



Supporting Ohioans with Autism

ACROSS AGENCIES, ACROSS THE STATE, ACROSS THE LIFESPAN

Annual Report & Recommendations • December 2023



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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

This year marked historic investments in and changes to the systems that support autistic Ohioans and their families. House Bill 33, the state's two-year budget, dedicated \$1.5 billion to the developmental disabilities community – the largest commitment ever.

The state budget includes \$10 million for the Department of Developmental Disabilities to support youth with complex needs and their families. This funding will strengthen partnerships, build capacity, and provide short-term stabilization and long-term residential settings for youth with the most complex needs. These funds will also help: expand Multi-Disciplinary Comprehensive Assessment Teams and family coaching; continue the Keeping Families Together initiative, and increase options for Intermediate Care Facilities that provide intensive services for youth with complex behavioral health needs and disabilities.

House Bill 33 also created the new, cabinet-level Department of Children and Youth (DCY). The department will focus on the efficient and effective delivery of services to Ohio's children and their families. DCY will lead key programs such as Ohio Early Intervention and Family and Children First, and place children at the core of its mission to promote positive lifelong outcomes for all Ohio youth.

In October, we saw the launch of Ohio PROMISE (Promote Resources, Opportunities, and Meaningful Inclusion through Support and Education), a new initiative focused on increasing access to quality child care and support services for children with special needs, including autism. The initiative includes a new credential, provider designation, family scholarship pilot, and The Early Childhood Inclusion Center of Excellence. This Center of Excellence is housed at OCALI.

In addition to these investments and initiatives, we believe the recommendations in this report will lead to meaningful change and better lives for Ohioans with autism and their families. We are proud and humbled to do this work with you.



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)

The IWGA meets monthly and utilizes a collective impact framework to accomplish its work. Members include:

- Ohio Department of Developmental Disabilities (DODD) (Lead Agency)
- OCALI (Convener)
- Ohio Department of Education and Workforce (DEW)
- Ohio Department of Health (ODH)
- Ohio Department of Job and Family Services (ODJFS)
- Ohio Department of Medicaid (ODM)
- Ohio Department of Mental Health and Addiction Services (OhioMHAS)
- Opportunities for Ohioans with Disabilities (OOD)

Foundational to this work is the voice of autistic Ohioans and their families. The IWGA seeks input from people with autism and their families through annual surveys, stakeholder engagement at meetings, and OCALI's advisory board. In 2023, the IWGA added six public members, including autistic Ohioans, family members, educators, and clinicians.

The IWGA has historically issued its recommendations separately from its annual report. Going forward, the recommendations and annual report will be one document.



2023 Autism Data

National

In March of 2023, the Centers for Disease Control released new data on the prevalence of autism spectrum disorder (ASD).ⁱ The Centers for Disease Control now estimates **1 in 36 children** has autism. This number comes from their Autism and Developmental Disabilities Monitoring Network, an active surveillance program that provides estimates of the prevalence of ASD among children aged 8 years.

According to this data set:

- Autism is almost 4x more prevalent in boys than girls.
- The median age of diagnosis is 49 months.
- For the first time ever, prevalence is higher in Black, Asian/Pacific Islander, and Hispanic children than White children.
- Many children with ASD had previously been told they did not have ASD.

“...this is the first [Autism and Developmental Disabilities Monitoring] Network report in which the prevalence of ASD among girls has exceeded 1%. Since 2000, the prevalence of ASD has increased steadily among all groups, but during 2018–2020, the increases were greater for Black and Hispanic children than for White children. These data indicate that ASD is common across all groups of children and **underscore the considerable need for equitable and accessible screening, services, and supports for all children.**”ⁱⁱⁱ

Ohio

The IWGA regularly looks at data specific to autism in Ohio. We use this data to guide our discussions and our efforts.

Some data points to consider:

- **Over half of Medicaid-eligible Ohioans with autism are not connected to Ohio’s County Boards of Developmental Disabilities.** Of the 45,000 Medicaid-eligible Ohioans who have recent claims related to autism, 54% of them (over 24,000 people) are not connected to Ohio’s developmental disability system.
- **The majority of Medicaid-eligible Ohioans with autism are under the age of 16.** Ages range from 2 to 97. One-third are 11 or younger, two-thirds are under 21.
- **Ohio’s local education agencies are serving more students with autism than ever before.** Over a five-year period in Ohio (2015 to 2020), the number of 6- to 21-year-olds eligible for special education services increased 7%. During that same five-year period, the number of students eligible under the category “autism” increased 31% (from 19,173 to 25,181).ⁱⁱⁱ



Annual Report

Moving Toward Our Vision

In 2022, the IWGA invited autistic Ohioans, their families, and community partners to create a vision. Over the course of six community discussion forums, people from across Ohio joined in naming what they want and don't want.

