

Supporting Ohioans with Autism

ACROSS AGENCIES, ACROSS THE STATE, ACROSS THE LIFESPAN

Annual Report & Recommendations • 2024





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A Note About Language

The terms "person with autism," "person with ASD," "autistic person," "autistic," 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. The IWGA respects the different opinions within the community on the use of this language and does not intend to endorse any preference. In addition, the terms "autism" and "autism spectrum disorder (ASD)" are used interchangeably throughout this document unless otherwise noted.



Message from Leadership

The investments and initiatives implemented over the past year to support Ohioans with disabilities show we are progressing in the right direction to achieve greater opportunity and accessibility in Ohio.

We have observed strong support from people with developmental disabilities, families, partner organizations, businesses, and communities for promoting inclusion and access and elevating the voices of those with lived and shared experiences.

The initiatives we have supported over the past year with the support of entities, such as OCALI, are yielding exciting outcomes and new opportunities for Ohioans living with disabilities. These promising developments have been aided by support and important conversations within our community. These discussions helped identify what people want for their communities, the resources they need to succeed, and what matters most. Keeping communication going has built stronger relationships and partnerships, creating powerful advocacy and results.

Ohio's Interagency Work Group on Autism (IWGA) has been and continues to be instrumental in fostering enhanced engagement opportunities and accelerating Ohio's vision. This is achieved when partners pursue a common agenda, engage in shared activities, and maintain ongoing communication and collaboration. In 2024, the IWGA pursued various opportunities to connect with partners in Ohio and nationally, gaining valuable insights to inform and further advance the IWGA's mission to improve the coordination of state efforts to address the service needs of individuals with autism and their families.

The following pages highlight these interactions in 2024 and the ways IWGA member agencies, state partners, and other stakeholders advanced work to accelerate Ohio's effort to cultivate a sense of belonging for Ohioans with autism and their families.

We are honored to collaborate and provide leadership together, and we look forward to continued engagement through the IWGA.



Kimberly Hauck,

Director Ohio Department of Developmental Disabilities



Reginald Fields,

Chair OCALI Advisory Board

Background

Ohio's Interagency Work Group on Autism (IWGA) was created in state law "to improve the coordination of the state's efforts to address the service needs of individuals with autism spectrum disorders and the families of those individuals." (ORC 5123.0419). Under the leadership of the Ohio Department of Developmental Disabilities, the IWGA initially convened in January 2008. The IWGA meets monthly and utilizes the collective impact framework to achieve its objectives.

In 2024, the IWGA consisted of the following state agencies and public representation:

- Ohio Department of Developmental Disabilities (Lead Agency)
- OCALI (Convener)
- Ohio Department of Education and Workforce
- Ohio Department of Health
- Ohio Department of Job and Family Services
- Ohio Department of Medicaid
- Ohio Department of Mental Health and Addiction Services
- Opportunities for Ohioans with Disabilities
- Ohio Department of Children and Youth
- Autistic Ohioans
- Family Member
- Educator
- Clinician

Essential to accelerating the work is the voice of autistic individuals, their families, and their communities. The IWGA seeks opportunities to gather input from Ohioans through stakeholder engagement, collaboration with statewide projects and partners, OCALI's Advisory Board, and other communication and networking channels.





Accelerating Our Vision

Gathered in 2022 through contributions from individuals with autism, their families, and community partners, the following key vision components reflect the aspirations of Ohioans with autism and their families. These elements continue to inform and guide the IWGA priorities.

- **Members.** Be full, welcome members of their classrooms, communities, place of employment, and houses of worship.
- Leaders. Be leaders and decision-makers.
- **Relationships.** Have a variety of safe, healthy relationships.
- **Valued.** Be valued, respected, and have their contributions recognized.
- **Choices.** Have a wide range of choices about where and how to live, work, and be supported.
- **Needs.** Get what they need when they need it consistently and easily.
- **Future.** Talk about and plan for positive, possible futures, throughout life, starting early.

The following pages highlight ways the IWGA member agencies have worked together with statewide partners and stakeholders to accelerate Ohio's vision.



Highlight

Everyday activities shape a person's life by establishing valued roles, making decisions, setting goals, and fostering responsibility.

Works4Me

<u>Works4Me</u> facilitates the transition from subminimum wage employment to competitive integrated jobs by offering new support and services for adults and out-of-school youth with disabilities. As an extension of <u>Ohio's Employment</u> <u>First</u> initiative, Works4Me fosters collaboration across the state to enhance community employment opportunities for all working-age adults with developmental disabilities.

