



# IOWA AUTISM COUNCIL

## 2020 Priorities

**Moving Iowa Forward**

Summary of Accomplishments in 2019 and Priorities and  
Recommendations for 2020

# Iowa Autism Council

December 2019

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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 2019 Iowa continued to make strides in supporting individuals with autism spectrum disorder (ASD) through the following activities and legislative acts:

- The Regional Autism Assistance Program (RAP) continued to provide community-based clinical consultation, multi-disciplinary care planning recommendations, and family to family support for Iowa children with autism and their families. They use standardized tools to identify children at risk for autism and help families find diagnostic services and community-based supports.
- 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.
- 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. This project was completed in June of 2019. A new initiative to incorporate LTSAE materials into WIC programs began in October of 2019.
  - The Iowa Department of Education (IDOE) continues the Autism Navigator project utilizing the *Autism Navigator® for Early Intervention Providers* online professional development courses for Iowa’s Early ACCESS providers, entering year five of the project.
  - RAP is also building on the IDOE initiative, providing professional development for all program Family Navigators utilizing *Autism Navigator® JumpStart to Coaching in Everyday Activities*, as well as supporting additional advanced registered nurse practitioners (ARNPs) and registered nurses (RNs) in taking the *Autism Navigator® Primary Care* course.

While Iowa continues to make strides in improving the lives of individuals with ASD and their families, it is critical to continue support initiatives that have allowed for these successes. Therefore, the Council recommends on-going support to the following programs as priority needs for 2020:

1. Continued funding of the Autism Support Program and consideration of modifications to address unintended consequences of insurance reform and provide for flexibility in program benefit limits.
2. Continued support of the BCBA Education Grant to build provider capacity in Iowa.
3. Continued funding for the Regional Autism Assistance Program to support families and strengthen early identification of ASD.
4. Continued implementation of the *Iowa Strategic Plan – 2016-2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*.

The Council also supports the following additional priority areas for 2020:

5. Increase statewide access to ABA treatment through telehealth models.
6. Support of the 2019 Legislative Priorities established by the Iowa Developmental Disabilities Council.
  - a) Establish a stable, long-term funding stream for the Regional MHDS system that supports the vision of the MH/DS redesign and growth of a system that expands access to services for Iowans with developmental disabilities and brain injuries.
  - b) Adequately fund and administer a state Medicaid program that ensures access to an array of services for Iowans with developmental disabilities.
  - c) Implement development of a statewide Children’s mental Health system that continues the recommendations from the Children’s System State Board Strategic Plan submitted to the General Assembly on November 15, 2018.
  - d) Expand the availability, knowledge, skills and compensation of professionals, paraprofessionals and direct support workers to build community capacity and ensure access to a comprehensive system of mental health and disability services.

For the Council,

Caleb Primrose  
Co-Chairperson

Erika Hertel  
Co-Chairperson

# Iowa Autism Council

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## 2020 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 a 2018 report from the Center for Disease Control's Autism and Developmental Disabilities Monitoring (ADDM) Network, it is estimated that **1 in 59** 8-year-old children (or 1.7 percent) has a diagnosis of autism spectrum disorder (ASD). These findings indicate that there continue to be many individuals living with ASD who need services and support now and throughout their lifespan.

### 2020 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 living with ASD have the opportunity to lead meaningful and successful lives in their community. The following are the 2020 priorities of the Iowa Autism Council:

#### 1. Continued funding of the Autism Support Program and consideration of modifications to address unintended consequences of insurance reform and provide for flexibility in program benefit limits.

Applied Behavior Analysis (ABA) is a scientific approach to understanding and modifying behavior, which helps to understand how behavior works, how it is affected by the environment, and how learning takes place. The goal of ABA therapy is to establish and enhance socially important behaviors, such as academic, social, communication, and daily living skills; essentially, any skill that will enhance the independence and/or quality of life for the individual. The Autism Support Program (ASP) was created in 2014 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 58 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 through the Autism Support Program has been 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 \$23,541 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, and ask the legislature to consider making a few modifications:

- Address unintended consequences of insurance reform.

