



IOWA AUTISM COUNCIL

2019 Priorities

Moving Iowa Forward
Summary of accomplishments in 2018 and Priorities and
Recommendations for 2019

Iowa Autism Council

December 2018

To the Governor and Iowa Legislature:

The Iowa Autism Council (Council) was formed in 2008 through legislation (Iowa Code §256.35A) 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 2018 Iowa continued to make strides in supporting individuals with autism spectrum disorder (ASD) through the following activities and legislative acts:

- Funding for the Regional Autism Assistance Program (RAP) was re-instated, which allowed services to be rebuilt with a focus on Family Navigators and educational opportunities across the state.
- The Autism Support Program (ASP) continued to provide funding for ABA services to individuals who would not otherwise have the needed funding to access these services.
- Senate File 192, which established a licensure process for Board Certified Behavior Analysts (BCBAs), was passed and signed into law.
- Work continued on the focus areas identified in 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) continues work in the focus area of the Strategic Plan called “Get a Good Start” with their LTSAE (Learn the Signs Act Early) Ambassador. Child Health Specialty Clinics (CHSC) received a grant to implement the LTSAE materials in several Early Head Start programs across the state.
 - RAP, as part of the Division of Child and Community Health, leveraged Division funds to provide equipment to the Pier Center for Autism to provide ABA services via telehealth.
 - Spring of 2018, the Iowa Department of Education completed year 3 of the multi-year, statewide ASD professional development initiative utilizing the Autism Navigator® for Early Intervention Providers online professional development courses for Iowa’s Early ACCESS providers.
 - RAP and the Iowa Department of Education have launched a pilot project for primary care providers utilizing Autism Navigator® for Primary Care course seats.
 - RAP has been expanding diagnostic services to southeastern Iowa, providing mentorship to psychologists in two clinics who recently completed ADOS-2 (Autism Diagnostic Observation Schedule – 2) training and providing them with ADOS-2 test kits.

While Iowa continues to make strides in the goal to improve the lives of individuals with ASD and their families, there continue to be many areas where our state falls short. The Council has identified the following areas of priority for 2019:

- Support for continued legislative commitment to, and funding of, the Autism Support Program and consideration of modifications to eligibility criteria to allow for a flexible funding option.
- Support for increasing options of reimbursable service provision to include telehealth.
- Continued funding of the Regional Autism Assistance Program (RAP).
- Support for continued implementation of the “Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families.”

For the Council,

Caleb Primrose
Co-Chairperson

James Curry
Co-Chairperson

Iowa Autism Council

2019 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.

According to Center for Disease Control's Autism and Developmental Disabilities Monitoring (ADDM) Network, the prevalence of autism spectrum disorder has increased once again. According to a report released in April of 2018, the latest estimate is **1 in 59** (or 1.7 percent of 8-year-old children) has a diagnosis of ASD. This prevalence is higher than the previous ADDM Network estimate released in 2016, which found a prevalence of 1.5 percent or 1 in 68 children. 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.

2019 Priorities and Recommendations

The State of Iowa has made 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 2019 priorities of the Iowa Autism Council:

➤ Continued Funding of the Autism Support Program and Consideration of Modification to Address Unintended Consequences of Insurance Reform

The Autism Support Program (ASP) was created to fund applied behavior analysis (ABA) services for children age 14 and under 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." ABA can be described as a scientific approach to understanding and modifying behavior, which helps to understand how behavior works, is affected by the environment, and how learning takes place. ABA therapy applies our understanding of how behavior works with the goal to establish and enhance socially important behaviors. Such behaviors can include academic, social, communication, and daily living skills; essentially, any skill that will enhance the independence and/or quality of life for the individual.

Since its inception, ASP has provided funding for 55 children. While this is a relatively small number of children statewide, parents report that the services their children receive have helped them make significant gains in communication and socialization that will positively impact the rest of their lives, and enable them to become more independent and productive adults. In addition, the actual cost of services accessed by families is far less than originally estimated. Each eligible child may utilize up to \$72,000 in ASP funds over a 24 month period for ABA services. To date, the average total program cost per participant is \$26,174 and the average length of time a child is enrolled in ASP is 10 months. The Council recommends continued support for this valuable and cost effective program.