With support from Ohio Governor Mike DeWine and a five-year grant, Works4Me aims to empower individuals to explore career options and seek jobs that align with their skills and interests. Opportunities for Ohioans with Disabilities, in collaboration with the Ohio Department of Developmental Disabilities, is actively engaging with other community and governmental organizations to leverage Works4Me to extend outreach to approximately 1,450 individuals with disabilities. In its second year, 14 providers are currently accessing Works4Me services for participants.

MAP Teams

Since 2016, <u>OCALI's Lifespan Transitions Center</u> team has led Ohio's Multi Agency Planning (MAP) Team project. This collaborative effort continues to bring together multi-agency planning teams comprised of core members from school districts, county boards of developmental disabilities, and our state vocational rehabilitation agency, Opportunities for Ohioans with Disabilities.

Twenty-two MAP Teams have been formed, to provide support to students across Ohio. The project aims to provide training and coaching for local, county-based teams, enabling them to identify barriers to students' post-school success. These teams work collaboratively to develop joint strategies to address the identified barriers to better support students and families during the transition planning process.

Advancing the project objectives and enhancing access to comprehensive resources to support teams, OCALI's Lifespan Transitions Center in partnership with the Ohio Department of Education and Workforce and the Ohio Department of Developmental Disabilities, launched the <u>Ohio</u> <u>MAP Tool</u> in 2023. Since its launch, this online tool has assisted MAP Teams and partner agencies in establishing clear, purposeful, and thoughtfully designed processes that foster cross agency, cross program, and cross disciplinary collaborative efforts.

Furthermore, the MAP Teams had the opportunity to present their plans, progress achieved, and outline for future efforts at the annual Spring <u>Team MAP Showcase</u>. With 14 MAP Teams represented at the 2024 Showcase, state leaders, agency partners, and stakeholders engaged with participants to gain insights into their collaborative efforts across agencies, programs, and disciplines, leading to measurable transition outcomes for youth and families.

Highlight

Access to meaningful connections and opportunities, fosters friendships, relationships, and sense of belonging.

Accessible Ohio

Since its launch in July 2023, <u>Accessible Ohio</u>, a program led by Opportunities for Ohioans with Disabilities (OOD), reinforces Governor Mike DeWine's Executive Order 2019-03D, which established Ohio as a disability inclusion state and a model employer of individuals with disabilities. The mission of Accessible Ohio is to prioritize accessibility from the start, promote inclusiveness, and ensure everyone can experience Ohio in an equitable way. Through the efforts of the Accessible Ohio Specialists, Ohio has made significant progress in helping partners identify goals and take steps to make their environments more accessible and inclusive for everyone.

In 2024, the Accessible Ohio Specialists provided over 200 no-cost consultations in the priority areas of planning and awareness, navigation, experience, and personal care. Additionally, the inaugural Accessible Ohio Conference and Expo was held in July 2024 and more than 300 people were present throughout the day, including nearly 200 attendees, Accessibility Showcase representatives, and staff. The conference included an opening keynote presentation, an interactive lunch session, and 20 educational breakout sessions. An Accessibility Showcase featured more than 40 vendors who offer products and services that promote accessibility and inclusion.

Clubhouse Model

In 2024, the Ohio Department of Mental Health and Addiction Services (OhioMHAS) continued its investment of expanding organizations implementing the Clubhouse Model across Ohio. A valuable resource, the International Clubhouse Model provides people with mental illness opportunities for friendship, employment, housing, education, and access to medical and psychiatric services within a supportive and safe environment.

OhioMHAS's collaboration with Clubhouse members in Ohio and its investment in this Model resulted in the addition of five new Clubhouses, adding to the 3 established programs. In 2020, they formed the <u>Clubhouse Ohio Coalition</u>. This expansion further brings to reality the supports necessary for Ohioans to build a better life, find employment, and pursue educational opportunities.

Members of the <u>Magnolia Clubhouse in Cleveland</u>, one of 300 Clubhouse programs worldwide, conducted an interview with OhioMHAS Director Cornyn, who expressed her support for the Clubhouse Model and the initiatives aimed at expanding the Model across Ohio.



Highlight

Proactively promoting safe, secure, and healthy living through individualized supports, resources, and choices, leads to positive outcomes throughout a person's life.

