



IOWA AUTISM COUNCIL

2017 Priorities

Moving Iowa Forward
Summary of accomplishments in 2016 and Priorities and
Recommendations for 2017

Iowa Autism Council

December 2016

To the Governor and Legislators of Iowa:

The Iowa Autism Council (Council), formed in 2008 by authorizing legislation 256.35A Section 126, acts “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 2016 Iowa has made significant strides in supporting individuals with autism spectrum disorder (ASD) through the following activities and legislative acts:

- A. Modifications to the Autism Support Program that will allow for more individuals and families to access this benefit. Modifications include:
 - Increasing the maximum age of eligibility for services from 9 to 14.
 - Amending the income qualification guidelines from “not to exceed 400% of the federal poverty level” to “not to exceed 500% of the federal poverty level.”
- B. 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 last year and the Council has been monitoring progress on the identified areas of focus.
- C. Creation of the “Board-Certified Behavior Analyst and Board-Certified Assistant Behavior Analyst Grants Program” which will provide grants to students seeking certification in behavior analytic practice, which will in turn increase access to applied behavioral analysis for individuals with ASD and in the state of Iowa.

Although these changes may not seem significant, they are very important steps in moving Iowa forward in realizing its vision to ensure that all Iowans with an autism spectrum disorder (ASD) have the opportunity to develop the skills and knowledge necessary to live independent and interdependent lives within their communities and to reach their full potential.

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 are priorities and recommendations for 2017, as determined by the Council:

- A. Insurance reform – require coverage for all evidence-based treatments for individuals with ASD to include all plans regulated by state insurance laws.
- B. Continued legislative commitment to, and funding of, the Autism Support Program.
- C. As Iowa prepares a Statewide Transition Plan to comply with the new federal requirements for residential and non-residential home and community-based settings (Home and Community-Based 1915(c) waiver and 1915(i) SPA amendment), the Council recommends that Iowa’s plan not be more restrictive than the federal rules/requirements.
- D. Support continued implementation of the “Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families.”
- E. In the event the minimum wage in Iowa increases, consider a modification in the reimbursement rate floor for service providers.
- F. Continue to reduce the wait lists for HCBS waiver services.

For the Council,
James Curry
Chairperson

Matthew O’Brien
Co-Chairperson

Iowa Autism Council

2017 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, which was released in 2016. 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.

2017 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.

➤ Insurance Reform:

As previously stated, it is the vision of the Council that all Iowans with ASD will develop the skills and knowledge necessary to live independent and interdependent lives within their community and to reach their full potential. To achieve this, individuals with ASD and their caregivers need to be able to access and obtain medically necessary, evidence-based services to enable the acquisition of such skills.

To this end, the Council has previously recommended amendments to the Autism Support Program to allow more families to access this funding for needed services. As a result, the 2015-2016 legislative session saw several positive changes to the Autism Support Program eligibility criteria. However, it is important to point out that the Autism Support Program was created to provide funding for applied behavioral analysis services for children who **meet specific criteria**.

These highly limiting criteria include limitations based on diagnosis, source of diagnosis, age of applicant, financial status of the applicant’s family, and services provided by an eligible Board Certified Behavior Analyst. Because of the limiting eligibility criteria of the Autism Support Program, it is not an option for many families.

In order for all Iowans to access medically necessary, evidence-based interventions that will allow them to learn the skills needed to live independent and interdependent lives within their communities, the Council believes now is the time for insurance reform in the State of Iowa.

Employees of the State of Iowa have had access to applied behavioral analysis services through the health benefit plans offered to state employees for several years. Wellmark reported that claims paid for State of Iowa members receiving “therapeutic behavioral services” in 2014 amounted to \$27,777.00, and in 2015, claims paid amounted to \$37,320.00. Wellmark also reported that claims paid for State of Iowa members receiving any medically necessary service with a diagnosis of ASD in 2015 amounted to \$175,734.52 with the highest claims amount paid in any year being \$205,573.49 in 2014. The claim totals for the years 2011 through 2013 are listed in the table below.