The passage of House File 215 in 2017, required more group insurance carriers in Iowa to cover ABA for children with ASD, and many families previously denied ABA insurance coverage have benefited from the expansion. There are, however, families who gained an ABA benefit only to learn that the out-of-pocket cost share they would have to pay is unaffordable. For these families, ABA services, while technically covered by their private insurance, are still out of their reach. ABA benefits that come with a high deductible, co-pay or co-insurance, push the out-of-pocket costs for an intensive service such as ABA beyond the typical family's ability to pay. In addition, ABA providers are limited in Iowa and some insurance companies do not have in-network providers who are geographically close enough to provide ABA to a family. If the family has to pay out-of-network rates to obtain the service, that further pushes up the costs to them.

For example, a family of four with a qualifying child on the autism spectrum, a family income of \$100,000, and no private insurance ABA benefit can receive assistance through the Autism Support Program and be responsible for paying 10% of the cost of the ABA services out-of-pocket. That cost is likely to range from \$150 to \$350 a month during the duration of the ABA therapy. That's \$1800 to \$4200 a year. For many families, that cost is a stretch, but one they can usually manage.

If the same family has a private insurance benefit and therefore does not qualify for assistance through the autism support program, they may be required to pay a deductible of \$10,000 and then a 50% co-pay of the next \$10,000, meaning they would have to spend \$10,000 out of pocket before they receive any reimbursement from their private insurer and then continue to be responsible for half the cost. Assuming their ABA costs were at the low end, or \$1500 per month (\$18,000 per year) they would have to cover \$14,000 of that cost each year while their insurer would pay only \$4000. For most families of four living on \$100,000 that \$14,000 price tag is out of reach and they may not be able to access the ABA services their child needs. Several families in this situation have applied for assistance through the autism support program during the last year and had to be denied because, technically, they had insurance coverage for ABA.

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 the cost of ABA and their insurance benefit by reimbursing families for high co-pays, co-insurance and/or deductibles that are spent for ABA services. Specifically, the Council suggests that the eligibility standard for ASP be expanded to add individuals with private insurance coverage with an ABA benefit that requires out-of-pocket costs exceeding 5% of the family income (for example: \$3000 for a family earning \$60,000 or \$6250 for a family earning \$125,000). The family would be required to meet all other existing eligibility requirements for the program, including the 500% FPL ceiling. Once determined eligible for ASP,

they would be able to apply for reimbursement of their out-of-pocket costs, less their ASP cost share. Such a modification would put these families with very limited insurance benefits on the same footing as families with no insurance benefit and require the same rate of cost participation to utilize the Autism Support Program. Such modification would require legislative action to change the ASP eligibility criteria.

➤ Continued Support of the BCBA Education Grant

Through the ASP legislation, \$250,000 has been allocated to assist students in meeting the financial obligations associated with completing an educational program in applied behavior analysis to become a Board Certified Behavior Analyst (BCBA). The first RFP for this grant was issued in September 2016: 21 applications were received and 12 were approved for funding, for a total of \$41,717. The second RFP was issued in January 2018: 16 applications were received and 6 were approved for funding, for a total of \$53,575. To date the obligated balance of awards is \$95,292 and about \$54,000 has been spent, leaving a significant balance yet to be awarded. A third RFP is expected to be posted by the end of this calendar year or early in the next calendar year.

BCBA Education Grant funding is particularly well timed because the fall of 2017 marked the beginning of Drake University's Master of Science in Applied Behavior Analysis, which provides the training and credentials needed to serve children with ASD through ABA therapy. The Drake program currently is the only program of its kind in the state of Iowa. Increasing the number of BCBA's practicing in Iowa will create more opportunities for families to access ABA services and the state should take any possible steps to ensure students can attend and complete the BCBA program.

The Council recommends that the ASP funding be maintained and continue to include the scholarship fund to be used for the BCBA (Board Certified Behavior Analyst) program.

➤ Increase 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 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. 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 family, usually only 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 an effective method for delivering ABA services to children with ASD. 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-person 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.

➤ Continued Funding for the Regional Autism Assistance Program

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), Division of Child and Community Health, University of Iowa, 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.

