

The Iowa Department of Education is submitting this report on behalf of the Iowa Autism Council. Two representatives of the Department serve as ex-officio, non-voting members of the Council.

Pursuant to Iowa Code section 256.35B, established through the 2024 Iowa Acts chapter 1170 (Senate File 2385), the Department will convene the Iowa Special Education Advisory Council in an advisory capacity. The Department is committed to ensuring all special education stakeholders, including persons with autism and those advocating on their behalf, have the opportunity to engage with the Council on the important work assigned to it.



IOWA AUTISM COUNCIL

Iowa Autism Council

Final Report

2024 Legislative Report

Summary of Accomplishments to Date Priorities
and Recommendations for the Future

Iowa Autism Council

Final Report – December 2024

Introduction

The Iowa Autism Council (Council) was formed in 2008 through legislation (Iowa Code section 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.”* As clearly defined in the purpose, the responsibilities of the Council have addressed the **lifespan** of autistic individuals and their families. The focus of the Council’s efforts for the last few years have been on adult services and supports.

However, with the signing of SF 2385 into law on May 17, 2024, the Autism Council is to be eliminated on July 1, 2025 and in its place, a new Iowa Special Education Council is to be created. This Special Education Council *“is to act in an advisory capacity to the Department of Education in promoting, directing, and supervising education for children requiring special education in the schools under the supervision and control of the department.”* However, this new council will not address the lifespan needs of individuals with autism and will leave autistic adults without a voice representing their needs.

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 **one 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.

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.

1. Summary of the Council's Accomplishments

Over the years, the Iowa Autism Council has made meaningful progress in advising the State on issues that impact autistic individuals and their families. Key areas of support and advisory efforts include:

- **Insurance Coverage Recommendation:** Successfully recommended for insurance coverage of autism services, notably Applied Behavior Analysis (ABA) therapy, which was previously excluded from coverage. This advising led to changes in insurance requirements, providing critical support for families.
- **Focus on Early Identification and Evaluation:** Worked to improve early identification and evaluation processes for autism, developing essential resources and support networks.
- **Identified Gaps in Services:** The Council played a vital role in identifying critical service gaps across various areas, including rural services, adult services, diagnostic services and funding for essential supports. The Council also highlighted the need for long-term care services, advocating for care provisions extending beyond the typical 12 to 24-month timeframe, which are essential for sustained support throughout the lifespan of individuals with autism.
- **Autism Support Program (ASP):** Supported the ASP to offer funding and services for individuals with autism, enhancing access to essential supports.
- **Regional Autism Assistance Program (RAP):** Supported and collaborated with RAP and their panel of experts on autism-related issues to strengthen statewide approaches to autism services.
- **Collaborative Forum:** Served as a collaborative platform that brought together diverse stakeholders—government agencies, providers, families—to share information and work toward common goals.
- **Elevated the Voices of Autistic Adults and their Caregivers:** The Council has maintained a lifespan focus, serving as the only formal platform for autistic individuals across all stages of life to share their voices and perspectives. Through its mission, the Council has prioritized inclusive representation and provided a crucial space for autistic adults to advise on policies, share lived experiences and influence systemic changes that impact their lives and the broader community.

2. Identification of Key Gaps and Needs Post-Disbandment

With the disbandment of the Iowa Autism Council, significant gaps and needs have emerged that require focused attention to ensure continued support, advocacy and access to services for the autism community in Iowa.

- **Advisory Body Absence:** The disbandment of the Iowa Autism Council would leave a significant gap due to the lack of a formal advisory body to offer guidance and recommendations on autism-specific issues and priorities. This Council has served as a direct link for autistic individuals to advise state government in practices that could positively impact the broader autism community, which has included advising the Governor, elected officials and State departments. No other organization in Iowa serving those with autism has this direct impact.
- **Champion for Autistic Perspectives:** Risk of losing a consistent voice for autism issues at the state level, potentially leaving no entity responsible for championing autism priorities with legislators.
- **Distinct Needs of Individuals in School Versus Adults Who Have Aged Out:** The disbandment of the Council creates a significant void in addressing the differing needs of individuals with autism who are still within the education system versus those who have aged out. While students in K-12 benefit from

structured supports and educational services, adults often face the sudden loss of many critical resources and programs upon leaving the school system. This transition can leave gaps in employment support, housing, community integration and other essential services, with few opportunities for advisement and tailored solutions. Without a dedicated body to address these issues, adults with autism risk being overlooked, further exacerbating disparities in care and support.