Year	Total Amount of Claims Paid
2011	\$119,258.96
2012	\$136,183.60
2013	\$180,255.42

This and other data show that insurance coverage of medically necessary services for individuals with ASD, including applied behavioral analysis services, is not cost prohibitive. Data sources include, but are not limited to, the state plan usage, the Autism Support Program usage, experience in other states, and national reports.

For example, in February 2016, The Pew Charitable Trusts issued a report titled: Coverage for Autism Treatment Varies by State. According to the report, 42 states have passed laws mandating coverage of Applied Behavior Analysis or autism-related services, which has helped more families access medically necessary services for their child with ASD. The report also indicates that requiring insurers to cover the treatment will save states money in the long run. “The lifetime costs of each person with autism is estimated to be \$3.2 million, including medical and treatment costs for families, and costs to society, such as loss of productivity. ABA therapy can reduce those costs, as children who receive treatments early have less trouble adapting, allowing them to potentially hold a job and pay taxes in the future.” However, many insurance companies and business groups oppose the mandates, arguing that they would result in steep premium increases. But, for some insurance companies, increases have been less than expected, at less than half of 1 percent. According to this report, “in Missouri, where the coverage for treatment was capped at \$40,000 a year until age 19, the state found that, in 2015, the mandate cost 30 cents per member per month. That’s at the lower end of the expected cost, said John Huff, director of the Missouri Department of Insurance. The department estimated the mandate would increase claim payments by 0.2 to 0.5 percent. In 2015, 32,997 claims were filed and the mandate had raised premiums by 0.25 percent, on the low end of expectations.”

Given the potential long-term benefit for Iowans, and the evidence of limited fiscal impact, the Council encourages the Governor and Legislature to mandate coverage for all evidence-based interventions for individuals with ASD (including applied behavior analysis) to include all plans regulated by state insurance laws. The Council is aware that not all employers would be subject to such a mandate, but mandating coverage would continue to close the gap between the number of individuals who could benefit from evidence-based interventions and the number who are actually able to obtain those services.

Iowans with ASD and their families deserve to have access to high-quality, medically necessary 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 communities.

➤ Continued legislative commitment to, and funding of, the Autism Support Program:

The Council is pleased with the most recent modifications to the Autism Support Program, approved in January 2016 and effective July 1, 2016. The Council is not advocating for additional changes at this time, but does encourage and recommend continued funding of the Autism Support Program.

As mentioned previously, the Autism Support Program was created to provide funding for applied behavioral analysis services for children who meet a specific set of criteria. The Autism Support Program is not the same as Medicaid. In fact, one of the eligibility criteria for the Autism Support Program states that the applicant must “be determined *ineligible* for coverage of applied behavioral analysis services under the medical assistance program, Iowa Code section 514C.28, or private insurance coverage.” There will always be families and individuals who do not qualify for Medicaid, cannot afford traditional insurance, or have insurance that does not provide the applied behavioral analysis coverage they need. That is why continuing to fund the Autism Support Program is so important. The Legislature has prudently maintained funding for the Autism Support Program and the Council recommends that this continue.

➤ Iowa’s Statewide Transition Plan for Compliance with federal home and community-based services (HCBS) regulations:

The State of Iowa received initial CMS approval of its Statewide Transition Plan (STP) to bring settings into compliance with the federal home and community-based services (HCBS) regulations found at 42 CFR Section 441.301(c)(4)(5) and Section 441.710(a)(1)(2). The Council is confident that the state is taking the necessary steps to obtain final approval of the STP and that all HCBS settings will fully comply with the federal requirements, but not add any additional restrictions to the range of service types available in Iowa.

➤ 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](#). 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.

In 2016, work toward implementation of the identified focus areas and strategies began. Key members of the strategic planning committee have been working with representatives from the National Autism Leadership Collaborative to utilize the Collective Impact framework to guide work in the first focus area, “Get a Good Start.” There has also been some work beginning in the focus area of “Have Access to and Obtain Needed Services.” For example, within the Iowa Department of Education, Wendy Trotter, the Education Consultant for Autism, is looking to develop a professional development framework to help guide Area Education Agencies and school districts in recognizing and utilizing evidence-based practices for students with ASD. In addition, the Iowa Regional Autism Assistance Program, administered by Child Health Specialty Clinics at the University of Iowa, plans to expand its telehealth capacity statewide so Iowans residing in underserved areas will have access to a diagnostic team member with the Autism Center at University of Iowa Children's Hospital.