Parent Consultants

Recognizing the complexities that can arise when navigating various systems, the <u>Ohio</u> <u>Department of Health (ODH) Parent Consultants</u> assist parents and families in understanding and accessing 30+ programs within the Bureau of Maternal, Child, and Family Health. Additionally, they create connections to other nonprofits, local partners, and state agencies, including the <u>Ohio</u> <u>Department of Children and Youth</u>.

Understanding that families with children with medical complexities often encounter significant challenges and unique pathways, the ODH Parent Consultants provide a parental perspective and voice to help alleviate some of the concerns and frustration parents may experience. Through their lived experiences, they can amplify the family voice and provide valuable feedback and insights within ODH and with other stakeholders aiming to strengthen services and supports for families throughout Ohio. In 2024, many families have received support from the ODH Parent Consultants. Additionally, the ODH Parent Consultants provide assistance to families utilizing services through the <u>Complex Medical Help (CMH)</u> <u>program</u>. CMH is a state-administered program that functions within ODH aimed at facilitating early identification of individuals with special health care needs and connecting them with appropriate healthcare providers and treatment.



Multi-System Youth & Family Support

Created in 2021, the <u>Multi-System Navigation</u> <u>Center (MSNC)</u> at OCALI works to help youth and their families navigate multiple partners, resources, agencies, and opportunities to access the services and tools needed for success in life. The MSNC achieves this by bringing together the best minds, best research, and best practices to assist youth and their families in navigating the complex and sometimes overwhelming process of obtaining the support they need.

In partnership with the Ohio Department of Developmental Disabilities and its Cross System Behavioral Health Team, the MSNC developed and implemented the Multi-Disciplinary Comprehensive Assessment Team (MCAT) and Multi-System Youth & Family Regional Coaches (MSY&F) initiative. Through this investment, the MCAT and MSY&F Regional Coaches initiative has created a highly specialized approach focused on supporting youth with a dual diagnosis of mental illness and intellectual/developmental disabilities, as well as their families. This approach identifies supports, interventions, and services tailored to the unique needs of youth, fostering the best opportunities for them to remain in their family home, school, and community.

Now in its third year, 52 county boards of developmental disabilities, in partnership with their local teams, such as team members from <u>Ohio Family and Children First Councils</u>, <u>Ohio RISE</u>, and district, school, or educational programs, have referred youth for the MCAT and MSY&F Regional Coaches support. Out of the 52 county boards that submitted referrals, 44% of them referred multiple youth from their respective counties to participate in the MCAT and MSY&F Regional Coaches process.

This initiative has equipped families with effective support strategies, enhanced the knowledge and capacity of local teams, established additional connections to local and state resources and services, improved family resilience and safer environments, and strengthened collaboration among agencies and partners.

"I appreciated the team approach and thought at the end of the process it provided a good amount of perspective on the best way to work with and move forward with our son's future plans/treatment." - Parent

"Our coach was an asset to me, my family, my child & the entire team..." - Parent



Advancing Goals and Priorities

In 2024, the IWGA focused on the following recommended goals and priorities established through focus groups, surveys, and public comments from autistic adults, family members, advocacy organizations, state agencies, services providers, county boards of developmental disabilities, educators/educational agencies, higher education, health care, and other Ohio stakeholders.

Information & Resources

The IWGA will make it easier to find accurate, reliable autism-specific information and resources.

The IWGA will pay special attention to:

- Making sure we have information and resources relevant to people living in rural communities.
- Making sure we have information and resources relevant to racial and ethnic minorities.
- Making sure we have information and resources relevant to autistic adults.

Services

The IWGA will identify issues related to the quality, capacity, availability, and funding of services across the state for autistic Ohioans and their families, providing recommendations for improvement.

The IWGA will pay special attention to:

- Childcare and respite.
- Educational services.
- Intensive support services.
- Services for adults.

Health Care

The IWGA will partner with stakeholders to build healthcare's capacity to serve autistic Ohioans and improve health outcomes.

The IWGA will pay special attention to:

- Underserved areas and groups (rural Ohio, racial & ethnic minorities).
- The transition from pediatric to adult care.
- Mental and behavioral health.
- Dental care.

Clinical Diagnosis

The IWGA will strengthen and promote Ohio's efforts to increase developmental monitoring and autism screening, facilitate referrals, support families, and build statewide capacity for timely autism assessment.