Ohioans with autism and their families told us they want to:

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

The next few pages highlight ways IWGA member agencies have worked together to move Ohio closer to this vision.

Daily Life & Employment

What a person does as part of everyday life — school, employment, volunteering, communication, routines, life skills.



Highlight:

Establishing Families as Partners

Using the research in [It Starts with Families](#), Ohio's Employment First Task Force agencies reviewed their family engagement policies and created [Establishing Families as Partners in Secondary Transition](#) or "Establishing Families." This learning series helps agency personnel understand important topics related to secondary transition, such as the value of family partnerships, diversity in families, biases, meaningful conversations, and universal design for better communication and experiences.

The series is for local professionals like school staff, vocational rehabilitation counselors, and service coordinators from county boards of developmental disabilities, and anyone providing service and support to transition-age youth with disabilities. The hope is that a team of multi-agency professionals serving the same or similar transition-age youth and their families can take this training together.

The Establishing Families learning series has also been included in DEW's State Systemic Improvement Plan for students with disabilities. All participating school districts will convene a cross-agency team and complete the series as a project activity.

To learn more about the Establishing Families as Partners in Secondary Transition professional learning opportunity, contact ItStartsWithFamilies@dodd.ohio.gov.



Community Living

Where and how someone lives – housing and living options, community access, transportation, home adaptations and modifications.



Highlight:

Ohio 811 Program

The Ohio 811 Program allows extremely low-income households comprised of one or more adults with a disability to live in an integrated setting through rental subsidy and access to supportive services. The program is funded by the United States Department of Housing and Urban Development and administered by the Ohio Housing Finance Authority (OHFA).

OHFA partners with the ODM, DODD and OhioMHAS to recruit and train Referral Agents to identify and refer candidates who need housing.

- ODM referral agents include HOME Choice transition coordinators, home and community-based services waiver case managers, MyCare case managers, or Managed Care staff with housing or transition responsibilities.
- DODD referral agents include county boards of developmental disabilities. Many county boards serve as referral agents; however, participation is voluntary.
- OhioMHAS referral agents include county Alcohol Drug and Mental Health (ADAMH) boards. Many ADAMH boards serve as referral agents; however, participation is voluntary.

At the end of State Fiscal Year 2023, 350 units were leased through the 811 Program.



Safety & Security

Staying safe and secure – emergencies, well-being, guardianship options, legal rights, and issues.



Highlight:

Ohio Disability & Health Project

The Ohio Disability and Health Program (ODHP) is a partnership between ODH, The Ohio State University Nisonger Center, the University of Cincinnati University Center for Excellence in Developmental Disabilities, disabilities and health partners, and the Ohio Colleges of Medicine Government Resource Center.

ODHP produced training for first responders and emergency planners:

- Disability Training for First Responders: Serving People with Disabilities
- Disability Training for Emergency Planners: Serving People with Disabilities

The trainings provide emergency planners and first responders with information and best practices that will ensure the safety of people with disabilities during emergency events. This training has been approved for Continuing Education Credit for EMS, fire, law enforcement, and nursing personnel by the Ohio Peace Officer Training Academy and The Ohio State University's Center for EMS.

In addition, ODHP has websites dedicated to addition training and resources for first responders and emergency planners.



Social & Spirituality

Building friendships and relationships, leisure activities, personal networks, and faith communities.



Highlight:

Bringing Fathers Forward

A workgroup of stakeholders throughout Ohio is collaborating to better support, empower, and engage fathers of children with developmental disabilities. The group began by surveying Ohio fathers. **They learned:**

- Father's frequently feel isolated and alone.
- Many fathers feel undervalued and disregarded in their roles as fathers to children with developmental disabilities.
- Fathers feel there isn't accurate and comprehensive information for them.

The workgroup has developed a [resource for fathers](#) and for professionals supporting fathers. To learn more and connect with resources, visit www.dodd.ohio.gov/BFF or email ohiolifecoursenexus@dodd.ohio.gov.



Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness and nutrition.