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 without 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 or co-pay, push the out-of-pocket costs for an intensive service such as ABA beyond the typical family's ability to pay. In addition, the number of ABA providers are limited in Iowa, and some insurance companies do not have in-network providers who are geographically close enough to provide ABA, as it is a time-intensive service that may require sessions several times each week. 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 a cost share equal to 10% of the cost of the ABA services. Typical costs of ABA services are in the range of \$3000 to \$4000 per month. That means the out-of-pocket cost to the family in this example would be \$300 to \$400 a month (10% of the total) during the duration of the ABA therapy. That's \$3600 to \$4800 a year. For many families, that cost is a difficult stretch, but one they can usually manage. For a family with more than one child diagnosed with ASD, these costs could be doubled, or more.

If the same family has a private insurance benefit and therefore does not qualify for assistance through the autism support program, their insurance plan may require them to pay a deductible of \$10,000 and then a 50% co-pay, 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 of the cost. Assuming their ABA costs were at the low end, or \$3000 per month (\$36,000 per year) they would have to cover \$23,000 of that cost each year while their insurer would pay only \$13,000. For families of four living on \$100,000 that \$23,000 price tag is out of reach and leaves them unable able to access the ABA services their child needs, and this is especially cost prohibitive for families with multiple children on the autism spectrum. Several families in this situation have applied for

assistance through the autism support program during the last two years 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 the insurance benefit by reimbursing families for high co-pays and/or deductibles that are spent for ABA services. Specifically, the Council suggests that the eligibility standards for ASP be expanded to add individuals with private insurance coverage that has an ABA benefit requiring out-of-pocket costs if the family meets 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. If their out-of-pocket costs are less than the ASP cost-share (zero to 15%, depending on income), they would receive no ASP assistance. 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.

- [Increase flexibility in program benefit limits.](#)

As previously noted, most children do not make use of the entire 24 months of services or the entire amount of funding available to them through the ASP program for a variety of reasons. This has meant that the program has been able to serve all applicants who have been determined eligible well within the fund allocated for the program, and has successfully operated at a considerably lower cost than initially estimated. At the same time, there are a few children who need to continue their ABA treatment beyond 24 months and have no other source of funding after their ASP eligibility has been exhausted. In these cases, the need goes unmet, even though ASP has funds available to continue to serve the child as well as serving new applicants.

When the original ASP legislation was passed, there were concerns that offering such a program would open the doors to unknown large numbers of families requesting ABA funding. That has not been the reality. Since the program began, it has served all eligible applicants at an annual cost of less than \$500,000 and without waiting lists. Allowing some flexibility in the program limits on number of months and total funding available per child could fill in service gaps for a small number of children. No additional program funding would be needed, but legislation to allow ASP to make exceptions to the time and funding limitations when program funds are available would provide greater flexibility in meeting the needs of children with autism at a critical time in their development.

[These suggested modifications would require legislative action to change the eligibility criteria, as well as change the benefit limitations of the ASP program, or allow exceptions to be made to the benefit limitations by the program administrator. However, making these minor program changes would increase access to ABA services statewide and could be made without increasing the current level of state funding to ASP.](#)

## 2. Continued support of the BCBA Education Grant to build provider capacity in Iowa.

The Board-Certified Behavior Analyst (BCBA) and Board-Certified Assistant Behavior Analyst (BCaBA) grant program was initiated to help address the shortage of Applied Behavior Analysis (ABA) providers in Iowa. 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 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.
- The third RFP was issued in April 2019: 22 applications were received and 13 were approved for funding, for a total of \$149,368.
- The fourth RFP release is anticipated to occur next spring.

Drake University's Master of Science in Applied Behavior Analysis program, currently the only one of its kind in the state of Iowa, provides the training and credentials needed to serve children with ASD through ABA therapy. 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.

## 3. Increase statewide access to ABA treatment through telehealth models.

Despite recent state efforts to increase the number of service providers and therapists conducting applied behavior analysis treatments, there is still a substantial delay in accessing services statewide and a complete lack of services in many areas of the state. Unless the number of service providers increases exponentially and expeditiously, and service centers develop in all communities within the state, it is highly unlikely that even a fraction of the individuals within the state of Iowa will have adequate access to ABA services in the years to come.

