

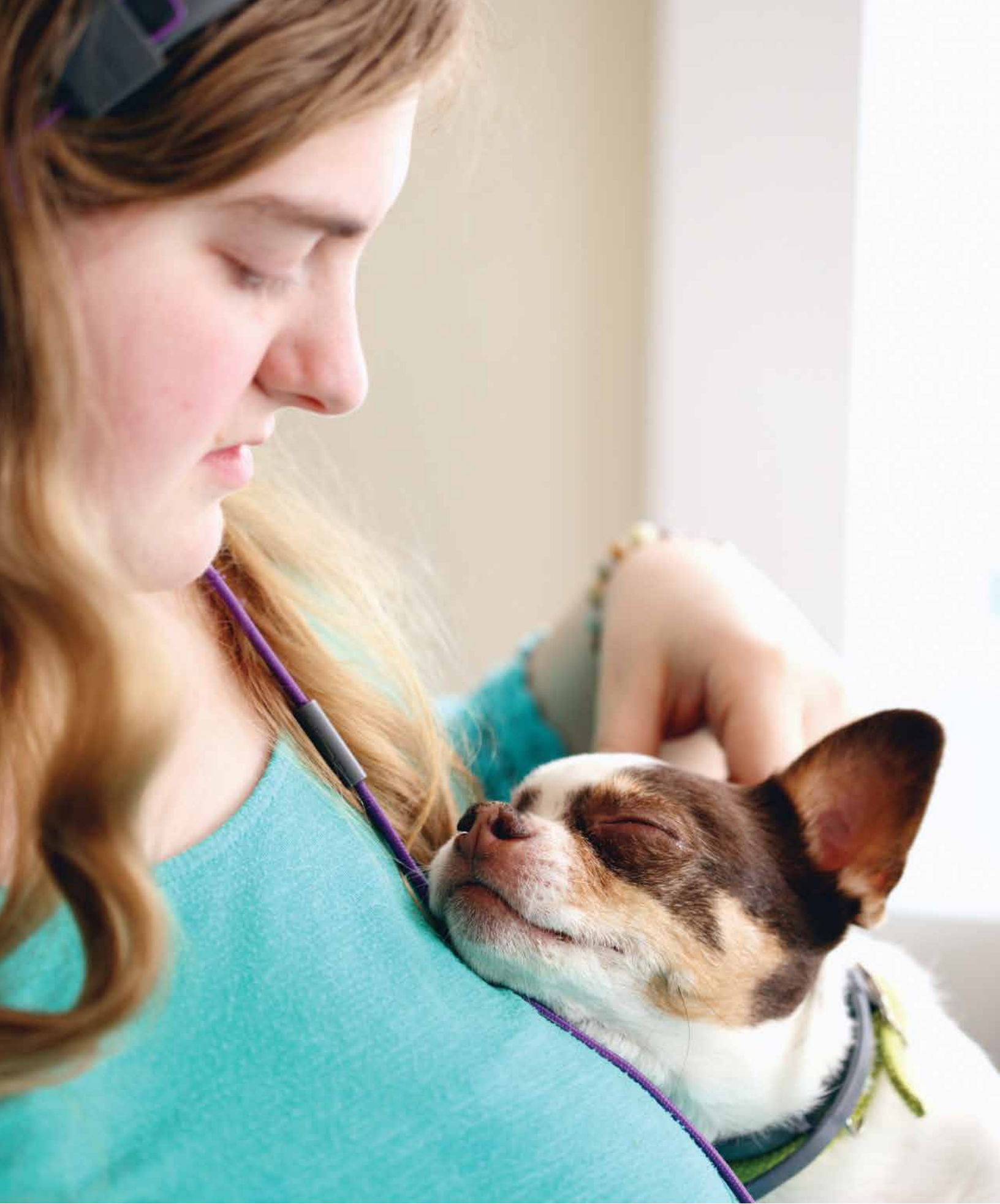
# 2022 PURSUING QUALITY LIVES

Supporting Ohioans with Autism Across Agencies, Across the State, Across the Lifespan



Ohio

Interagency Work  
Group on Autism



# TABLE OF CONTENTS

Why Autism?	3
Ohio's Vision	6
Daily Life & Employment	8
Community Living	10
Safety & Security	12
Social & Spirituality	14
Healthy Living	16
Advocacy & Engagement	18
Endnotes	20



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



# WHY AUTISM?

## Why Autism?

According to the latest data from the [Centers for Disease Control and Prevention \(CDC\)](#), 1 in 6 children have a developmental disability. One in 44 children have autism. Autism occurs in all racial, ethnic, and socioeconomic groups, and is four times more common in boys than girls.

