



# Iowa Autism Council

## 2021 Priorities

Moving Iowa Forward

Summary of Accomplishments in 2020 and  
Priorities and Recommendations for 2021

# Iowa Autism Council

December 2020

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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 2020 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 outreach efforts to share information with families and stakeholders about autism, RAP, Child Health Specialty Clinics, and the Center for Disease Control and Prevention’s (CDC) *Learn the Signs. Act Early.* program.
  - RAP offers the *Autism Basics* Webinar Series twice per year. This 4-week webinar series of training sessions for parents of newly diagnosed children and providers features Kelly Pelzel, PhD and is approved for foster parent continuing education credit.
  - RAP, in collaboration with the University of Iowa Stead Family Children’s Hospital Autism Center and the Autism Society of Iowa, offered a training for case managers from Iowa’s Managed Care Organizations (MCOs), Iowa Department of Human Services (DHS), and others. *Autism Spectrum Disorder: A Primer for Case Managers Training* was recorded and continues to be available for access.
  - 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 six of the project.
  - RAP has continued to offer courses through Autism Navigator® for additional staff, building on an initiative by the Iowa Department of Education (IDOE). They have been 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.

- Child Health Specialty Clinics, the Regional Autism Assistance Program, University of Iowa Stead Family Children’s Hospital, the Center for Disabilities and Development, and the Developmental Disabilities Council have sponsored a series of Transition to Adulthood webinars. This webinar series was designed for Iowa parents, legal guardians, and caregivers of transition-aged youth (12-21 years). Eight sessions covered topics involved in the transition of youth to adult health care and specialty services.

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 2021:

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 funding for the Regional Autism Assistance Program to support families and strengthen early identification of ASD.
3. Continued support of the BCBA Education Grant to build provider capacity in Iowa.
4. Continuation of the flexibility granted during COVID for telehealth access to build on and increase statewide access to ABA treatment through telehealth models.
5. 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 2021:

6. Consider opening the role of Behavior Technician to include the Registered Behavior Technician (RBT) credential as well as allowing for those with a 4-year degree to be eligible without the RBT credential.
7. Support of the Legislative Priorities established by the Iowa Developmental Disabilities Council.

For the Council,

Caleb Primrose  
*Co-Chairperson*

Erika Hertel  
*Co-Chairperson*

# Iowa Autism Council

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## 2021 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 2020 report from the Center for Disease Control's Autism and Developmental Disabilities Monitoring (ADDM) Network, it is estimated that **1 in 54** 8-year-old children 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.

## 2021 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 2021 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 and funds 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 through state fiscal year 2020, ASP has provided funding for 64 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 \$25,422 and the average length of time a child is enrolled in ASP is 12 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 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.

### 3. 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 by assisting students in meeting the financial obligations associated with completing an educational program in applied behavior analysis to become a BCBA. The program pays up to half of the tuition and fees during each semester/quarter for a BCBA or BCaBA program while the awardee is in college. Awardee must become certified, upon graduation and fulfill a 2 year employment commitment in Iowa to complete the program or pay the funds back if the service commitment is not completed.

1. Average number of dollars appropriated annually - The program has received two appropriations of \$250,000 each for FY16 and FY17 for a total of \$500,000. The program collects interest on those initial appropriations that are used for the program. No new appropriations since FY18
2. Year program Started – The program was created by 2016 Iowa Acts, HF 2460 that amended Iowa Code section 135.181 and administrative rules for the program (641--107) were adopted and became effective on November 16, 2016
3. Number of applications received since inception – 59
4. Number of awards since inception – 31 total awards<sup>1</sup>
5. Number of dollars awarded since inception – \$210,148 (Note funds are obligated upon applicant acceptance and are awarded (paid out) as the applicant’s education progresses)
6. Number of applications received FY 2019/2020 RFP – 22 applications received
7. Number of awards FY 2020 – 10
8. Number of dollars awarded FY 2020 –\$114,993
9. Number of applicants received FY 2021 RFP – 1 (currently under Phase 2 review – NOIA anticipated December 7 for award determinations)

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<sup>1</sup> Out of 31 awardees, three withdrew before contracts were signed, two did not fulfill their service obligation, and one contract was terminated.