The IWGA will pay special attention to:

- Using all available options and resources for screening and diagnosis to the greatest extent possible.
- Making sure underserved areas and populations have equal access to screening and assessment.
- Connecting people with resources between screening and assessment.

Systems

The IWGA will identify opportunities to streamline, simplify, and better coordinate eligibility, planning, and funding across Ohio's service delivery systems, providing recommendations for improvement.

The IWGA will pay special attention to:

- Reviewing the assessment tools, timelines, and processes used by each system (i.e., eligibility, level of care).
- Connecting people with the right system(s) for the right reason(s) at the right time.
- Removing redundancy and creating consistency and transparency across systems, and across the state.

These goals remain at the heart of the IWGA's work and will continue to be a priority and focus for 2025.

The IWGA looks forward to gathering input and engaging with Ohioans in 2025 to further advance the achievement of its goals.



2024 Insights

In 2024, the IWGA actively pursued opportunities to learn, discover, and connect with stakeholders to inform and enhance its recommendations. These interactions yielded valuable insights and fostered connections that facilitated discussions and advanced actions in line with the IWGA priorities aimed at improving support for autistic individuals and their families.

IWGA members participated in a discussion to explore how the <u>IWGA website</u> can serve as a vehicle for enhancing access to accurate, reliable, autism specific information, services, and resources. During this workgroup discussion, the IWGA members identified current experiences and perspectives and explored potential options for using the website to improve responsiveness to all audiences through an audit and redesign considerations.

To strengthen and promote Ohio's initiatives aimed at enhancing understanding and building statewide capacity for timely developmental monitoring and autism screening, the IWGA members invited partners engaged in early identification to share about their work and explore ways the IWGA can support their efforts. The presenters from Nationwide Children's Hospital, The Ohio State University Nisonger Center, Act Early Ohio (University of Cincinnati), and OCALI's Center for the Young Child provided valuable insights into statewide initiatives offering options and resources for screening, diagnosis, and supports for families. The IWGA Webinar: Early Identification was accessible to the public and offered on-demand.

The IWGA and Ohio's Employment First Taskforce (EFTF), both of which were created in statute and include representatives from state agencies, convened jointly in April to celebrate Autism Acceptance Month. Members engaged in discussions to identify priorities and opportunities for collaboration, concentrating on key areas related to information and resources, systems, health care, and services. Several common ideas emerged, including the potential for cross-system collaboration to enhance capacity and alignment, the need for education opportunities for professionals to help families navigate programs and resources, and the importance of fostering connections, engagement, and support for families by providing them with accurate, tailored information.

In order to remain informed about the latest services available to autistic Ohioans and their families, IWGA members engaged with representatives from Ohio PROMISE, an identified IWGA Enabler, to gain insights into this new statewide initiative and its focus on promoting inclusivity in childcare centers and supporting childcare providers in serving children with autism, disabilities, and specific healthcare needs. Presenters from the Department of Children and Youth and the Early Childhood Inclusion Center of Excellence at OCALI highlighted the initiatives within each of the five pillars of Ohio PROMISE, including the Professional Early Childhood Inclusion Credential and the Early Childhood Inclusion Center of Excellence.

Utilizing The Big Table, a day dedicated to community-wide conversations, the IWGA hosted a gathering featuring presentations and guided table discussions with the objective to gain insights into current and emerging initiatives, identify barriers, and explore potential solutions to effectively inform and shape the IWGA recommendations. Invited stakeholders included the IWGA Enablers, family and community organizations, self-determination/ advocacy organizations, and OCALI Advisory Board Members. This opportunity for connection and discussion spotlighted several key themes to support the advancement of the IWGA goals and priorities, including enhancing collaboration across systems, promoting community engagement, representing lived and shared experiences, and improving navigation supports along with timely access to services. The IWGA members will focus on fostering ongoing dialogue and pursuing initiatives and learning opportunities related to these themes.