Highlight:

Improving Outcomes

Adults with disabilities have worse mental health, physical health, and chronic condition outcomes than adults without disabilities. OCALI's Office of Policy and the Ohio Association of Health Plans partnered to offer another series of roundtables for health care professionals, Improving Outcomes 2023. The focus of this year's series was social determinants of health. **Topics included:**

- Mental and behavioral health
- Sexual and reproductive health
- Accessible housing and transportation
- School experiences, outcomes, and resources
- Poverty and food insecurity
- Employment
- Family caregivers

In 2023, *Improving Outcomes* won The National Association of State Directors of Developmental Disabilities Services and Public Consulting Group Cathy Anderson Award for Public-Private Partnership.



Advocacy & Engagement

Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.



Highlight:

Ohio House Bill 33 – State Budget

House Bill 33, the state budget, made the largest investment in the history of Ohio's developmental disabilities community. People with disabilities and their families were active in the process, advocating not only for dollars but also policy changes.

Some of these policy changes and financial investments included:

- Ensuring at least one person with a developmental disability is appointed to each county board of developmental disabilities.
- Funding for adult changing tables in public places and local businesses.
- Increasing rates for many home and community-based services, including Shared Living, remote support, respite, adult day support, transportation, and the behavioral, medical, complex care, and competency add-ons.
- Investing \$3.2 million per fiscal year in dedicated funding for the Technology First initiative.
- Establishing the Accessible Ohio initiative, the first-ever coordinated effort in Ohio to support cities, counties, state agencies, attractions, and venues to be accessible and inclusive.



Recommended Goals & Priorities for 2024

To ensure the IWGA's goals and priorities were informed by autistic Ohioans, their families, and a wide range of stakeholders, the IWGA provided several ways and opportunities for people to give input:

- Survey
- Focus groups
- Public input at IWGA meeting

Statewide Survey

- October 2023
- 200 Responses
- Themes
- Focus areas

Focus Groups

- November 2023
- 40+ Stakeholders
- Environmental scan
- Draft goals & priorities

IWGA Meeting

- December 15, 2023
- Public input on "final" draft
- Revisions if needed

Annual Report & Recommendations

- December 31, 2023
- Annual Report
- Goals & Priorities

Survey

In October 2023, the IWGA launched a statewide survey to get input from across Ohio. We asked people to tell us how much progress Ohio has made toward its vision, what's working well in Ohio, what's difficult to do or get in Ohio, and any ideas they had for goals or priorities.

We heard from almost 200 people across the state. Respondents included people with disabilities, family members, program administrators, educators, service providers, healthcare workers, and more. **They told us:**

- It's **hard to find information**. There's no one place to go.
- There are **long waits** and **long drives** for assessments and services.
- Everything **depends on where you live**.
- Eligibility **doesn't make sense** and systems **don't work together**.
- Quality is **inconsistent**.

- There **aren't enough options** for adults.
- Professionals **don't know autism**.
- It's **hard to find X** (doctor, dentist, therapist).

They also told us two areas Ohio is not achieving its vision are:

- People with autism and their families **consistently and easily get what they need when they need it**.
- People with autism and their families have a **wide range of choices about how they live, work, and are supported**.

Focus Groups

In November 2023, the IWGA invited a cross-section of stakeholders to attend one of four focus groups. The meetings included: autistic adults, family members, advocacy organizations, state agencies, service providers, county boards of developmental disabilities, educators/educational agencies, higher education, health care, researchers, clinicians, and public children's service agencies.

We shared survey themes with each group and asked for help refining draft goals and priorities. **We used the CLEAR framework to establish our goals:**

C Collaborative – Requires stakeholders to work together.

L Limited – Consistent with scope, time, and resources.

E Energizing – Excites and inspires.

A Achievable – Can be broken down into smaller, accomplishable steps.

R Refinable – Can be adjusted and modified if necessary (new information, new circumstances).

Each focus group offered insight and suggested revisions that resulted in better, stronger goals that more closely align with the IWGA's mission and respond to the needs of autistic Ohioans and their families.

Public Input

A draft of the recommended goals and priorities was shared with over 1,000 Ohioans through the IWGA listserv and on social media. People were invited to share public comments at the December 15 IWGA meeting.

Final Recommendations

With gratitude to all who contributed, the IWGA is pleased to offer DODD our recommend goals and priorities for 2024.

Clinical Diagnosis



Goal:

Over the next 12 months, 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.