One way to alleviate the current and future service vacuum is to establish state rules and regulations that would allow for applied behavior analysis therapies to be delivered via telehealth. Telehealth involves the provision of health care remotely by means of technology. Numerous studies from the University of Iowa have demonstrated that such services can be delivered via telehealth with the same effectiveness as in-person service, but at a lower cost (Lindgren et al., 2016). Additionally, when telehealth services are provided within the home setting (i.e., clinic-to-home service model), studies have shown greater treatment generalization

to other locations (e.g., improvement in community and school settings), and increased caregiver knowledge and skills in behavior management. Thus, telehealth offers an equally effective therapy model, but with the added benefits of lower cost, increased treatment generalization, and improved caregiver understanding and skills.

Despite recognition as a pioneer and continued leader in telehealth research, the State of Iowa has fallen behind much of the United States in the usage of telehealth for autism service provision. Unlike Iowa, many states are actively providing behavior analytic services via telehealth. Moreover, in similarly large, rural states telehealth is offered using a clinic-to-home model that allows families to receive services in their home and avoid considerable travel costs and time. In part, our unfortunate status as one of the few states without active telehealth services for ASD is the result of unclear state rules and regulations and possible misinterpretation of new American Medical Association billing codes (called Adaptive Behavior Assessment or ABA codes) by Iowa Medicaid Enterprise, which has held that these new codes exclude services provided via telehealth.

The council recommends legislative action to support telehealth service provision to reach all individuals with ASD in the State of Iowa who are in need of ABA and other therapies, including the following actions:

- Clarification of state rules and regulations to indicate that qualified health service providers may provide telehealth services using a clinic-to-home model.
- Review of the Iowa Medicaid Enterprise interpretation of ABA codes for the inclusion of telehealth and/or inquiry to the Centers for Medicare & Medicaid Services (CMS) for guidance on this issue.

#### 4. Support of the 2019 Legislative Priorities established by the Iowa Developmental Disabilities Council.

The Iowa Developmental Disabilities Council (Iowa DD Council) established the following *2019 Legislative Priorities* to ensure that all children and adults in Iowa with developmental disabilities have access to high quality services and supports that promote a life in the community:

1. Establish a stable, long-term funding stream for the Regional MHDS system that supports the vision of the MH/DS redesign and growth of a system that expands access to services for Iowans with developmental disabilities and brain injuries.
2. Adequately fund and administer a state Medicaid program that ensures access to an array of services for Iowans with developmental disabilities.
3. Implement development of a statewide Children's Mental Health system that continues the recommendations from the Children's System State Board Strategic Plan submitted to the General Assembly on November 15, 2018.
4. Expand the availability, knowledge, skills and compensation of professionals, paraprofessionals and direct support workers to build community capacity and ensure access to a comprehensive system of mental health and disability services.

The Council recommends and supports the *2019 Legislative Priorities* established by the Iowa DD Council to ensure all children and adults in Iowa with developmental disabilities (which includes ASD) have access to high quality services and supports that promote a life in the community.

## 5. Continued funding for the Regional Autism Assistance Program to support families and strengthen early identification of ASD.

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*.

The Council recommends the continued support of, and funding for, this vital program.

## 6. 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 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, with the project completing in June of 2019. The LTSAE Ambassador began partnering with WIC as of October 1<sup>st</sup> for a Developmental Monitoring Project pilot and has already provided education to all of 20 WIC coordinators in Iowa. In addition, 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.
- The Iowa Department of Education continues to build the capacity of Iowa's Early ACCESS providers to identify early warning signs of autism in infants and toddlers, and to coach families to embed appropriate intervention strategies into their everyday routines and activities utilizing the Autism Navigator<sup>®</sup> for Early Intervention Providers online professional development courses. Since 2015, 221 Early ACCESS providers have enrolled in the Autism Navigator<sup>®</sup> online course.
- RAP is also building on the IDOE initiative, providing additional training for all program Family Navigators and utilizing Autism Navigator<sup>®</sup> JumpStart to Coaching in Everyday Activities, as well as supporting additional advanced registered nurse practitioners (ARNPs) and registered nurses (RNs) in taking the Autism Navigator<sup>®</sup> Primary Care course.