The services and supports the RAP program provides are instrumental in meeting the goals of the [Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families.](#)

Last year the Iowa Department of Public Health cut 70% of the RAP program budget, eliminating numerous services, programs, and opportunities. Thankfully their funding was reinstated allowing RAP to rebuild their valuable program and continue to serve children with ASD and their families. The Council recommends the continued support of, and funding for, this vital program.

➤ 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.

Since 2016, we have seen a lot of progress in three of the five focus areas of the Strategic Plan:

A. Get a Good Start

- RAP continues work in the focus area Get a Good Start of the Strategic Plan with their LTSAE (Learn the Signs Act Early) Ambassador. Child Health Specialty Clinics (CHSC) received a grant to implement the LTSAE materials in several Early Head Start programs across the state. All CHSC Regional Centers have a supply of LTSAE materials for additional distribution to families and to share at outreach opportunities.
- RAP continues to provide ASD screenings in CHSC Regional Centers. In the fall of 2018, two additional clinical staff members, including a registered nurse practitioner (ARNP) and a registered nurse (RN), began STAT (Screening Tool for Autism in Toddlers and Young Children) training.
- Spring of 2018, the Iowa Department of Education completed year 3 of the multi-year, statewide ASD professional development initiative utilizing the Autism Navigator® for Early Intervention Providers online professional development courses to help 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.
- RAP and the Iowa Department of Education have launched a pilot project for primary care providers utilizing Autism Navigator® for Primary Care course seats.
- RAP has been expanding diagnostic services to southeastern Iowa, providing mentorship to psychologists in two clinics who recently completed ADOS-2 (Autism Diagnostic Observation Schedule – 2) training and providing them with ADOS-2 test kits.

B. Have Access to and Obtain Needed Services

- RAP, as part of the Division of Child and Community Health, leveraged Division funds to provide equipment to the Pier Center for Autism to provide ABA services via telehealth, to allow families in rural areas to be able to access necessary services that are otherwise not available in their area.

- The Department of Education has developed an ASD Supports Design Team that has been meeting for the last year and a half to develop a more consistent statewide approach to providing supports to districts for use of evidence-based practices for students with ASD. They have been working on developing a tiered system of supports for school personnel to assist them in their knowledge and use of evidence-based practices. They have also been carefully integrating this work with other statewide initiatives such as Specially Designed Instruction and Social Emotional Learning.
- The Autism Support Program (ASP) which funds applied behavior analysis (ABA) services for children age 14 and under with ASD has provided funding for 55 children since its inception. While this is a relatively small number of children statewide, parents report that the services their children receive have helped them make significant gains in communication and socialization that will positively impact the rest of their lives, and enable them to become more independent and productive adults.
- RAP continues to assist families with coordination of services, including diagnostic assessments and therapies, exploring insurance coverage and payment options for ABA and other needs, navigating the education system, and locating services and supports in their communities.

C. Have Well Informed, Empowered, and Supported Families and Caregivers

- RAP connects families to information about ASD, evidence-based interventions, assists with the development of advocacy skills, and provides family to family support.
- In the fall of 2018, RAP collaborated with the Iowa Family Leadership Institute to provide two trainings in CHSC Regional Centers. “Empowering the Family Voice” focused on explaining family-centered care, helping families learn how to partner in decision-making, and how to communicate effectively with providers.
- RAP includes Family Advisors on the RAP Expert Panel Advisory Committee, recognizing the importance of their role as autism experts.
- The Autism Navigator® project also focuses on collaborating with and coaching caregivers to equip and empower them to help their child learn and grow.

However, as we are now three years into the five-year strategic plan, we need to turn our attention to the last two focus areas to ensure they too are being addressed:

D. Successfully Transition to Adult Life

E. Be Assured of Ongoing Coordination of Systems of Care and Support

Therefore the Council will pay specific attention to the focus areas D and E in 2019 to ensure we are addressing lifespan supports and services for individuals 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

2018 Voting Members

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

2018 Ex-Officio Members

<u>Name:</u>	<u>Position/Representation:</u>
Boston, Angela	Iowa Insurance Division
Buehler-Sapp, Beth	Iowa Department of Education
Fanselow, Connie	Iowa Department of Human Services
Keith, Andrea	Iowa Vocational Rehabilitation
Kliewer, Chris	Board of Regents
Shannon, Rik	Iowa Developmental Disabilities Council
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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