Ohio Interagency Work Group on Autism State Fiscal Year 2020 Report

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



This past year, we have experienced a time when the need for high quality, atthe-ready resources are essential for people with autism and their families, perhaps more so than any other time in recent history. We are fortunate that the foundation for collaboration and coordinated resources had already been built in Ohio through the hard work of the IWGA and its agencies, so that we could work together to deploy and enhance the support and services needed immediately. As a state, we are poised to be able to provide even more valuable tools and resources to the Ohioans who need our services as we work together to build upon this foundation.



Jeff Davis, Director
Ohio Department of Developmental Disabilities



At a time when disparities in services, care, and resources are more evident than ever, it is encouraging that Ohio is working to remove barriers, increase access, and ensure meaningful representation and inclusion. These concepts cut across the recent challenges in our society, including the disproportionate impact of COVID among minority and disabled populations and the movement for racial justice throughout the world. People with autism are fortunate to have a group of agencies working together in Ohio to ensure the support they need is available, while also working to address these challenges in a meaningful and impactful way so every human being has an opportunity to live their best lives for their whole lives.

Reginald Fields, President OCALI Advisory Board



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 (Lead Agency)
- OCALI (Convener)
- Ohio Department of Education
- 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

Foundational to this work is the voice of individuals and families. The IWGA seeks input and utilizes OCALI's advisory board as the primary means for parents, individuals, advocacy groups, and other stakeholders to contribute to the state's autism policy development and implementation.

In May 2018, the IWGA released <u>Pursuing Quality Lives</u> (PQL). PQL built on the work of <u>Quality Lives</u>, Ohio's original autism recommendations, and served as the blueprint for IWGA work in State Fiscal Years (SFY) 2019 and 2020.

In July 2019, the IWGA <u>reported</u> on its collective efforts to address the priorities in PQL. The following report summarizes IWGA efforts during SFY2020, including those related to COVID-19, and lays the groundwork for updated priorities going into SFY 2021.

COVID-19

COVID-19 (the new coronavirus) has changed all of our lives. In March 2020, public gatherings ceased, school-buildings closed, childcare was limited, and a stay-at-home order was issued.

People with disabilities and their families felt particular impacts. Conversations around healthcare rights and rationing of care were front and center. The need for personal protective equipment across the nation made it difficult to find or expensive to afford. The role of home and community based services and direct support professionals (DSPs), already in short supply, became critical.

People with disabilities and their families also had a much to offer. Social media platforms were filled with posts from people with disabilities about how to self-isolate, what to do when you can't go anywhere, how to protect your health and advocate for your rights. The disability community rallied in support of DSPs as "essential workers," workers who had always been essential to them.

Our annual report would not be complete without mention of this virus and how the IWGA member-agencies responded. While each of the state-agencies dedicated sections of their website to COVID-19, the IWGA also met to discuss coordinating resources.

As the IWGA's "backbone" agency for collective impact, OCALI became responsible for compiling resources and developing tools for families. OCALI's Family Center quickly launched a #HereToHelp campaign and website with links to keep families informed, connected, healthy, and supported.

As a result of these efforts, in the first two months of the pandemic:

- Almost 10,000 new people signed into Ohio's Autism Certification Center...as many as the previous 12 months combined.
- Nearly 19,000 people created an Autism Internet Module account...up from an average of 2,500 per month previously.
- Over 43,000 Facebook views of "4 minutes at 4:00," a resource created in response to the pandemic.
- More than 390,000 videos relaying accurate, evidence-based information were viewed...up from 48,000 the month before.



GET A GOOD START

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

- In 2019, the IWGA conducted it's first annual <u>family survey</u>. The survey focused on family experiences around the time of diagnosis and assisted the IWGA in identifying gaps. Nearly 300 families responded. The survey revealed strengths and opportunities in Ohio.
 - Strengths:
 - Diagnosing early
 - Connecting families to services/supports at time of diagnosis
 - Providing services through Early Intervention or school

Opportunities:

- Learning more about the experiences of racially/ethnically diverse families
- Screening and evaluating rather than telling families to "wait and see"
- Putting tools, information, and resources in the hands of families who have to wait
- In an effort to promote information sharing and provide an array of resources, IWGA members were represented on multiple advisory councils and participated in state and national conversations regarding the need for quality care for children with special needs.
- Additionally, OCALI's <u>Center for the Young Child</u> launched: "tidbits for toddlers;" a "suite of resources" for early childhood providers; and a series of early care and education seminars.