- **Centralized Collaboration:** Loss of a centralized forum for collaboration and information sharing among key stakeholders, including government agencies, providers and families.
- **Resource and Referral Maintenance:** The disbandment of the Council raises concerns about who will maintain and disseminate up-to-date information regarding resources and referrals for individuals with autism and their families. Individual Council members have served as vital resources within their communities, offering direct contact and guidance, and fostering connections with the general community to ensure information and support reach those who need it most.
- **Addressing Rural Needs:** The autism community in rural areas continues to face unique and significant challenges due to limited access to services and supports. The Council has consistently highlighted these disparities and worked to ensure that rural families receive equitable access to diagnosis, treatment and ongoing care. Without the Council's guidance, there is a risk that the specific needs of these underserved communities will be overlooked, further exacerbating existing gaps in service availability and access.
- **Lack of Representation for Autistic Adults:** With the disbandment of the Council, there will be no other formal platform where the voices of autistic adults can be consistently heard and considered within any advisory body. This risks the loss of valuable input and perspectives from those directly impacted. The challenges faced by autistic adults are distinct and often differ greatly from those of autistic youth, encompassing issues such as employment, housing, long-term care and community integration. Losing this representation diminishes opportunities for meaningful advocacy and tailored solutions for this population.

3. Recommendations to Address Gaps

To ensure continuity and address identified needs, the following recommendations are proposed:

- **Autism-Focused Advisory Committee:** Establish an autism-focused advisory committee under the Iowa Department of Health and Human Services (HHS) or another organization such as the Iowa Developmental Disabilities (DD) Council to provide a formal mechanism for the autism community to maintain a direct way to advise the State on issues related to the autism community.
- **Recommendations for Comprehensive Lifespan Autism Support:** To effectively address the complex and evolving needs of autistic individuals across their entire lifespan, the State of Iowa must continue receiving guidance on autism-specific issues that span early childhood, school years, adulthood and senior stages. This could be achieved by establishing a dedicated committee or appointing an autism expert focused on coordinating lifespan services and advising policymakers. Additionally, forming government bodies or internal groups within Iowa HHS with a distinct autism focus would ensure ongoing advisement and advocacy. These structures would provide a consistent platform for the voices of autistic individuals, enabling the identification and resolution of unmet needs and service gaps throughout all stages of life, from initial diagnosis to end-of-life care.

- **Service Expansion:** Explore ways to expand evidence-based autism treatments, such as ABA therapy and other therapies, into rural areas to address geographic disparities in access to services.

4. Priorities for Continued Progress.

The following priorities are critical to maintaining and expanding support for the autism community in Iowa:

- **Modification of the ASP:**
 - **Remove the 24-Month Time Limit:** Eliminate the time restriction on services to allow for more flexible and long-term planning.
 - **Eliminate the \$36,000 Annual Cap:** Remove the funding cap to provide more comprehensive support for individuals with autism.
- **Insurance Coverage for Evidence-Based Services:** Inclusion of ABA therapy and other evidence-based autism services under the Hawki insurance program to expand access to critical treatments.
- **Expansion of Rural Services:** Develop and implement strategies to improve access to autism services in rural areas. Collaborate with the Iowa Department of Transportation, Vocational Rehabilitation and other agencies to create innovative service delivery models.
- **Adult Transition Services:** There remains a critical lack of support for individuals with autism as they transition from high school to adulthood. This period often marks the loss of many structured services provided during K-12 education, leaving young adults without adequate guidance and resources for employment, higher education, independent living and social integration. Addressing this gap requires dedicated programs and supports tailored to ensure a smooth transition and ongoing opportunities for growth, independence and community participation.
- **Adult-Focused Services:** After age 18, individuals with autism often experience a significant reduction in available supports, leaving many without the critical resources necessary for continued personal development and independence. The lack of adult-focused services can lead to challenges in accessing employment, healthcare, community engagement and daily living supports. Addressing these needs requires comprehensive, lifespan-oriented services that bridge the gap between youth-oriented programs and adult support systems, ensuring consistent care and opportunities for autistic adults to thrive in all aspects of life.

Conclusion:

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.

For the Council,

Wendy Andersen
Co-Chairperson

Caleb Primrose
Co-Chairperson

Iowa Autism Council Members

2024 Voting Members

Name:

Andersen, Wendy (*co-chairperson*)
Carlson, Bill
Grant, Michelle
Horton, Evelyn
Kortenkamp, Rhonda
Mulligan, Cheryl
Primrose, Caleb (*co-chairperson*)
Wixted, Colin
Vacant
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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
Education Representative
Person with ASD
Insurance Industry Representative
Research
Family member of person with ASD
Family member of person with ASD
Mental Health Professional
Service Provider

2024 Ex-Officio Members

Name:

Abramski, Megan
Boston, Angela
Buehler-Sapp, Beth
Crowe, Carlyn
Elser, Carrie
Hertel, Erika
Keith, Andrea
Trotter, Wendy

Position/Representation:

Iowa Department of Health and Human Services
Iowa Insurance Division
Iowa Department of Education
Iowa Developmental Disabilities Council
Board of Regents
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
(located under the Iowa Autism Council)