



IOWA AUTISM COUNCIL

# Iowa Autism Council 2023 Priorities

Moving Iowa Forward

Summary of Accomplishments in 2022 and  
Priorities and Recommendations for 2023

# Iowa Autism Council

## December 2022

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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 2022 Iowa continued to make strides in supporting individuals with autism spectrum disorder through the following activities and legislative acts:

- The Regional Autism Assistance Program (RAP) continued to provide community-based clinical consultation, multidisciplinary 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 Applied Behavior Analysis (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 Iowa Department of Education (IDOE) continued the Autism Navigator project utilizing the *Autism Navigator® for Early Intervention Providers* online professional development courses for Iowa’s Early ACCESS providers. The project is now entering year eight.
  - The IDOE has also introduced a new project, Social Emotional Engagement - Knowledge and Skills (SEE-KS) at a few schools in Iowa, with intent to scale across the state. SEE-KS is a professional learning approach that provides freely accessible tools for: 1) measuring student engagement, 2) identifying instructional strategies to increase engagement at universal and higher tiers of support, and 3) providing a structured, appreciative inquiry-based process for educators to mentor one another to sustain the work.
  - IDOE has also begun to build-out existing Specially Designed Instruction (SDI) K6 Literacy modules to include a concentrated focus on reading comprehension with considerations for neurodivergent learners (including ASD).
  - RAP continued outreach efforts to share information with families and stakeholders about autism, RAP, Child Health Specialty Clinics, and the Centers for Disease Control and Prevention’s (CDC) *Learn the Signs. Act Early.* program.
  - RAP continued to offer 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, from the University of Iowa Health Care Department of Child and Adolescent Psychiatry, and is approved for foster parent continuing education credit.

- In an effort to improve their services to individuals with autism, Iowa Vocational Rehabilitation Services created the Autism Advisory Committee to create resources for staff working with individuals with Autism.
- Telehealth continues to be allowed for services including ABA through the Federal Declarations due to the pandemic. The Department of Health and Human Services (DHHS) has drafted a request to the Centers for Medicare and Medicaid Services (CMS) for the inclusion of ABA on the list of approved codes.
- House File 2167 passed and was approved by the Governor in April of 2022. This Act updated the definition of autism and re-classified it as a mental health diagnosis. The Act defines autism spectrum disorder as “a mental health condition that meets the diagnostic criteria for such disorder as published in the most recent edition of the diagnostic and statistical manual of mental health disorders by the American Psychiatric Association.” This Act may result in individuals or families who are covered by Iowa regulated insurance plans to have the protection of federal mental health parity laws, which could eliminate the age and dollar cap amounts that are in the code.
- The appropriations bill provided rate increases for Waiver and Habilitation services, Intermediate Care Facilities for Intellectually Disabled and ABA services. These rate increases allow providers the ability to raise wages for direct service professionals in an effort to impact the staffing shortages that are impacting services.

While Iowa continues to make strides in improving the lives of individuals with ASD and their families, 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. Therefore, the Council proposes the following priorities for 2023:

1. Continued funding of ASP and consideration of modifications to address unintended consequences of insurance reform by providing for flexibility in program benefit limits.
2. Continuation of the work to assure statewide access to ABA through telehealth, including championing for the addition of ABA billing codes to the approved list provided by CMS.

The Council also makes the following recommendations to continue to support progress in Iowa:

3. Continued funding for the RAP to support families and strengthen early identification of ASD.
4. Continued support of the Legislative Priorities established by the Iowa Developmental Disabilities Council.
5. Continued support for implementation of *Iowa’s Autism Strategic Plan – 2022 - 2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*.
6. Explore the gaps in adult services for individuals with ASD and consider innovative ways to expand services for adults.

For the Council,

Caleb Primrose  
Co-Chairperson

Wendy Andersen  
Co-Chairperson

# Iowa Autism Council

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## 2022 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 and to meet the unique needs of adults with ASD.

According to a 2022 report from the Centers for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring (ADDM) Network, it is estimated that **1 in 44** 8-year old children have been identified with autism spectrum disorder. These findings indicate that there continue to be many individuals living with ASD who need services and support now and throughout their lifespan.

#### ***A Note about Language:***

The terms “person with autism,” “person with ASD,” “autistic person,” and “person on the autism spectrum” are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. We respect the different opinions within the community on the use of this language and do not intend to endorse any particular preference. In addition, the terms “autism” and “autism spectrum disorder (ASD)” are used interchangeably throughout this document unless otherwise noted.