Priorities:

The IWGA will pay special attention to:

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



Considerations:

While the IWGA does this work, it's important to remember:

1. We mean clinical diagnosis across the **lifespan**, not only for children.
2. We want to make it **easier** for people to be screened and assessed **quickly** and **closer** to home.
3. We want to help people understand the **difference between clinical diagnosis and educational identification** – which one(s) you need, when, why, and how.



Enablers:

These are some statewide projects and partners that support our goal:

- [Act Early Ohio](#)
- [Autism Diagnosis Education Program](#)
- [ID Early for Autism Spectrum Disorder](#)
- Ohio's University Centers of Excellence in Developmental Disabilities: [Ohio State University Nisonger Center](#) and [University of Cincinnati](#)
- [Tele-ASD-PEDS](#)



Information & Resources



Goal:

Over the next 12 months, the IWGA will make it easier to find accurate, reliable autism-specific information and resources.



Priorities:

The IWGA will pay special attention to:

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



Considerations:

While the IWGA does this work, it's important to remember:

1. There are **people who don't use or have access to technology** – there must be more than a website.
2. We need **plain language** and **easy read** information and resources.
3. We need information and resources for **different audiences** – people with autism, families, educators, service providers, clinicians, etc.



Enablers:

These are some statewide projects and partners that support our goal:

- [Family Resource Network of Ohio](#)
- [Interagency Work Group on Autism Website](#)
- [Ohio Coalition for the Education of Children with Disabilities](#)
- [Ohio Family Networks](#)

“Parents don’t know what to ask for because we don’t know what is possible! Please be more transparent as to support and services.”

– Survey Respondent



Health Care



Goal:

Over the next 12 months, the IWGA will partner with stakeholders to build healthcare's capacity to serve autistic Ohioans and improve health outcomes.



Priorities:

The IWGA will pay special attention to:

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



Considerations:

While the IWGA does this work, it's important to remember:

1. There's a difference between **availability** (number, type, location) and capacity (skills, knowledge, ability) – we need both.
2. We need solutions for the **current** workforce and the **future** workforce.
3. To explore **innovate models** of building expertise, sharing information, collaboration, and consultation.



Enablers:

These are some statewide projects and partners that support our goal:

- Improving Outcomes
- National Center for Disability, Equity, and Intersectionality (University of Cincinnati)
- Nisonger Center Dental Clinic
- Ohio Disability & Health Project
- Ohio Telepsychiatry Project

“Finding mental health care is hard. Finding good mental health care is almost impossible.”

– Survey Respondent



Systems



Goal:

Over the next 12 months, 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.



Priorities:

The IWGA will pay special attention to:

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



Considerations:

While the IWGA does this work, it's important to remember:

1. Families are **exhausted**. We need to make it easier for them to find and access what they need.
2. There is great benefit to **human connection**, having a single point of contact, and someone to help you navigate.
3. We need to **screen people in**, not out. What's the minimum we need for eligibility, not the maximum.



Enablers:

These are some statewide projects and partners that support our goal:

- Family and Children First Councils
- Multi Agency Planning Teams
- Multi System Navigation Center
- Ohio Children's Initiative Child and Adolescent Needs and Strengths (CANS) tool
- Ohio Systems of Care

“State agencies are competing with each other at times and playing hot potato at other times...systems are intentionally not working together. Figure out how to blend funding so that everyone gets more bang for their buck.”

– Survey Respondent



Services



Goal:

Over the next 12 months, 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.



Priorities:

The IWGA will pay special attention to:

1. **Childcare** and **respite**.
2. **Educational** services.
3. **Intensive** support services.
4. Services for **adults**.



Considerations:

While the IWGA does this work, it's important to remember:

1. We need a shared understanding or **definition of quality**.
2. We need to think about **social connectedness**, friendships, isolation and **physical needs** like housing and transportation.
3. No one should have to be in crisis in order to get their needs met – we need to be **proactive**.



Enablers:

These are some statewide projects and partners that support our goal:

- [OCALI Autism Center](#)
- OCALI Center for the Young Child [Early Childhood Inclusion Center of Excellence](#) & [OhioPROMISE](#)
- [OhioRISE](#)
- [Ohio's MI/DD Coordinating Center of Excellence](#)
- [Supporting Youth with Intensive and Complex Needs](#)



References

ⁱ <https://www.cdc.gov/ncbddd/autism/new-data.html>

ⁱⁱ Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-2):1–14. DOI: <http://dx.doi.org/10.15585/mmwr.ss7202a1>

ⁱⁱⁱ IDEA Section 618 Data Products: Static Tables: <https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>