Ohio is home to approximately 1,000,000 children under the age of 9. Based on the CDC prevalence data, this means approximately 170,000 Ohio children have a developmental disability, including 23,000 with autism.<sup>1</sup>

Researchers estimate that by 2025, direct and indirect costs of caring for children and adults with autism spectrum disorder (ASD) in the United States will exceed \$460 billion – more than the cost of stroke and hypertension combined, and likely to exceed the costs of diabetes and attention deficit hyperactivity disorder (ADHD).<sup>i</sup>

Despite these levels of spending, the life experiences of people with autism and their families include:



Almost 1/3 of parents of children with ASD have had to **reduce their work hours** to care for their child – compared to 12% of parents of children with special health care needs (SHCN) and 2% of parents of children with no SHCN.<sup>ii</sup>



Nearly one in three young adults with autism has had **no community participation** – no volunteer or community service, no lessons or classes, no other community activities outside of school.<sup>vi</sup>



Mothers of children with ASD are **less likely to work outside the home**. When they do, they work fewer hours and earn 56% less than mothers of children with no health limitations and 35% less than mothers of children with other special health care needs.<sup>iii</sup>



Over half of young adults with autism are **unemployed and unenrolled in higher education** in the two years after high school – this is lower than any other disability category. By the age of 25, more than 50% of individuals with ASD have never obtained paid employment.<sup>vii</sup>



Beginning in childhood, students with ASD are **bullied by peers** at a rate 3-4 times that of non-disabled peers. In fact, 1 out of 2 students with autism are victims of bullying.<sup>iv</sup>



Autistic people are more likely to **attempt death by suicide** – and up to seven times more likely to die by suicide – compared to those who are not autistic. This risk of death by suicide is even greater among autistic people without intellectual disabilities. The greatest risk is among autistic women, who are 13 times more likely to die by suicide than women who are not autistic.<sup>viii</sup>



Young adults with autism have the **lowest rates of independent living** – the majority of those who live independently are white (27%) compared to black and Hispanic young adults (0%).<sup>v</sup>

Ohio's Interagency Work Group on Autism (IWGA) exists to coordinate, collaborate, and ensure Ohio is working together to improve these outcomes.

<sup>1</sup> Based on birth rates and prevalence.

## Find help:

**Crisis Text Line**, text the keyword “4hope” to 741 741 to be connected to a trained Crisis Counselor within 5 minutes.

## 988 Suicide & Crisis Lifeline

Call or text 988 or chat 988lifeline.org, which provides 24/7, free and confidential support to people in suicidal crisis or emotional distress

## Mental Health Treatment Locator

## IWGA Membership

- Ohio Department of Developmental Disabilities (DODD) - Lead Agency
- OCALI - Convener
- Ohio Department of Education (ODE)
- 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 (OMHAS)
- Opportunities for Ohioans with Disabilities (OOD)

## Updates for 2022: Charting the LifeCourse

Quality Lives and PQL were organized by guiding principle. These guiding principles included:

- **Get a good start.** Identification and diagnosis can happen at any age and should occur at the first suspected signs.
- **Obtain needed services.** Individuals with ASD should have access to high-quality services.
- **Develop skills to succeed.** Life skills develop and change as an individual grows. Skill development is a continuous need throughout an individual's life.

- **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.
- **Help others understand.** It is imperative that professionals and community members recognize and understand the characteristics of ASD to serve, support, and empower individuals and their families.
- **Live well.** Knowing how to network and navigate available community resources is fundamental to developing and sustaining effective supports for a successful future.
- **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.

While the guiding principles remain the same, Pursuing Quality Lives 2022 (PQL22) has been updated and organized by the life domains found in Charting the LifeCourse Framework.

The LifeCourse Framework is based on the core belief all people have the right to live, love, work, play, and pursue their life aspirations. The framework helps people and families of all abilities, and at any age or stage of life by supporting them to:

- develop a vision for a good life,
- think about what they need to know and do to achieve their vision,
- identify how to find or develop supports as they work toward their vision, and
- discover what it takes to live the lives they want to live.

This change was made to further align the work of the IWGA with Ohio's other efforts to support people with disabilities and families. The Ohio Department of Developmental disabilities has invested in LifeCourse Ambassadors throughout the state who introduce this framework to people with disabilities, families, schools, providers of service, community businesses, and county boards of developmental disabilities.