### 2023 Priorities

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 with autism have the opportunity to lead meaningful and successful lives in their community.

The Council, therefore, proposes the following **priorities** for 2023:

#### 1. Continued funding of the ASP and consideration of modifications to address unintended consequences of insurance reform by providing for flexibility in program benefit limits.

- ABA is a scientific approach to understanding and modifying behavior and understanding 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 that improve the independence and quality of life for the individual.

- ASP was created in 2014 to fund ABA services for children with ASD who are not eligible for ABA services under the state’s medical assistance program or through private insurance coverage.
- Since its inception through state fiscal year 2022, ASP has provided funding for 75 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 ASP has been far less than originally estimated. More children would have received ASP funding if providers were available in all parts of the state. 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 about \$25,000 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 asks the legislature to consider making the following modifications consistent with the program goals to fill current gaps in funding availability to Iowa families:

**a) Access for families whose insurance requires a high out-of-pocket cost for deductibles and co-pays.**

- Since January 2018, more group insurance carriers in Iowa have been required to cover ABA for children with ASD, and many families have benefited from the expansion of coverage. 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.
- 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 for a time-intensive service that may require sessions several times each week.
- 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. If the family has to pay out-of-network rates to obtain the service, that further pushes up the costs to them.

**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 ASP 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 \$3,000 to \$4,000 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) for the duration of the ABA therapy. That’s \$3,600 to \$4,800 a year.
- If the same family has a private insurance benefit and therefore does not qualify for assistance through ASP, their insurance plan may require them to pay an annual deductible of as much as \$10,000 and then a 30% to 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 \$3,000 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 to access the ABA services their child needs.

- The Council recommends that legislators consider expanding the eligibility standards for ASP 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% federal poverty level 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 ASP.

**b) Greater 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 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 historically had 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 for the number of months and total funding available per child could fill in service gaps for a small number of children.
- 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.

The Council recommends the following actions to increase access to ASP:

- a) modifying the eligibility criteria and,
- b) increasing flexibility to the benefit limitations by allowing exceptions to be made with approval by the program administrator, within the parameters of available funding.

Such program changes could increase needed access to the program without exceeding the historical funding level of \$500,000 per fiscal year.

## 2. Continuation of the work to assure statewide access to ABA through telehealth, including championing for the addition of ABA billing codes to the approved list provided by CMS.

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 CMS supported the use of telehealth during the crisis and have granted payment parity between telehealth and in-person services.

Telehealth 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 behaviors are greatest when the caregiver is involved in treatment, which is often necessary in a clinic-to-home telehealth model.

Work is underway with the Department of Health and Human Services and Iowa Medicaid to ensure that Iowans will continue to be able to access appropriate services through telehealth. Rules are currently being considered to address documentation requirements and other logistics of the provision of these services through combined audio/video methods on an ongoing basis. Currently the billing codes are temporary and moving those codes to billing codes that are listed as approved by CMS would help ensure families continue accessing services.

The Council supports these efforts to ensure that families in Iowa will continue to receive support and services via telehealth as well as through in-person encounters to increase access to services, especially in rural areas.

## 2023 Recommendations

The Council also **recommends** the following actions to continue to support Iowans with autism and their families:

### 3. Continued funding for RAP to support families and strengthen early identification of ASD.

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 RAP provides have been instrumental in meeting the goals of the *Iowa Autism*

*Strategic Plan 2016 - 2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*; and will continue to be instrumental in meeting the goals of the new strategic plan for 2022-2027.

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

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

The Iowa Developmental Disabilities Council (DD Council) works to create change with and for persons with developmental disabilities so they can live, work, learn and play in the community of their choosing. The DD Council has engaged Iowans with disabilities, their families, providers and other advocates throughout the state in discussions about policy and funding that support independent living opportunities for Iowans with disabilities. These individuals and their families want to choose where they live and work, but those choices are too often limited by the inadequacy of available community-based options.

The DD Council continuously advocates for policies that make Iowa a better place for people living with disabilities. Each year, they develop a legislative agenda that outlines their priorities. The following are the priorities established for 2023:

- Fully fund healthcare services and community-based supports to address the workforce crisis in both rural and urban areas.
- Support an inclusive and accessible community for all Iowans.
- Reduce and eliminate ALL Home and Community-Based Services (HCBS) waiting lists.

