

Quality Lives

Supporting Ohioans with Autism for
Meaningful and Successful Lives



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"I feel blessed in life that even though I am challenged by autism I can still bring forth change. I wrote in my book, 'Go to those with autism that you love and embrace them in a new way; one that shows you are not there to change them into the humans you desire them to be, but the humans they were meant to be. Assist them in the ways to allow them a chance to be successful in their life dreams and desires.' I do feel Ohio is working hard to bring this quote to a reality. We are blessed to have so much unity and so many hardworking individuals that strive to make my life and many others living with autism a valued life, a safe life, a life worth living."

Sondra Williams

Self-Advocate
OCALI Advisory Board

"The final recommendations that are brought forward after public input will assist in developing an interagency plan that streamlines support and improves services for individuals with autism across Ohio. It is imperative that those recommendations truly reflect the needs and hopes of the public, a viewpoint that I know Governor Kasich shares."

John Martin

Director
Ohio Department of Developmental Disabilities

"During the past decade in Ohio, we have made significant progress in providing meaningful services to children and adults with autism. But we can, and must, do more. We believe this set of recommendations will be a valuable resource and guide to policymakers and others who will make decisions regarding our most vulnerable citizens."

Jon Peterson

Revisioning Chair
OCALI Advisory Board



In 2001-2002 there were

3,052 children identified with autism in Ohio schools

That number rose to **15,449** in 2010-2011

Understanding Autism

Autism is a complex neurological developmental disability that can cause significant social, communication, behavior, and sensory challenges. Autism, in all its forms, is a whole-person and life long disability – it impacts every aspect of the individual from birth to death. Autism affects each individual differently and in varying degrees and, therefore, is referred to as autism spectrum disorder (ASD).

We know that early intervention can make a significant difference in the lives of children with ASD. This makes early identification crucial – the sooner ASD is identified and early intervention programs begin, the greater the potential for life success.

How common is autism?

According to the Centers for Disease Control and Prevention (CDC), autism affects 1 in every 88 children in the United States. This represents a 23% increase since CDC's last report in 2009. It is the fastest growing developmental disability in the United States and is more common in children than

Down syndrome, cancer, diabetes, and AIDS combined. Autism is currently diagnosed five times more often in boys than girls, with 1 in 54 boys being identified.

What research is being done today?

Researchers are identifying many genes that are related to autism, but genes alone can not account for the rise in prevalence, so scientists are also investigating other areas, such as environmental or immunological triggers.

It is likely that we will never identify a single cause of autism, so it is important to understand what can support individuals as contributing members of their community. Through continued research efforts, we are learning more about effective strategies, interventions, and lifetime supports for individuals with ASD.

“I am an exhausted mom of a child with autism. I feel like I am alone and fighting to get services for my son. It shouldn't be this hard.” Parent of a 12-year-old with autism



“We have to work together. We’re not going to let the silos and the turf exist because we didn’t make an effort to knock it all down and deliver better services to people in need.” Governor John Kasich

Responding to Autism Across Systems and Across the Lifespan

Well-positioned to create new Ohio blueprint

Ohio Heard the Call

Ohio’s rich and long-standing history of addressing autism spectrum disorders has been driven by the strong network of families and advocates. This, coupled with a collaborative spirit, has brought together committed groups of parents, individuals, legislators, state leaders, and service providers to bring autism to the forefront of state policy discussions. This was clearly demonstrated with the passionate work of the Ohio Autism Taskforce (OAT).

In 2003, Ohio lawmakers created the Ohio Autism Taskforce through HB 95. Made up of stakeholders from across the state, the task force was charged to generate a report and recommendations for

improving services, supports, and outcomes for individuals with ASD and their families. This legislated, time-limited task force laid the foundation for improving Ohio’s response to autism through a set of 43 recommendations for the state. Many of these recommendations came to life and launched new assets and resources for Ohio.

Efforts of autism advocacy organizations have continued to push for improvements in supports and services, and have - and will continue to be - an important part of change in Ohio.

Ohio is Raising the Bar

Ever-evolving research and new information about autism, paired with a growing prevalence rate, presents new challenges that call for Ohio to intensify its efforts. Thus, a process for revising the OAT recommendations has been a logical and necessary step to meet these challenges.