## Community Discussion Forums

Using the LifeCourse Framework as a foundation, the IWGA hosted a series of virtual community forums throughout state fiscal year 2022. Each forum began with the question, “What is your vision for Ohioans with autism?” Attendees discussed what would make the vision possible along with Ohio’s strengths and challenges.

The forums were attended by people from across that state: autistic Ohioans, their families, and community partners (educators, service providers, advocacy organizations, community members).

A survey was also developed for people who could not attend the virtual forums. Feedback from these forums and surveys is reflected throughout PQL22.

In addition to the information gathered through the discussion forums and surveys, PQL22 reflects input from and alignment with:

- National and state data
- IWGA member agencies strategic plans and priorities
- OCALI Center Directors
- OCALI Advisory Board



# OHIO'S VISION

Created by Autistic Ohioans, Families, and Community Partners



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. Below are themes that emerged over the six forums. A specific vision for each LifeCourse domain can be found on the following pages.

## Vision for What I Want

To be full, welcome members of our classrooms, communities, places of employment, houses of worship.

To be leaders and decision-makers.

To have a variety of safe, healthy relationships.

To be valued and respected and have our roles and contributions recognized.

To have a wide range of choices about where and how we live, work, and are supported.

To consistently and easily get what we need when we need it.

To have thoughtful conversations about and planning for our future throughout our lives, starting early

## What I Don't Want

To only, ever, always be with other people who have disabilities or are paid to be with us.

To have "cookie cutter" or "canned" options.

To have our voices or choices ignored and have other people make decisions for us.

To fight or struggle to get the support, care or services we need.

To always be responding to crises and emergencies.

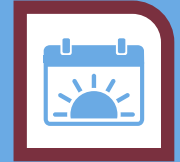
To be isolated, alone, or scared.

To be left out of conversations, decisions, and organizations that are about us.



# DAILY LIFE & EMPLOYMENT

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



**“AS SOMEONE WHO WORKS ON TRANSITION PLANS FOR HIGH SCHOOL STUDENTS, SOMETIMES I DON’T KNOW THE ANSWERS. IF THEY’RE NOT LINKED WITH THEIR COUNTY BOARD OF DEVELOPMENTAL DISABILITIES, WHERE DO YOU GO? HOW DO YOU KNOW WHAT TO DO?”**

– Transition Coordinator

In Ohio, we value and support all activities of daily life, from visiting grandma to working full time. People on the spectrum – all along the spectrum -- are supported. Their communication and sensory needs are considered. Autistic Ohioans do things that matter to them. They can try different things and learn from them – there is no “failure.” All the systems share a vision and work together toward what’s possible.

Ohio has a culture where everyone can ask for help and support without feeling like a burden. Families talk early and often about what’s possible and have support from other families. From living on their own to having a job to being in relationship, the expectations families have for their autistic family member are high, and they talk more about what’s possible than what’s not.

Employers and community members welcome autistics. Autistic employees are valued and have the accommodations and supports they need. They have careers where they can advance and grow. There are a variety of jobs, and employment is based on interests and passions, not only open positions. People with autism can pursue their dreams.



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state’s efforts to ensure:

1. Families are supported early and often to envision a positive, possible future for their children and access what’s needed to achieve that vision
2. Employers and co-workers have accurate, reliable information about autism, available resources and supports
3. Autistic Ohioans have opportunities for life-long learning and career advancement that align with preferences, interests, needs, and strengths.



**There is no “cliff” –  
there are valued  
roles, possibilities,  
and information.**

# COMMUNITY LIVING

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



**“IT KIND OF SUCKS IF THE ONLY PEOPLE THAT YOU SEE ON A DAILY BASIS, ON A REGULAR BASIS ARE NOT REALLY A LOT OF FRIENDS OR FAMILY, BUT JUST PEOPLE WHO ARE PAID TO SEE YOU.”**

– Autistic Adult

## VISION

In Ohio, people with autism and their families are full members of their communities. They are welcome, respected and connected. From childcare to housing, they can make real choices because they have real options. They have robust supports and a variety of resources to explore their options and make their choices.

People with autism live where and with whom they want. Safe, affordable housing is readily available. It supports community living and is easy to access.

There are a variety of meaningful ways to access community. “On demand” transportation is available, while things like “walkable communities” and technology also make it possible to connect and get what you need.

Technology is used to support community living and connection. People with autism and their families have early, frequent opportunities to learn about and utilize technology. Technology is available and affordable across the lifespan.



