priorities and recommendations for 2016:

- A. The Council supports the use of a statewide strategic plan which will support the efficient use of funding and an effective system of high quality, evidence-based, interdisciplinary, culturally appropriate services, and supports for individuals with ASD in Iowa.
- B. The Council recognizes that if the state of Iowa is to make real progress in its current efforts to support individuals and families affected by ASD, meaningful insurance reform is needed in both Medicaid and non-Medicaid programs to continue to provide access to medically necessary care and to expand the provider network in Iowa.
- C. The Council continues to encourage amendments to the eligibility requirements for the Autism Support Program to allow more individuals affected with ASD to access the funds. It is also necessary to take further steps to attract professionals to deliver autism services in Iowa.

For the Council,

James Curry
Chairperson

Iowa Autism Council

2016 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 ASD is on the rise. According to a report released from the Center for Disease Control and Prevention on March 27, 2014, 1 in 68 children have been identified with an ASD. However, in the November 13, 2015, edition of the [National Health Statistics Reports](#) put out by the U.S. Department of Health and Human Services, Center for Disease Control and Prevention, the 2014 estimated prevalence rate is now 1 in 45 children, ages 3 through 17.

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.

2016 Priorities and Recommendations

As referenced earlier, Iowa has made some significant progress in supporting Iowans with ASD throughout the lifespan. However, there is still more that can be done to ensure all Iowans affected by ASD have the opportunity to lead meaningful and successful lives in their community.

The following priorities and recommendations are being made by the Council for 2016:

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

The Council recognized the need for developing a statewide strategic plan, which when reviewed regularly, would chart a course for Iowans to systematically and comprehensively improve its response to ASD and create opportunities for individuals with ASD to have meaningful and successful lives in their community.

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

In November 2015, a draft of the state strategic planning document was presented to the Iowa Autism Council. The Council voted to accept the five-year strategic plan and to adopt it as a guiding document to enhance the system of care for Iowans with ASD. A copy of the Iowa Strategic Plan is included in this report for review.

➤ Amendments to the Autism Support Program

The Council continues to support the legislated Autism Support Program. However, the Council continues to encourage the Legislature to adopt amendments to the Autism Support Program that will allow for increased usage of the funds without taxing the funding limits imposed by Senate File 505:

1. Amend the income qualification guidelines. Income that exceeds the guidelines represents the largest percentage of applicants disqualified from accessing the services covered by the Autism Support Program. The Council would support inclusion of an income to expense ratio in addition to consideration of total income or increasing the “income as a percentage over the poverty line” guideline.
2. Amend the age limit for persons eligible to access the funds to age 21. Currently, the fund only authorizes ABA services up to age 9. While data supports that ABA services show the greatest effect on early skill acquisition when administered prior to age 9, ABA is not applicable to just early skill acquisition. ABA services can be beneficial throughout the life of the individual and allowing use of the funds through age 21 will allow qualifying individuals to maximize the period in which growth can be achieved.
3. Increase the reimbursement rates for autism services provided or supervised by BCBA. Senate File 505 did allow reimbursement for services provided by a BCaBA who is supervised by a BCBA but the fact remains that there is a scarcity of both BCaBA and BCBA professionals in Iowa. Simple economics dictate that better reimbursement rates will attract more practitioners to Iowa.

➤ Autism Insurance Mandate

As prevalence rates for ASD continue to rise at an alarming rate, caregivers are turning to private and public options to finance the necessary care for their family member with ASD. Employees of the state of Iowa have had access to Applied Behavior Analysis (ABA) services, covered by their state employee insurance plan, for several years. It was reported at our November council meeting by a representative of Wellmark that claims paid for state of Iowa employee members receiving ABA services to date for 2015 was only \$43, 923.50. There is ample data from several sources that can be reviewed to show that in the state of Iowa, paying for ABA services would not be cost prohibitive. Data sources include, but are not limited to, the state plan usage, the Autism Support Program and, anecdotally, other states.

The Council advises the Governor and Legislature to pass private insurance reform that would expand coverage for ASD treatments to include all plans regulated by state insurance rules. Iowans with ASD and their families need to have access to high-quality, evidence-based interventions

throughout their lifespan, and without reliable funding streams to access these services, we are failing to ensure that all Iowans are given the opportunity to reach their full potential and have meaningful and successful lives in their community.

➤ **Monitoring of the Medicaid Modernization Initiative**

Upcoming changes to Medicaid from the Medicaid Modernization initiative, which will convert existing Medicaid administration to Managed Care Organizations (MCO's), are a concern and the Council will continue to monitor the transition to best assist families with accessing the information they need to make decisions and navigate this transition. We hope to see continued coverage of medically necessary services for individuals with ASD within the new systems.

In addition, the Council is also concerned with the transition of management of the Autism Support Program from the current provider (Magellan Behavioral Health) to the new MCO's. There is concern regarding continuity of services for the families currently accessing the program. The Council will continue to monitor this situation as well.