Ohio enters this revising process with a well-built foundation and a renewed commitment to empower and support Ohioans with ASD and their families. Supported through statute, Ohio’s Interagency Work Group on Autism (IWGA), along with the Ohio Center for Autism and Low Incidence (OCALI), its Advisory Board, and a powerful force of autism advocacy

networks form a strong infrastructure to support innovative change. Ohio’s infrastructure is built on multi-agency collaboration, partnerships that unite both the private and public sector, and a central shared resource through OCALI to move policy to action.

New recommendations will require multi-system solutions and an attentive focus on issues that cross the lifespan.



Ohio's Autism Infrastructure

Working together across agencies, across the state, across the lifespan

Interagency Work Group on Autism (IWGA)

(ORC 5123.0419)

- Governor's Office
- Ohio Department of Developmental Disabilities (lead)
- Ohio Office of Budget and Management
- Ohio Department of Education
- Ohio Department of Health
- Ohio Department of Mental Health
- Ohio Department of Job & Family Services
- Ohio Rehabilitation Services Commission
- OCALI

Accomplishes: A formal process for various state systems to work together to inform policy development and implementation

OCALI Advisory Board

(ORC 3323.33)

- Persons with autism and low incidence disabilities
- Parents and family members
- Educators and other professionals
- Medical professionals
- Service providers
- Higher education instructors
- Representatives of state agencies

Accomplishes: A formal process for parents, individuals, advocacy groups, and other stakeholders to contribute to the state's policy development and implementation

OCALI: Ohio's Shared Resource for Autism

(ORC 3323.31)

- Informing public policy
- Providing consultation and promoting collaboration
- Researching, developing, and deploying evidence-based practices

Accomplishes: The central source for high quality autism information, professional development, and technical assistance for Ohio

A Well Thought Out Process

Hundreds influence autism recommendations

April 2011

IWGA requests that OCALI Advisory Board revise the OAT recommendations

August 2011

OCALI Advisory Board reviews and revises previous recommendations

September 2011

OCALI analyzes autism recommendations from 36 states to inform the revisioning of Ohio's recommendations

Nov/Dec 2011

Statewide focus groups provide feedback on recommendations
OCALI Advisory Board reviews feedback and drafts new recommendations

March 2012

OCALI Advisory Board continues to refine recommendations and drafts starting points

April/May 2012

Public comment opens on draft recommendations through an online survey and five public forums - overwhelming response

June 2012

OCALI Advisory Board integrates public comment and finalizes recommendations with starting points

August 2012

OCALI Advisory Board formally presents recommendations to IWGA and state leadership including the Governor's Office and Cabinet Directors

"I would love to have someone help me. I always feel so guilty all the time if I had only done this or done that. I am in torment everyday... because I can't find the help I need for my son."

Parent of a 17-year-old with autism

"Treating the whole person is critical to reaching full success."

Service Provider

"As a nation and a state, we are severely lacking in services for adults with disabilities. We can't just leave our children locked away for the rest of their lives once they finish school."

Parent of a 14-year-old with autism



RECOMMENDATIONS

Summary of the Recommendations

The Ohio Interagency Work Group on Autism (IWGA) requested that the OCALI Advisory Board lead the effort to review the previous recommendations and create a blueprint for tomorrow. The Ohio Autism Recommendations is a dynamic document that incorporates the needs, opinions, and feelings of Ohioans who are impacted by autism as family members, service providers, self-advocates, and neighbors. It is the culmination of over one year of work that reflects the growing body of knowledge about ASD, the evolving research on best practices, and a belief system that autism impacts the whole person. The 15 recommendations within seven categories provide an appreciation of the diversity among communities and disparity of services across Ohio.

Ohio is at the forefront of recognizing that meaningful change will only occur through interagency communication, collaboration and shared contribution. The tactical plan that will emerge from the Ohio Autism Recommendations will transform the lives of those impacted by autism today. Reviewed annually, it will chart a course for Ohioans to systematically and comprehensively improve its response to autism and create opportunities for individuals with ASD to have meaningful and successful lives in their community.

Get A Good Start

Identification and diagnosis can happen at any age and should occur at the first suspected signs.