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state’s efforts to ensure:

1. Community leaders and organizations are welcoming of people with autism and their families and include them in focus groups, advisory boards, planning, and projects
2. Autistic Ohioans and their families understand their living options, can navigate the needed resources, and advocate for their needs
3. Technology is leveraged and maximized to increase community access, independent living, transportation, and other community supports



**They are  
welcome,  
respected and  
connected.**

# SAFETY & SECURITY

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



**“WHEN YOU HAVE KIDS WITH SPECIAL NEEDS, YOUR SOCIAL CIRCLES SHRINK, AND YOU STOP GETTING INVITED TO THINGS...WE NEED TO HELP FAMILIES [RECONNECT] AS WELL...MY KIDS NOT SEE A RICH CIRCLE OF SUPPORT BECAUSE IT WASN'T THERE...WE DON'T MODEL IT WELL AND I THINK WHOLE FAMILIES NEED HELP WITH THAT.”**

– Parent

## VISION

In Ohio, people with autism and their families are safe, resilient and resourced. They can think and talk about the future. They are learning from other families and people with autism. They have networks of support that allow them to thoughtfully plan across the lifespan, starting early

People with autism and their families have positive relationships in their communities. They are safe, known and involved in community building. From law enforcement officers to drive through operators, community members help create safety. Everyone knows what to do in the event of an emergency

Tools and resources are available to navigate life changes, losses, emergencies, and aging. People with autism and their families are prepared. Planning and decision making happen “with” not “for.”



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state's efforts to ensure:

1. Ohio's public safety and emergency response systems (i.e., police, fire, emergency rooms) have accurate information about autism, purposeful, pro-active interaction with autistic Ohioans, and resources for handling encounters and emergencies.
2. Families have the information, knowledge, and resources to engage in long term planning for themselves and their autistic family member
3. Autistic Ohioans and their families have tools and resources to stay safe, including information on preventing/responding to abuse and neglect, interacting with public safety officers, and disaster preparedness



**In Ohio, people with autism and their families are safe, resilient and resourced.**

# SOCIAL & SPIRITUALITY

Building friendships and relationships, leisure activities, personal networks, and faith community



**“I THINK A LOT OF FAITH COMMUNITIES SEE PEOPLE WITH DISABILITIES AS THE OBJECT OF MINISTRY AND OUTREACH RATHER THAN THE SUBJECT OF MINISTRY AND OUTREACH. HOW DO YOU EMPOWER PEOPLE WITH DISABILITIES TO FILL THOSE ROLES?”**

– Faith leader

## VISION

In Ohio, people with autism and their families experience belonging. Faith and spirituality are recognized as important aspects of many people’s lives. Faith communities and leaders invite autistic Ohioans and families to share their experiences and are active in making change and modeling inclusion. Resources are available to support this work

Autistic Ohioans have healthy, intimate relationships of their choosing. They learn about consent and protection. They meet and connect with people in a variety of ways and are safe from abuse or exploitation. They have knowledge of and access to technology that can support connection.

People with autism and their families are well connected. They have many different opportunities to explore hobbies and activities and build relationships around shared interests. They are invited and included and asked to come back.



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state’s efforts to ensure:

1. Spiritual communities actively and meaningfully include people with disabilities and their families, and have the knowledge, tools, and resources to do so.<sup>1</sup>
2. Autistic Ohioans and their families are supported to build relationships and develop robust networks that go beyond “eligibility-based supports”
3. Educators and providers support people in developing skills, hobbies and interests that build relationships.

<sup>1</sup> We have chosen the term “spiritual communities” to best reflect our conversations. This could be a place of faith, such as a church, temple, or synagogue, or it could be a meditation group, journaling club, or yoga class. It recognizes an area that has been frequently overlooked in the lives of people with disabilities, and does not mean everyone will choose to join a faith community or express spirituality in any particular way, or at all.

**In Ohio, people with  
autism and their families  
experience belonging.**



# HEALTHY LIVING

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



**“HOW CAN WE JUST ENCOURAGE FAMILIES AND PEOPLE WITH AUTISM TO GO INTO THEIR COMMUNITIES AND, ESSENTIALLY, BE KNOCKING ON THE DOOR OF THE COMMUNITY? THERE HAS TO BE SOMEBODY ON THE OTHER SIDE THAT IS ACCEPTING OF THEM, THAT SAYS, ‘COME IN!’”**

– IWGA Member

## VISION

In Ohio, people with autism and their families have access to the care they need, when they need it – regardless of age, race, ethnicity, zip code, or insurance. They are empowered to make healthcare decisions and advocate for themselves or their family member. They are respected members of any team.