The full agenda can be viewed on their website ([iowaddcouncil.org/legislative-agenda](http://iowaddcouncil.org/legislative-agenda)).

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 autism spectrum disorders, have access to high-quality services and supports that promote a life in the community.

#### 5. Continued support for implementation of *Iowa's Autism Strategic Plan – 2022 - 2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*.

In November 2022, the Council adopted the *Iowa's Autism Strategic Plan – 2022 - 2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families* (full document to be posted on the RAP website page - [chsciowa.org/regional-autism-assistance-program.asp](http://chsciowa.org/regional-autism-assistance-program.asp)). This document serves to chart a course for Iowa to systematically and comprehensively improve its response to ASD and create opportunities for individuals with autism to have meaningful and successful lives in their communities. The plan identifies the following focus areas:

- A. Get a good start
- B. Have access to and obtain needed services
- C. Have well informed, empowered, and supported families and caregivers
- D. Successfully transition to adult life
- E. Be assured of ongoing coordination of systems of care and support

The Council continues to see the benefit of such a strategic plan as the principal guide for developing and

maintaining optimal services and supports for autistic individuals and their families.

The Council supports the implementation of Iowa's Autism Strategic Plan to continue to systematically move Iowa forward in maintaining optimal services and supports for autistic individuals and their families, empowering them to have meaningful and successful lives in their communities.

## 6. Explore the gaps in adult services for individuals with autism and consider innovative ways to expand services for adults.

Services and therapies for *children with autism* are generally addressed in the educational system and/or covered by Medicaid or private insurance. However, when individuals with ASD age out of their educational setting and transition to adulthood, the service and support system they have known for years is often dramatically reduced. In the autistic community, this is referred to as "falling off the cliff."

Autistic adults who also have an intellectual disability may continue to qualify for services through either the Intellectual Disability (ID) waiver or the Health and Disability (HD) waiver, which differ in services offered. However, many who function on a higher intellectual level may not qualify for a waiver, and consequently struggle to get the supports they need to address social, communication, or behavioral needs that interfere with independent living, employment, and successful integration into their communities. In addition, eligibility for services does not mean that service providers are available in the community in which a person lives.

Regardless of intellectual ability or waiver status, adults with autism are at risk for:

- Social isolation
- Unemployment or underemployment
- Lack of assistance in resolving workplace issues
- Lack of transportation
- Vulnerability in relationships if they do not have a guardian or conservator
- Diminishing support as parents age and family members relocate

The need to develop innovative strategies to effectively provide services and supports to adults with autism is long overdue. Iowa needs to invest in determining what the key unmet needs are for autistic adults, and what supports and services adults with ASD need to enable independent living, meaningful employment, and successful integration into their communities.

The Council will form a subcommittee to explore what resources and services are available for autistic adults and identify gaps.

## Conclusion:

The State of Iowa continues to make progress toward improving the lives of individuals with ASD and their families. 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 autistic individuals 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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## 2022 Voting Members

Name:

Andersen, Wendy (*co-chairperson*)

Boyle, Stephanie

Grant, Michelle

Horton, Evelyn

Gronau, Pam

Lenzmeier, Betsy

Mulligan, Cheryl

O'Brien, Matthew

Primrose, Caleb (*co-chairperson*)

Stephenson, Blake

Wixted, Colin

*Vacant*

*Vacant*

Position/Representation:

Family member of person with ASD

Family member of person with ASD

Family member of person with ASD

Residential Service Provider

Family member of person with ASD

Family member of person with ASD

Education Representative

Service Provider

Person with ASD

Research

Insurance Industry Representative

Family member/person with ASD

Mental Health Professional

## 2022 Ex-Officio Members

Name:

Boston, Angela

Buehler-Sapp, Beth

Elsner, Carrie

Fanselow, Connie

Hertel, Erika

Keith, Andrea

Lovelace, Brooke

Trotter, Wendy

Position/Representation:

Iowa Insurance Division

Iowa Department of Education

Board of Regents

Iowa Department of Health and Human Services

Regional Autism Assistance Program/CHSC

Iowa Vocational Rehabilitation

Iowa Developmental Disabilities Council

Iowa Department of Education

Further findings are available with previous years' 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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