- 1. Intensify** and expand public awareness of the early signs of ASD and educate the public on the benefits of early identification
- 2. Improve** educational identification and medical diagnosis of ASD at the earliest possible age and across the lifespan
- 3. Build** the competence and confidence of families and professionals to provide care during the process of obtaining education and diagnostic services that consider the whole person (medical, developmental, educational, social-emotional, and vocational) and for the entire lifespan

Obtain Needed Services

Individuals with ASD should have access to high-quality services.

- 4. Increase** access to high-quality services throughout the lifespan (i.e., medical, education, related services, transportation, recreational) across Ohio with an emphasis on outreach to populations and communities that are currently underserved such as urban, rural, culturally diverse, and minority populations
- 5. Create** a process to ensure that plans for service are dynamic, flexible, person-centered, and transfer continuity of programming across settings and/or systems throughout the lifespan

Develop the Skills to Succeed

Life skills develop and change as an individual grows. Skill development is a continuous need throughout an individual's life.

- 6. Develop** a standard of practice that recognizes the importance of individuals with ASD developing skills in social acquisition and competence, self-regulation, and communication to succeed in each stage of life (i.e., early childhood, school, employment)



91.6% of children ^{with ASD} have four or more functional difficulties

National Survey of Children with Special Health Care Needs

Strengthen Support Along the Way

Family is the most important, consistent and instrumental influence in a child's life. A strong base of support is important.

7. Empower individuals with ASD and their families to advocate for the services and supports they need as soon as autism is suspected, as well as throughout the individual's lifespan

8. Create options for crisis intervention that ensure the health, safety, and stabilization of individuals with ASD and their families across the lifespan

9. Promote health insurance coverage for individuals with ASD

Help Others Understand

It is imperative that professionals and community members recognize and understand the characteristics of ASD in order to serve, support, and empower individuals and their families.

10. Increase the number and type of professionals and community members who are prepared to provide high-quality, caring service, and promote community inclusion for individuals with ASD

Live Well

Knowing how to network and navigate available community resources is fundamental to developing and sustaining effective supports for a successful future.

11. Ensure that high-quality choices are available that match the skills, interests, abilities, passions, and supports needed by individuals with ASD to have a happy, productive adult life and be included in the community

12. Empower individuals across the spectrum to advocate for their rights and to take responsibility for their life choices as they become adults

Sustain the Future

Thoughtful planning and coordination is necessary to uphold broad, but connected, service systems that are responsive to individuals with ASD and their families.

13. Strengthen the quality and accountability of programs and services for individuals with ASD and their families

14. Formalize methods for state-level agency coordinated data sharing and funding

15. Promote shared service models and public-private partnerships to increase cost-effectiveness and efficiency

Get a Good Start

Identification and diagnosis can happen at any age and should occur at the first suspected signs.

Why this category is important:

As knowledge about early warning signs of autism continues to increase, the potential for recognizing and diagnosing ASD during the first few years of life becomes more of a reality. Research continues to establish and demonstrate that the earlier intervention begins, the greater the benefit and outcomes for the individual (Boyd, Odom, Humphreys, & Sam, 2010; Wallace & Rogers, 2010).

“I knew my son was different. I went from doctor to doctor, place to place. It took over a year to find out my son has autism.”

Parent of a 8-year-old with autism



“We know the typical ages of onset, when signs are noted, and diagnosis can take place. Early intervention can begin and make some real differences. We must meet the call.” *School Administrator*

1

Intensify and expand public awareness of the early signs of ASD and educate the public on the benefits of early identification

Starting Points:

- Coordinate and utilize available information from national and state sources to increase opportunities for public awareness through multiple media outlets
- Create and widely distribute targeted informational packets

2

Improve educational identification and medical diagnosis of ASD at the earliest possible age and across the lifespan

Starting Points:

- Increase statewide capacity, access to and number of highly-qualified professionals for early identification and/or diagnosis
- Embed best practice methods into preprofessional preparation and continuing education opportunities
- Investigate reimbursement options for identification/ diagnosis

3

Build the competence and confidence of families and professionals to provide care during the process of obtaining education and diagnostic services that consider the whole person (medical, developmental, educational, social-emotional, and vocational) and for the entire lifespan

Starting Points:

- Identify, create and disseminate multi-media materials that recognize the importance of a whole person approach to serving individuals with ASD (identifying common co-occurring issues for individuals with ASD as related to medical, developmental, educational, social-emotional, and vocational)
- Increase professional care coordination, the use of an integrated team approach, and the sharing of information across all those involved in care

Obtain Needed Services

Individuals with ASD should have access to high-quality services.