The IWGA and <u>Ohio's Employment First Taskforce</u> (EFTF), convened jointly again in October for Disability Employment Awareness Month. Agency Directors were invited to present initiatives their agencies are implementing to ensure that autistic Ohioans have access to opportunities for continuous learning, career exploration and growth, and connections to systems and support that align with their strengths, talents, and interests. The IWGA and EFTF members had the opportunity to hear from leaders with the Ohio Department of Developmental Disabilities, Opportunities for Ohioans with Disabilities, Ohio Department of Education and Workforce, Ohio Department of Health, Ohio Department of Jobs and Family Services, Ohio Department of Medicaid, Ohio Department of Mental Health and Addiction Services, Ohio Department of Transportation, and Ohio Department of Children Youth. The presentations were followed by dialogue to explore and evaluate opportunities for further engagement, enhancement, and development of the ideas presented.

"Showed that other stakeholders were focused on the same things we were exploring; we are on to something."

- Gathering Participant





National Conversations and Data

National Data

The Autism and Developmental Disabilities Monitoring (ADDM) Network, a program established by The Centers for Disease Control (CDC), estimates 1 in 36 children has been identified with autism.¹

In 2023 ADDM released a Community Report on Autism providing a snapshot of ASD among 4-year-old and 8-year-old children in multiple communities across the United States in 2020.²

Key findings from the ADDM Network

- Children born in 2016 were 1.6 times as likely as children born in 2012 to be identified as having ASD by 48 months of age.
- COVID-19 disrupted progress in early ASD identification leading to a potential backlog of unidentified cases.
- Among 8-year-old children, boys were nearly 4 times as likely as girls to be identified with ASD.
- 2020 marked the first time the percental of girls identified with ASD to be over 1%.
- Among 8-year-old autistic children with IQ scores available, more than 37.9% also had intellectual disability.

National Conversations

In 2024, the IWGA had the opportunity to participate in national conversations pertinent to the autism community.

IACC

Conversations began with a virtual presentation and dialogue with the leaders from the <u>Interagency</u> <u>Autism Coordinating Committee (IACC)</u>. This discussion provided valuable insights into the federal-level activities, highlighting common goals such as greater acceptance and inclusion, enhancing accessibility of services, developing solutions across entire spectrum and lifespan, and increasing equity while reducing disparities. Furthermore, IACC shared that their 2024 Strategic Plan will focus on co-occurring physical and mental health conditions and the impact on health and well-being of people with autism.

As an emerging theme from recent discussions and an area identified for further analysis, the IWGA will also explore the impact of co-occurring conditions on the health and well-being of autistic Ohioans taking into consideration the following data, among other studies and resources to guide future dialogue.

- 2024 IACC Strategic Plan and Request for Public Comments on Co-Occurring Conditions in Autism. Request for Information resulted in over 1,200 responses, including those with lived experience perspectives.³
- Emerging Research. Report that nearly 78% of children with autism have at least one co-occurring mental health disorder.⁴

- Mental Health Conditions Among Ohio Youth.
 Children with autism are at a higher risk for having a mental health condition.⁵
- Identified Disparities. Contributing factors and efforts to reduce disparities in the identification of co-occurring health conditions, education services, and transition planning for adolescents with autism.⁶

NALC/NALS

The IWGA collaborated with leaders from other states through the National Autism Leadership Collaborative (NALC) and the National Autism Leadership Summit (NALS). Through these efforts, the IWGA members provided a collective response to a state survey aimed at gathering insight on current activities and identifying areas for further learning to contribute to national discussions.

Additionally, NALS facilitated collaboration on autism coordination initiatives with federal and international partners, along with leaders from 33 states, including Ohio. Collective priorities identified and discussed during the NALS breakout sessions encompassed as range of topics, including accessibility to appropriate services, community engagement, employment and workforce development, support for minority populations, early screening and diagnosis, rural population needs and diversity, assistance for general educators, and importance of collaboration and partnership building.

Further opportunities for the exchange of ideas, innovative practices, and coordination of state and federal autism initiatives will continue in 2025.



References

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³U.S. Department of Health and Human Services, Interagency Autism Coordinating Committee (Retrieved Dec 2024) <u>https://iacc.hhs.gov/meetings/iacc-meetings/2024/strategic-plan-update/</u> <u>september23/</u>

⁴Organization for Autism Research, The Intersection of Autism and Mental Health (Lorentz, 2021) (Retrieved Dec 2024) <u>https://researchautism.org/oaracle-newsletter/the-intersection-of-autism-and-mental-health/</u>

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⁶Health Conditions, Education Services, and Transition Planning for Adolescents with Autism, National Library of Medicine, NIH (Hughes, et al. 2024) <u>https://pubmed.ncbi.nlm.nih.gov/38501189/</u>