OBTAIN NEEDED SERVICES

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

• IWGA members participated in the development of <u>Ohio's State Health Improvement Plan</u> and <u>Ohio's Disability and Health Program</u>.

 The IWGA focused on healthcare transitions, hearing from Nationwide Children's Hospital, Ohio Healthy Transition Project, and University of South Dakota's Sanford School of Medicine, and <u>surveyed</u> youth who had recently transitioned, highlighting the need for continued work in this area.

DEVELOP SKILLS TO SUCCEED

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

- The Ohio Department of Education and OCALI developed <u>Positive Behavioral Interventions and Supports (PBIS): It Takes the Whole Building</u>. This video course teaches the core principles and essential components of PBIS and emphasizes the role all building staff play in shaping school culture and meeting the needs of the whole child.
- IWGA and Employment First Task Force (EFTF) members collaborated in developing a pilot project geared at improving day and employment services for individuals with ASD, specifically those with complex needs (project currently onhold due to COVID-19).
- IWGA lead agency, DODD, partnered with OCALI to develop and pilot training for Direct Support Professionals (DSPs). The pilot consists of an on-line training module, "<u>Did You Notice?</u> An Exploration of Communication," paired with a virtual reality encounter, simulating real-life interactions with a variety of people with developmental disabilities.

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.

- The <u>Autism Certification Center</u> added nearly 30,000 users in Fiscal Year 2020, bringing total accounts to over 63,000 users.
- DODD engaged OCALI to strengthen it's efforts to serve multi-system youth (MSY) and their families. OCALI developed training to build capacity of direct support professionals; provided technical assistance to regional teams across Ohio, including direct consultation to Developmental Centers; and participated in <u>Ohio's System of Care Project ECHO for Multi-System Youth</u>.
- The IWGA continued to elevate ASD in policy discussions by aligning efforts with key state initiatives, including: multi-system youth, early care and education, employment and workforce development.



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.

- OCALI's Office of Policy convened a Columbus Foundation "Big Table" conversation, inviting a group of community leaders from areas such as higher education, hospitality, city and regional planning, local government, and faith to engage in conversations about their role in creating accessible communities.
- Opportunities for Ohioans with Disabilities and OCALI worked together to offer the first ever sensory-friendly morning at The Ohio State Fair. In addition, a toolkit was developed and shared during a workshop at The Ohio Fair Manager's Annual Meeting. The Secretary of State's Office also hosted a voter demonstration booth so people with disabilities could register and practice voting.

LIVE WELL

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

- The IWGA and EFTF continue to meet semi-annually, and this year jointly conducted a survey of youth who had recently exited school. That <u>survey</u> echoed national findings: paid work experiences and IEP participation in high school are keys to post-high school success.
- In direct response to the IWGA's "adulthood" committee, The Ohio Department of Job and Family Services Office of Workforce Development added information regarding ASD Strategies in Action (available through the Autism Certification Center) to their "Workforce Professionals" page.

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.

- IWGA members participate in several state working groups focused on data sharing, collaboration, identification and alignment of efforts, including: Multi-System Youth Action Plan Committee; Children's Behavioral Health Prevention Network Stakeholder Group; Ohio Interagency Council for Youth; Family First Leadership Advisory Committee.
- OCALI's Center for the Young Child and Lifespan Transition Center have been tasked by IWGA member-agencies with improving and enhancing transitions across the lifespan. Their efforts have resulted in teams across the state being trained in the best practices to support transitions.

WHAT'S NEXT?

The IWGA is updating Pursuing Quality Lives for SFY2021 and 2022. Those updates are based on:

- Responses to family surveys
- Responses to youth/young adult survey
- Input from and alignment with IWGA member agencies and current administration
- Input from OCALI Advisory Board and OCALI Center Directors
- State and national data, research, and evidence-based practices

Pursuing Quality Lives 2020 will be available on the <u>IWGA website</u> in July.