Why this category is important:

The location of residence, racial or ethnic background, socioeconomic level, or level of parental education should not be limiting factors to obtaining services. By increasing the number of service providers, awareness of those who already exist, and the technology methods that could be utilized, access to services increases. Services should be driven by comprehensive, person-centered plans and developed by a team. The plan should ensure services that are individualized, defined by research-based strategies, and well embedded in an individual's routine (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Myles, Grossman, Aspy, Henry, & Coffin, 2007).

"We have to drive 200 miles to get to the nearest autism services. Sad, and often leads to an inability to get services."

Parent of a 3-year-old with autism



“Services might be out there, but it’s difficult for them to navigate the system and/or be able to afford the services once they are able to find them.” **Parent of a 13-year-old with autism**

4

Increase access to high-quality services throughout the lifespan (i.e., medical, education, related services, transportation, recreational) across Ohio with an emphasis on outreach to populations and communities that are currently underserved such as urban, rural, culturally diverse, and minority populations

Starting Points:

- Partner with public and private entities to conduct a comprehensive, multi-system, statewide asset mapping of available services and supports for individuals with ASD at the local level (with consideration of level of quality and ease of accessibility)
- Conduct a study to determine critical points across the lifespan and the corresponding information that individuals with ASD and their families need to navigate the service system
- Conduct a multi-agency review of eligibility criteria to determine how individuals with ASD can best get the services they need
- Investigate policy solutions to the disparity of inequitable access and available services across the state
- Build multi-agency investment in OCALI’s centralized service and supports database to make it more comprehensive and easy to use

5

Create a process to ensure that plans for service are dynamic, flexible, person-centered, and transfer continuity of programming across settings and/or systems throughout the lifespan

Starting Points:

- Build capacity across agencies in the use of a comprehensive planning method for individual program planning
- Provide training about how to create and implement comprehensive plans, and how to seamlessly transfer them to various settings across service providers/agencies

Develop the Skills to Succeed

Life skills develop and change as an individual grows. Skill development is a continuous need throughout an individual's life.

Why this category is important:

Different skills are needed from birth through adulthood. Social competence, self-regulation, and communication are three areas that make individuals with ASD unique. Skill development, education, and supports in these areas can positively impact all aspects of an individual's life outcomes. This skill development is of the same critical importance at any point across the lifespan (Kuhlthau, Orlich, Hall, Sikora, Kovacs, Delahaye, & Clemons, 2010; Ma, 2009; Marriage, Wolverton, & Marriage, 2009).

"[Our son] was a high school student before anyone addressed those skills. This time lost affected his employability, his functioning independently, and social communication. He is still living at home and not working."

Parent of a 25-year-old with autism



“Curriculum in social competence, self-regulation, communication, and life skills is as important if not more important than good grades. We need to set up our students for life success!” **Intervention Specialist**

6

Develop a standard of practice that recognizes the importance of individuals with ASD developing skills in social acquisition and competence, self-regulation, and communication to succeed in each stage of life (i.e., early childhood, school, employment)

Starting Points:

- Review research, learning guidelines, and existing programs to determine core academic, social, vocational/employment, and daily living/life skills that are needed at targeted points across the lifespan
- Establish an accompanying training metric to measure training implementation and use
- Investigate, develop and implement guidelines for universal screening in social competence, self-regulation, and communication for individuals with ASD
- Create accompanying documents to train families and professionals on how to use the screening tool, why it is important, how to interpret the results, and how to teach and maintain skills
- Develop and implement a decision framework for social competence, self-regulation, and communication for individuals with ASD that addresses the identified targeted points across the lifespan paired with the skills needed to succeed
- Create accompanying documents to train families and professionals on how to implement a decision framework, incorporate it into academic/job skills, incorporate peer models, and take data/measurement to demonstrate progress

Strengthen Support Along the Way

Family is the most important, consistent, and instrumental influence in a child's life. A strong base of support is important.