B. Have Access to and Obtain Needed Services

- The Autism Support Program (ASP) which funds applied behavior analysis (ABA) services for children age 14 and under with ASD has provided funding for 58 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.
- The Department of Education led an ASD Design Team to develop a theory of action related to statewide supports for students with ASD. The Design Team identified social engagement as the first area of focus for statewide work. The Department of Education then posted a Request for Proposals (RFP) to solicit proposals from vendors to provide a multi-year plan to build capacity to support social emotional engagement across multi-tiered system of supports within the State of Iowa's Specially Designed Instruction (SDI) Framework. Respondents were asked to specifically include approaches that will be used to ensure the strategies meet the needs of students across varying developmental levels, including students with autism. A vendor and plan was selected and a contract has been awarded. The project will begin in 2020.

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.

- RAP offered an Autism Basics free four-week webinar series with presenter Kelly Pelzel, PhD twice in 2019. The series is for parents or primary caregivers of children with a new autism diagnosis and has been approved for continuing education for foster parents. Sessions included:
  1. What is Autism?
  2. Autism Interventions
  3. Challenging Behavior
  4. Educational Programming

The series was recorded, enabling parents, caregivers, providers and others who to access the information at their convenience.

- 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.
- D. Successfully Transition to Adult Life
- RAP held a Caregiver Retreat and Transition Conference in June of 2019. Child Health Specialty Clinics, Center for Disabilities and Development at University of Iowa Stead Family Children’s Hospital, Iowa Department of Education, Iowa Vocational Rehabilitation Services, and Money Follows the Person were represented by speakers.
  - Child Health Specialty Clinics works with children and youth ages 12 and above on the health care transition to adulthood and created a new *Transition to Adult Health Care Quick Guide* to prepare youth for the experience of becoming consumers of adult health care.
  - Iowa Vocational Rehabilitation Services continues to work with local high schools to implement pre-employment transition services to youth with IEPs and 504 plans to assist with a seamless transition after high school. Those services include; job exploration, work-based learning, counseling on opportunities, work readiness, and self-advocacy skills.
- E. Be Assured of Ongoing Coordination of Systems of Care and Support
- A task team was established to develop a survey to gather data related to progress made in the focus areas within the Strategic Plan that will be distributed statewide to both families and providers.
  - The Council will establish a task team to proactively begin working on a new five-year strategic plan for 2022-2027.

Therefore, the Council recommends continued implementation of the Iowa Strategic Plan – 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families, to systematically move Iowa forward in maintaining optimal services and supports for individuals with ASD and the families of those living with ASD, empowering them to have meaningful and successful lives in their communities.

## Conclusion:

The State of Iowa continues to make progress toward improving the lives of individuals and families living with 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, many individuals with ASD and their families still have unmet needs, some of which have obvious solutions, and others which will require additional hard work, dedication, and compassion. The people of Iowa, including the Office of the Governor and the Iowa Legislature, should not be satisfied with the current status of services and supports in our state; therefore, we must work together to meet the unique needs of Iowans with ASD.

## Reference:

Lindgren 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

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## 2019 Voting Members

Name	Position/Representation
Bowker, Christine	Family Member of person with ASD
Hertel, Erika ( <i>co-chairperson</i> )	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
Stephenson, Blake	Research
Phan, Jenny	Family member of person with ASD
Primrose, Caleb ( <i>co-chairperson</i> )	Person with ASD
Beer, Andrew	Mental Health Professional
Vacant	Insurance Industry Representative
Zehr, Michael	Family member of person with ASD

## 2019 Ex-Officio Members

Name	Position/Representation
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](http://www.educateiowa.gov)  
(located under the Iowa Autism Council)

You may also contact:

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