



IOWA AUTISM COUNCIL

# Iowa Autism Council 2024 Priorities

Moving Iowa Forward

Summary of Accomplishments in 2023 and  
Priorities and Recommendations for 2024

# Iowa Autism Council

## December 2023

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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 2023 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.
- The *Iowa Strategic Plan – 2022-2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families* was completed and released. This strategic plan was formally adopted by the Council this year and the Council will continue monitoring statewide progress.

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 2024:

1. Continued funding of ASP with modifications to provide for flexibility in program benefit limits.
2. Ensure that the service needs of children and adults with the full range of Autism Spectrum Disorders (ASD) are considered in Iowa’s redesign of the home and community-based services (HCBS) waiver program.
3. Encourage the Hawki insurance plans to cover ABA therapy and all necessary services for autistic individuals, or to allow the use of ASP funding for a longer period of time and with more flexibility than is currently allowed.

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

1. Continued funding for the RAP to support families and strengthen early identification of ASD.
2. Continued support of the Legislative Priorities established by the Iowa Developmental Disabilities Council.
3. Continued support for implementation of *Iowa Strategic Plan – 2022-2027: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families*.
4. Continued exploration of 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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## 2024 Priorities and Recommendations

### General

The Iowa Autism Council (Council) recommends the State of Iowa maintain the Iowa Autism Council with its intentional focus on Iowans with autism. The Review of Iowa's Board and Commissions Final Report with Findings and Recommendations dated September 29, 2023 recommended reorganization of the Autism Council with the following statement: *"Awareness of autism issues are critical in the education space; however, the Council could be reorganized to include representation for students with other disorders that may affect learning"*.

Although responsibility for the Iowa Autism Council falls under the Department of Education, the Council does not solely focus on education and school-aged individuals. Iowa Code §256.35A states that the Council is 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"*; thus, the responsibilities of the Council cover the life span of autistic individuals and their families and goes beyond how "learning" is affected. In fact, a large part of the focus of the Council's recent work has been on adult services and supports.

Additionally, acknowledging that the goal of the review committee is to streamline the State's boards and commissions and to eliminate duplication, adding "representation for students with other disorders that may affect learning" to the Autism Council would be duplicative of the Special Education Advisory Panel, as well as the Iowa Developmental Disabilities Council.

According to a 2023 report from the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network, it is now estimated that **1 in 36** 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.

The Council believes that the State of Iowa needs to have intentional representation for the autistic community (family/individuals with autism and/or autism service providers) through continuation of the Iowa Autism Council in order to recognize and support the unique needs of Iowans with autism, and to help further this population's ability to live, work, play, and thrive in Iowa.

#### ***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.

# 2024 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 2024:

## 1. Continued funding of Autism Support Program (ASP) with modifications to provide 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 to include families with high out-of-pocket insurance costs 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. Ensure that the service needs of children and adults with the full range of Autism Spectrum Disorders (ASD) are considered in Iowa's redesign of the home and community-based services (HCBS) waiver program.

The full range of ASD includes individuals with intellectual disabilities as well as individuals who function at average or higher intellectual levels but have significant deficits in social, communication, or behavioral skills. Adults with autism often struggle to access services to address the lifelong needs related to those deficits and to support them in being as independent and productive as possible.

Currently, the Iowa Department of Health and Human Services (Iowa HHS) is rebuilding its community-based services through the Hope and Opportunity in Many Environments (HOME) project to improve and ensure that everyone has access to high-quality behavior health, disability, and aging services in their community. The goal is to enhance services, allowing people to remain in their communities with their loved ones, and making it easier for them to access the help they need. As Iowa HHS rebuilds this vital waiver program, it is imperative that they consider the support needs of autistic individuals so that they too can access the services they need to be productive and independent in their communities.

The Council recommends that the support needs of individuals with autism are taken into consideration as the HOME team works to improve systems for all Iowans accessing community-based services.

## 3. Encourage the Hawki insurance plans to cover ABA therapy and all necessary services for autistic individuals; or modify/expand the ASP program to allow these individuals to utilize this funding source for a longer period of time to assist with therapy needs.

Behavioral Health Intervention Services (BHIS) including Applied Behavioral Analysis (ABA) are not a covered benefit for Hawki members. While children enrolled in Hawki can access the limited funding for ABA available through the Autism Support Program, their coverage limits are less fulsome than those for children who are enrolled in Iowa Medicaid and many children with private health insurance coverage. This results in a number of Iowan's not being able to adequately access necessary services to address their needs.

The Council recommends the Hawki insurance plan expand their coverage to include BHIS and ABA as a covered benefit; or modify/expand the ASP program to allow these individuals to utilize this as a funding source to meet their therapy needs.

# 2024 Recommendations

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

## 1. 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 provide are instrumental in meeting the goals of the *Iowa Strategic Plan – 2022-2027: 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.

## 2. 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 2024:

- Students with disabilities of all ages receive a quality education with the supports they need to learn and thrive.
- Iowans with disabilities are employed and working toward financial independence.
- Iowans with disabilities live independently in their community by getting the support they need.
- Affirm the right to vote for people with disabilities by ensuring their access to participation.

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.



### 3. 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](https://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.

### 4. Continued exploration of 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 formed a subcommittee in 2023 to explore what resources and services are available for autistic adults and identify gaps. The subcommittee will continue their exploration into the areas of: therapies, residential options, transportation, waiver vs. no waiver services, post high school transition, vocational transition and life skills.

## 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.

# Iowa Autism Council Members

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## 2023 Voting Members

### Name:

Andersen, Wendy (*co-chairperson*)

Boyle, Stephanie

Carlson, Bill

Grant, Michelle

Gronau, Pam

Horton, Evelyn

Kortenkamp, Rhonda

Mulligan, Cheryl

Primrose, Caleb (*co-chairperson*)

Wixted, Colin

*Vacant*

*Vacant*

*Vacant*

### Position/Representation:

Family member of person with ASD

Family member of person with ASD

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

Education Representative

Person with ASD

Insurance Industry Representative

Research

Mental Health Professional

Service Provider

## 2023 Ex-Officio Members

### Name:

Boston, Angela

Buehler-Sapp, Beth

Crowe, Carlyn

Elser, Carrie

Fanselow, Connie

Hertel, Erika

Keith, Andrea

Trotter, Wendy

### Position/Representation:

Iowa Insurance Division

Iowa Department of Education

Iowa Developmental Disabilities Council

Board of Regents

Iowa Department of Health and Human Services

Regional Autism Assistance Program/CHSC

Iowa Vocational Rehabilitation

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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