Why this category is important:

Parental understanding of and connection to resources and supports makes a significant difference in the success of the individual with ASD and the overall stability of the family. If a crisis occurs that challenges the family's stability and base of support, options must be available. Effective supports focus on the relationship among family, community, and school, and respect a family's needs, uniqueness, safety, cultural values, and financial status (Benson & Kersh, 2011; Mohammadi, 2011; Schultz, Schmidt, & Stichter, 2011; Siegel, Doyle, Chemelski, Payne, Ellsworth, et al., 2011).

"It is critical that families have respite to recharge their own batteries, to reacquaint themselves with each other, and to have objective space from which to view their child and his/her future."

Service Provider



“Parents are in desperate need to be able to link to services and resources.” **Intervention Specialist**

7

Empower individuals with ASD and their families to advocate for the services and supports they need as soon as autism is suspected, as well as throughout the individual’s lifespan

Starting Points:

- Establish a statewide 24-hour 1.800 number to link families to local resources including other families
- Link families to the OCALI services and supports database
- Create a centralized location on the OCALI website to gather support and advocacy network information for individuals with ASD and their families
- Increase accessibility to support and advocacy networks by distributing information throughout the community about meeting times and location
- Establish a coordinated network of advocates to guide families and individuals with ASD in their efforts

8

Create options for crisis intervention that ensure the health, safety, and stabilization of individuals with ASD and their families across the lifespan

Starting Points:

- Conduct a statewide mapping of programs that serve individuals with ASD in crisis for both pre-planned or emergency situations
- Identify best-practice crisis intervention/stabilization models and their potential for being implemented in Ohio for individuals with varying needs across the spectrum
- Provide training in crisis intervention/crisis management to parents, school personnel, first responders, law enforcement officials, etc.
- Create crisis intervention teams for responding in emergency situations that include diverse well-trained professionals
- Increase respite and mentoring options for families that include hourly options versus only full 24-hour care
- Write a policy brief with recommendations for removing barriers to accessing and providing crisis intervention services, creating opportunities across systems for developing and providing these services, and addressing the limited access to existing options

9

Promote health insurance coverage for individuals with ASD

Starting Points:

- Create a mandate to require insurance coverage for services deemed medically necessary throughout the lifespan
- Advocate for those organizations/companies not under mandate to also provide insurance coverage for services deemed medically necessary throughout the lifespan
- Track national trends in insurance legislation (i.e., by state, military)
- Analyze the experience of other states as a result of passing legislation

Help Others Understand

It is imperative that professionals and community members recognize and understand the characteristics of ASD in order to serve, support, and empower individuals and their families.

Why this category is important:

Throughout a lifetime, a person with ASD encounters professionals and community members across a variety of settings. This includes teachers, related-service providers, healthcare professionals, first-responders, boy/girl scout leaders, clergy, coaches, and others. The better these people understand the characteristics of ASD and how best to interact, the better equipped they are to do their job of teaching, treating, supporting, caring for, welcoming and including individuals with ASD (Cheely, Carpenter, Letourneau, Nicholas, Charles, & King, 2011; Leblanc, Richardson, & Burns, 2012; Morse, 2010).

“My son has had the same job for 12 years and everyone at work loves him. He needed a lot of help for awhile, but now he is doing just fine. But he couldn’t have done it without help.”

Parent of a 32-year-old with autism



“We need to help community members recognize that individuals with ASD may need to do some things differently, but that shouldn’t eliminate them from participating.” **Service Provider**

10

Increase the number and type of professionals and community members who are prepared to provide high-quality, caring service, and promote community inclusion for individuals with ASD

Starting Points:

- Expand and customize information to build learning opportunities for peers, professionals and community members
- Investigate existing incentive programs/models that could be replicated in Ohio to attract students and retain professionals to serve individuals with ASD (i.e., loan forgiveness, tax credits, tax deduction)
- Educate employers on the characteristics, strengths, skills, and needs of individuals with ASD to increase better employment options and successful employment outcomes
- Investigate existing incentive programs/models that could be replicated in Ohio to encourage employers to hire individuals with ASD

Live Well

Knowing how to network and navigate available community resources is fundamental to developing and sustaining effective supports for a successful future.