Drake University's Master of Science in Applied Behavior Analysis program and the University of Iowa's Graduate Certificate in Applied Behavior Analysis program provide 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 continued support of this program to expand provider capacity in Iowa.

#### **4. Continuation of the flexibility granted during COVID for telehealth access to build on and Increase statewide access to ABA treatment through telehealth models.**

The COVID-19 pandemic has resulted in the severe reduction or closure of many service and healthcare agencies dedicated to providing services and care to individuals with autism and their families. As the pandemic has persisted, what was initially thought to be a temporary hiatus from important services and supports has become a permanent discontinuation for many families, halting gains and likely leading to regression of skills for some individuals.

Iowa has been a pioneer and international leader in research demonstrating the effectiveness and efficiency of telehealth-delivered services for individuals with autism and their families. However, until the pandemic occurred, the State of Iowa lagged behind most of the United States in terms of telehealth service options for individuals with autism. Fortunately for some Iowans, as the pandemic hit the opportunity to continue important services was realized through the use of telehealth. During COVID-19, telehealth has garnered tremendous support from governmental institutions, service providers and payers, and recipients of the services. For example, in response to the pandemic, enforcement of the Federal HIPAA laws and interstate practice rules and regulations were relaxed, resulting in greater access to healthcare services via video and telephone encounters. Additionally, insurance providers and the Centers for Medicare and Medicaid Services supported the use of telehealth during the crisis and have granted payment parity between telehealth and in-person services.

In addition to the continuity of services and decreased health risks, telehealth has offered both service providers and recipients many added benefits. While telehealth reduces costs and time associated with travel to and from appointments, it also allows families living in underserved or geographically distant regions in Iowa to access previously unavailable services. Numerous studies from the University of Iowa have demonstrated that such services can be delivered via telehealth with the same effectiveness as in-person services, but at a lower cost (Lindgren et al., 2016). Arguably the greatest benefit to a clinic-to-home telehealth model is the opportunity to provide services in the most natural context to the individual. Studies have repeatedly shown that generalization of treatment is greatest when it is provided in the most natural setting (i.e., the home) and caregiver knowledge and skills to manage behavior are greatest when the caregiver is involved in treatment, which is often necessary in a clinic-to-home telehealth model.

Although everyone is hopeful that COVID-19 will subside at some point in the near future, providers and families who have benefited from telehealth may lose this option. Relaxation of the Federal laws and payor agreements to cover proven telehealth models will likely return to pre-pandemic

status when COVID-19 subsides and currently, there are no state rules or regulations that ensure that telehealth may be delivered using the current clinic-to-home model.

Thus, the Council recommends legislative action to preserve the current opportunity for families in Iowa to receive support and services via telehealth. In particular, the Council recommends that providers have the option to provide scientifically validated (i.e., evidence-based) services using clinic-to-clinic, clinic-to-school, and clinic-to-home models whenever appropriate.

## 5. Consider opening the role of Behavior Technician to include the Registered Behavior Technician (RBT) credential as well as allowing for those with a 4-year degree to be eligible without the RBT credential.

Behavior Technicians who are direct care staff work under Board Certified Behavior Analysts to provide Applied Behavior Analysis (ABA) treatment. In Iowa, Behavior Technicians are required to have a 4-year degree and training in ABA. There is a shortage of Behavior Technicians who meet these criteria in some parts of the state. The Behavior Analyst Certification Board regulates a credential that is called a Registered Behavior Technician (RBT) that has not been sufficient as a prerequisite in Iowa if the person does not also have a 4-year degree. The RBT credential is acquired by taking an approved 40-hour course in ABA and passing a national exam. RBTs maintain their credential by receiving a high level of direct supervision by a BCBA. If the state were to move to the requiring the RBT, the amount of supervision required would reduce manageable caseload sizes by BCBA.

It is the recommendation of the Council that Iowa consider opening the role of Behavior Technician to include the RBT credential as well as allowing for those with a 4-year degree to be eligible without the RBT credential. This could effectively multiply the number of people who can work in the field of behavior analysis in Iowa.