Autistic Ohioans experience personalized care. Care is delivered by professionals with training in intellectual and developmental disabilities. Providers treat the whole person. They regard autistic patients and their families as experts. They coordinate and support care across the lifespan, services and settings. They are responsive and proactive.


People with autism and their families access wellness activities in their communities, schools, and workplaces. Community gardens, recreational leagues, and the like are designed to include people with disabilities.



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state’s efforts to ensure:

1. Ohio families, medical providers, early care workers and others know how to access free, developmental screening and monitoring.
2. Autistic Ohioans experience improved health, including access to affordable, quality healthcare and wellness activities.
3. Cross-system teams understand social determinants of health, healthcare access, and wellness as part of “capacity for independent living” in transition planning



**In Ohio, people with autism and their families have access to the care they need, when they need it – regardless of age, race, ethnicity, zip code, or insurance.**

# ADVOCACY & ENGAGEMENT

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



**“THERE’S A TENDENCY FOR A LOT OF SO-CALLED ‘NORMAL PEOPLE’ TO VIEW PEOPLE WITH SOME SORT OF DISABILITY AS SOMEHOW MAYBE, AT BEST, WORKING SOME LOW-END POSITION. THEY DON’T VIEW THEM AS LEADERSHIP MATERIAL.”**

– Autistic adult

## VISION

In Ohio, people with autism and their families are respected as experts. Their voices are central to discussions. They have a platform to share their experiences and are empowered to do so. Organizations, agencies, and professionals value their input and know how to listen and support their inclusion

Autistic Ohioans and their family members lead advocacy organizations, serve on boards, and are represented in policy work. They have access to training, mentors, and coaches


Ohio has an active community of practice around supported decision making. People with autism and their families have access to tools and resources, know how to build networks and explore alternatives. People with autism are asked their opinion and encouraged to make decisions, early and often. Ohio is building decision-makers.



## Targeted Priorities

Over the next two years, the IWGA will coordinate and collaborate the state's efforts to ensure:

1. Ohioans have access to information about supported decision making and alternatives to guardianship and opportunities to learn from one another
2. Autistic Ohioans and their families can participate in advocacy and leadership training, learn how to share their stories, and participate in public policy
3. Community organizations and agencies know how to recruit and include people with disabilities in leadership roles

A woman with long, light-colored braided hair is smiling warmly as she looks down at a young boy. The boy is also smiling broadly at the camera. They are both wearing denim clothing. The background is a solid dark grey color.

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# ENDNOTES

- i Leigh JP, Du J. Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States. *J Autism Dev Disord*. 2015 Dec;45(12):4135-9. doi: 10.1007/s10803-015-2521-7. PMID: 26183723.
- ii Kristy A. Anderson, Jessica E Rast, Anne M. Roux, Tamara Garfield, and Paul T Shattuck. (2020) National Autism Indicators Report: children on the autism spectrum and family financial hardship. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University
- iii S Hodgetts, D. McConnell, L. Zwaigenbaum, and D. Nicholas. (2017). The impact of autism services on mothers' psychological well-being. *Child: care, health and development*, 43(1), 18-30.
- iv Harmuth, E., Silletta, E., Bailey, A., Adams, T., Beck, C., & Barbic, S. P (2018). Barriers and Facilitators to Employment for Adults With Autism: A Scoping Review. *Annals of International Occupational Therapy*, 1(1), 31-40.
- v Anne M Roux, Paul T Shattuck, Jessica E Rast, Julianna A Rava, and Kristy A Anderson (2015) National Autism Indicators Report: Transition into Young Adulthood . Philadelphia, PA: Life Course Outcomes Research Program, A .J Drexel Autism Institute, Drexel University
- vi Jean P Hall, and Noelle K Kurth (2019) A Comparison of Health Disparities Among Americans With Intellectual Disability and/or Autism Spectrum Disorder and Americans With Other Disabilities *Inclusion*, 7(3), 160-168.
- vii Harmuth, E , Silletta, E , Bailey, A ., Adams, T , Beck, C , & Barbic, S P (2018) Barriers and Facilitators to Employment for Adults With Autism: A Scoping Review *Annals of International Occupational Therapy*, 1(1), 31-40.
- viii <https://theconversation.com/autistic-people-are-six-times-more-likely-to-attempt-suicide-poor-mental-health-support-may-be-to-blame-180266>



Pursuing Quality Lives 2022

[www.iwg-autism.org](http://www.iwg-autism.org)