Why this category is important:

ASD is a lifelong condition. The majority of a person's life is spent in adulthood. Challenges for individuals with ASD do not end with formal schooling. For most, a fully developed support system should continue throughout the individual's life. Opportunities for skill development, advocacy, recreation, and needed supports must be made available to enrich their lives so they become independent, happy, contributing, productive adults in their community (McDonough & Revell, 2010; Murphy, Beecham, Craig, & Ecker, 2010; Shattuck, Seltzer, Greenberg, Orsmond, Bolt, et al., 2007).

"Services that are not affordable are not accessible services."

Parent of a 10-year-old with autism

"Our family has paid almost \$100,000 out of pocket for our son for his therapies and he is only 15 years old. There are no other options... Something has to change!!"

Parent of a 15-year-old with autism



“Even the most sophisticated of parents can easily feel overwhelmed when trying to find resources ‘out there.’ Having a link, someone who understands autism, can make all the difference.” **Parent of a 12-year-old with autism**

11

Ensure that high-quality choices are available that match the skills, interests, abilities, passions, and supports needed by individuals with ASD to have a happy, productive adult life and be included in the community

Starting Points:

- Conduct a statewide analysis to identify how, where, and through whom individuals with ASD are obtaining services and supports after high school, the quality of services being received and how they are being paid for (i.e., vocational, adult day care, residential, supported living, recreation and leisure, transportation, postsecondary education, employment, healthcare)
- Implement age-appropriate transition plans and begin the transition planning process of giving information and helping individuals understand their options much earlier than age 14
- Conduct a survey of adults with ASD to determine what services they would choose if the services could be available (housing, post-secondary options, jobs, recreation, etc.)

12

Empower individuals across the spectrum to advocate for their rights and to take responsibility for their life choices as they become adults

Starting Points:

- Promote opportunities for training on self-advocacy (i.e., life skills, financial, personal, and sexual safety, security and awareness), including how and where to go for help
- Create a central clearinghouse of information about adult advocacy networks throughout Ohio
- Link adult individuals with ASD to advocacy networks for increased community, opportunities and support
- Teach individuals with ASD how to navigate the system in order to obtain maximum financial help and still maintain their services

Sustain the Future

Thoughtful planning and coordination is necessary to uphold broad, but connected, service systems that are responsive to individuals with ASD and their families.

Why this category is important:

No one agency can provide all of the services needed by an individual with ASD throughout his lifespan. A foundation of interagency collaboration exists and must continue to be strengthened as a basis of support, decision-making, change, innovation, and improvement. Interagency collaboration improves the infrastructure, builds capacity of service delivery, and streamlines access for individuals with ASD and their families (Jensen & Spannagel, 2011; Ganz, 2007).

“My son isn’t capable of advocating for his rights - he doesn’t even know what his rights are. I’m his advocate and won’t live forever, so he’ll need someone to take responsibility for him. We need those networks now.”

Parent of a 4-year-old with autism



“It seems like each year we start over. When my daughter moves to a new grade or gets new services it’s like starting from zero.”

Parent of a 14-year-old with autism

13

Strengthen quality and accountability of programs and services for individuals with ASD and their families

Starting Points:

- Research, develop and implement quality indicators to inform decision making, challenge thinking, evaluate program success, and promote continuous improvement across all state department programs
- Provide policy makers with information that is based on current research, data, and national trends to inform decision-making and ensure high-quality program development

14

Formalize methods for state-level agency coordinated data sharing and funding

Starting Points:

- Increase compatibility of shared data by collectively establishing a common definition of ASD across agencies
- Build interagency investment to meet statutory requirements designating OCALI as the lifespan clearinghouse for ASD as established by the Interagency Work Group on Autism
- Create interagency agreements for coordinated funding of programs and initiatives related to ASD

15

Promote shared service models and public-private partnerships to increase cost-effectiveness and efficiency

Starting Points:

- Investigate shared service models that demonstrate quality, cost-efficiency, consistency, accountability, and sustainability
- Continue to use public-private partnerships as a model on state, regional, and local levels

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Ohio Autism Recommendations

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