Again this year, several Council members attended the National Autism Leadership Summit on November 14-15, 2016. The 2016 National Autism Leadership Summit continued to focus on implementing Collective Impact and creating systems for efficient and effective work in autism at the state level. Key objectives of the summit include:

- To gain strategies for connecting and creating partnerships with key leaders in your state
- To hear accounts of implementation and impact from various states
- To obtain highlights of lifespan initiatives and policies at the state and national level
- To engage in networking and brainstorming with other state leaders

At the Summit, participating Council members heard from state and national leaders, participated in workgroups, and networked with individuals from other states, all in an attempt to improve the systems and supports Iowa has to offer.

➤ **Minimum wage vs. reimbursement rate floor:**

The minimum wage in Iowa is currently changing county by county. While reimbursement rates for autism services have a set floor, there is a real possibility that the reimbursement rate may not be enough to cover the increased gap created by a minimum wage increase, creating increased burden for providers. If minimum wage is addressed at the state level, we strongly encourage a process that allows providers to remain competitive in the workplace. This process should allow providers to renegotiate reimbursement rates to provide for the recruitment and retention of staff. The Council would be in favor of language similar to that found in the Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/ID) stating, generally, that the rates adjust according to fixed criteria.

➤ Reduction of wait times associated with HCBS Waiver Program:

The Council was pleased to learn that during the 2016 legislative session, the Iowa General Assembly appropriated \$2 million to reduce the waiting list for Iowa's HCBS Waiver program. Subsequently, the Iowa Department of Human Services authorized the release of additional waiver "slots" to individuals on the waiting list. However, the wait times associated with the various HCBS waivers available in the State of Iowa continue to be a barrier for many families. Studies show that there are windows during which the maximum benefit of medically necessary, evidence-based interventions can be realized in certain growth areas for individuals on the autism spectrum. These long wait times to access waiver services negatively impacts a family's ability to secure the best treatment options for their loved ones. They potentially reduce the time available to realize the benefits of evidence-based services, through no fault of the individual or family. The Council recommends the Legislature take appropriate steps to reduce and eventually eliminate these wait lists so that families and individuals can access medically necessary services in the most timely and efficient manner possible.

Iowa Autism Council Members

2016 Voting Members

<u>Name:</u>	<u>Position/Representation:</u>
Arkland, Brandon	Person with Autism
Croonquist, Theresa	Insurance Industry Representative
Curry, James (<i>chairperson</i>)	Family member of person with Autism
Heiss, Rachel	Family member of person with Autism
Hertel, Erika	Family member of person with Autism
Jennings, Jeffrey	Family member of person with Autism
Logsdon, Angela	Family member of person with Autism
Muller, Steve	Residential Service Provider
O'Brien, Matthew (<i>co-chairperson</i>)	Service Provider
Paprocki, James	Mental Health Professional
Phan, Jenny	Family member of person with Autism
Turbes, Jan	Research
<i>Vacant</i>	Insurance Industry Representative

2016 Ex-Officio Members

Boston, Angela	Iowa Insurance Division
Buehler-Sapp, Beth	Iowa Department of Education
Casey, Sean	Iowa Department of Education
Etscheidt, Susan	University of Northern Iowa
Fanselow, Connie	Iowa Department of Human Services
Harker, Becky	Iowa Developmental Disabilities Council
Jackson, Mary	Iowa Vocational Rehabilitation
Trotter, Wendy	Iowa Department of Education
Underwood-Levin, Tara	The University of Iowa, Division of Child and Community Health/ Child Health Specialty Clinics.

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:

Wendy Trotter, Education Consultant – Autism
Iowa Department of Education
wendy.trotter@iowa.gov
515-725-0510