Iowa Autism Council Members

2015 Voting Members

Arkland, Brandon	Person with a Disability- Candeo
Beytien, Alyson	Family member of person with Autism
Croonquist, Theresa	Wellmark Blue Cross and Blue Shield
Curry, James	Family member of person with Autism
Heiss, Rachel	Licensed Psychologist (service)
Hertel, Erika	Family member of person with Autism
Jennings, Jeffrey	Family member of person with Autism
Johnson, Steve	Magellan Behavioral Care of Iowa
Kohler, Frank	University of Northern Iowa
Logsdon, Angela	Family member of person with Autism
Muller, Steve	Homestead
O'Brien, Matthew	University of Iowa
Phan, Jenny	Family member of person with Autism
Turbes, Jan	Northwest Area Education Agency
Underwood-Levin, Tara	Child Health Specialty Clinics

2015 Ex-Officio Members

Buehler-Sapp, Beth	Iowa Department of Education
Burke-Boston, Angela	Iowa Insurance Division
Casey, Sean	Iowa Department of Education
Harker, Becky	Iowa Department of Human Services
Jackson, Mary	Iowa Vocational Rehab
Larkin, Laura	Iowa Department of Human Services
Fanselow, Connie	Iowa Department of Human Services
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)

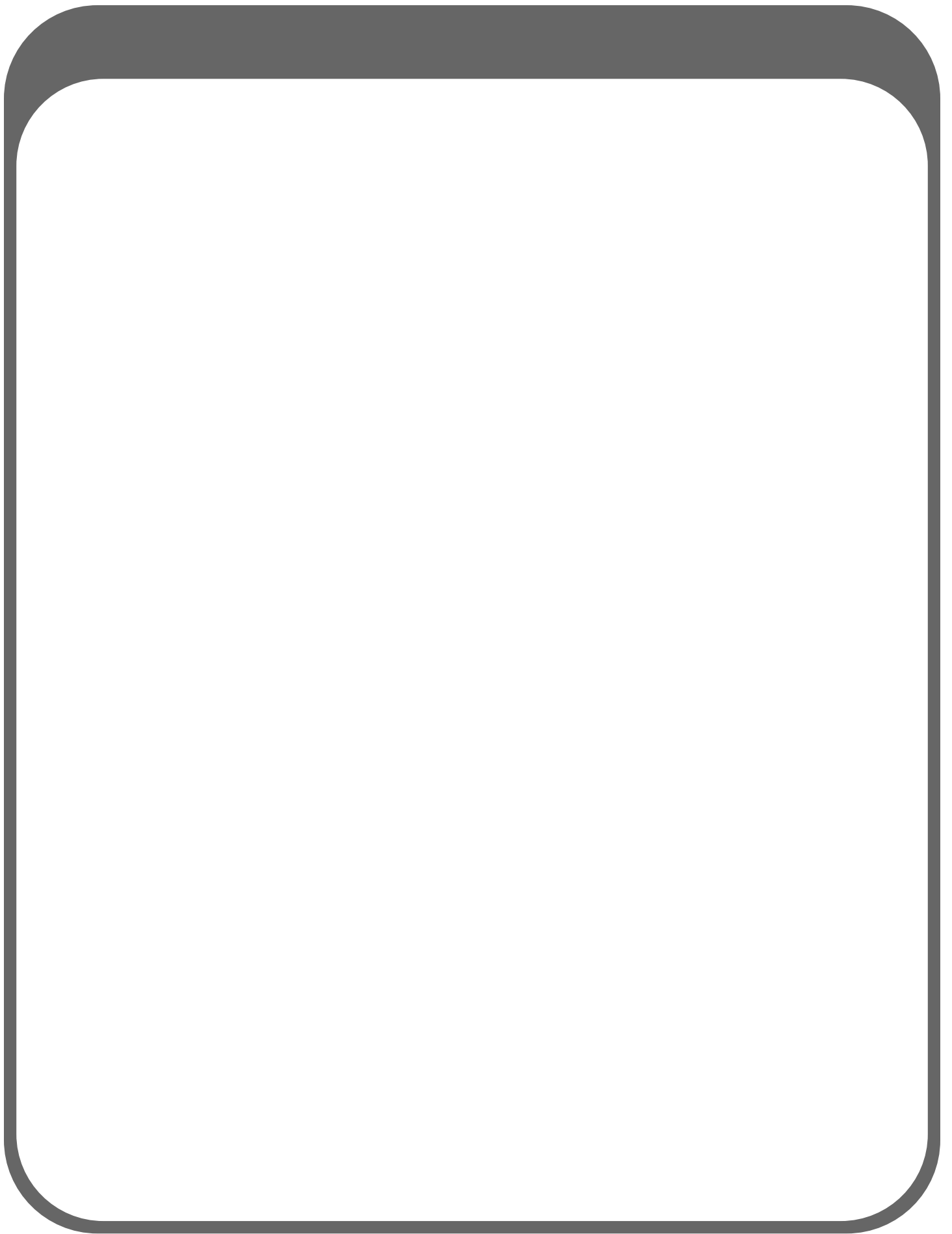
You may also contact:

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515-725-0510

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**

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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.

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- ◆ **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).**

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- **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.

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- ♦ **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.**

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- **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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