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

The Iowa Developmental Disabilities Council (Iowa DD Council) established *Legislative Priorities* in 2019 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 *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.

## 7. 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

- The Regional Autism Assistance Program (RAP) continues work in the focus area Get a Good Start of the Strategic Plan with their LTSAE (Learn the Signs Act Early) Ambassador, partnering with WIC for a Developmental Monitoring project. In addition, all Child Health Specialty Clinics Regional Centers have a supply of LTSAE materials for additional distribution to families and to share at outreach opportunities.
- The University of Iowa Stead Family Department of Pediatrics Division of Child and Community Health (DCCH) and Child Health Specialty Clinics (CHSC) was recently awarded an Association of University Centers on Disabilities (AUCD) grant titled *Support for Early Childhood State Systems through the Act Early Network to support Recovery and Build Resiliency Skills, Behaviors and Resources of Children, Families, and Communities*. Its main purpose is to encourage parent engaged developmental monitoring to improve early identification and early intervention. Each state Act Early Ambassador is the state lead and specific stakeholders are asked to serve on the team to develop a needs assessment taking into consideration COVID-19 barriers and solutions. Three key targeted statewide programs will participate in the initiative, including WIC, Child Care Resource and Referral, and 1st Five, all of which have statewide presence
- RAP continues to provide ASD screenings in CHSC Regional Centers, helping to determine if a child needs further evaluation for autism from a diagnostic provider.
- 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® for Early Intervention Providers online professional development courses. Since 2015, approximately 260 Early ACCESS providers have enrolled in the Autism Navigator® online course.

- RAP has continued to offer courses through Autism Navigator® for additional staff, building on an initiative by the Iowa Department of Education (IDOE) and 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.

#### 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 64 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 University of Iowa Stead Family Department of Pediatrics Division of Child and Community Health (DCCH) and Child Health Specialty Clinics (CHSC) received the *Innovations in Care Coordination Grant* which put initiatives in place to bolster the Regional Autism Assistance Program. This grant places Family Navigators within Primary Care practices to assist families in finding resources and services. Sites include Waterloo, Storm Lake, Des Moines, and Dubuque. This grant also includes the Iowa Autism Learning Community webinar series to help primary care providers around the state that serve children with developmental disabilities, including Autism.

#### 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 offers an Autism Basics free four-week webinar series with presenter Kelly Pelzel, PhD twice per year. 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 is 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

- Child Health Specialty Clinics, the Regional Autism Assistance Program, University of Iowa Stead Family Children's Hospital, the Center for Disabilities and Development, and the Developmental Disabilities Council is sponsored a series of Transition to Adulthood webinars. This webinar series was designed for Iowa parents, legal guardians, and caregivers of transition-aged youth (12-21 years). Eight sessions covered topics involved in the transition of youth to adult health care and specialty services.
- 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 (IVRS) 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. IVRS established a new Autism Advisory Team which has started to build resources and supports for staff to better serve individuals with Autism.

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

- The Regional Autism Assistance Program (RAP) continues outreach efforts to share information with families and stakeholders about autism, RAP, Child Health Specialty Clinics, and the Center for Disease Control and Prevention's (CDC) Learn the Signs. Act Early. program.
- RAP, in collaboration with the University of Iowa Stead Family Children's Hospital Autism Center and the Autism Society of Iowa, offered a training for case managers from Iowa's Managed Care Organizations (MCOs), Iowa Department of Human Services (DHS), and others. Autism Spectrum Disorder: A Primer for Case Managers Training was recorded and continues to be available for access.
- 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 team will 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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## 2020 Voting Members

<u>Name:</u>	<u>Position/Representation:</u>
Beer, Andrew	Mental Health Professional
Grant, Michelle	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
Lenzmeier, Betsy	Family member of person with ASD
Mulligan, Cheryl	Education Representative
Nopoulos, Nicholas	Insurance Industry Representative
O'Brien, Matthew	Service Provider
Phan, Jenny	Family member of person with ASD
Primrose, Caleb ( <i>co-chairperson</i> )	Person with ASD
Stephenson, Blake	Research
Zehr, Michael	Family member of person with ASD

## 2020 Ex-Officio Members

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