

Ohio's Interagency Work Group on Autism

convened by

The Ohio Department of Mental Retardation
and Developmental Disabilities

Status Report July 2009

A look at the history ...

On June 26, 2003 Governor Taft signed into law House Bill 95, biennial budget legislation which provided provisions for the creation of the Ohio Autism Taskforce (OAT). The bill required the OAT to investigate the increasing incidence of autism in Ohio and to determine what, if any, gaps existed in the delivery of services to individuals with autism spectrum disorders (ASD) in Ohio. The Taskforce consisted of twenty-two members; eighteen members appointed by the Governor and four members of the Ohio General Assembly. The Governor's appointments included an individual with autism, parents of individuals with autism, providers, educators, pediatricians, members of the Governor's cabinet and others interested in and connected to the issue of autism. Based upon its findings, the OAT presented a set of recommendations to the Governor, Speaker of the House, and President of the Senate in March 2005. The OAT Recommendations provided impetus for establishment of several state initiatives.



In October, 2007, the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD) prepared a status report to introduce Governor Strickland's Administration to the 2005 Ohio Autism Task Force Recommendations. ODMRDD's status report indicated the completion of several recommendations, but also revealed much work still to be done to address the service and support needs for Ohioans with autism spectrum and related disorders. In 2008, ODMRDD was designated as the lead agency for the Strickland Administration to assure that Ohio's plan to serve individuals with autism was effective, broad-based, and an integral part of the State's efforts for all individuals with developmental disabilities.

To meet this charge, the Department pulled together some key state agency partners to form an Interagency Work Group on Autism (IWGA). The group, which convened January 2008, has been meeting to identify opportunities to better communicate and coordinate the way the state agencies do business to assure that efforts to serve individuals on the autism spectrum are responsive and effective.

The following outlines the work of the IWGA to date.

Building the Partnership...

The Interagency Work Group on Autism, formed in January 2008, includes representation from:

- Governor's Office
- Office of Budget and Management
- Executive Medicaid Management Administration
- Ohio Center for Autism and Low Incidence
- Rehabilitation Services Commission
- Ohio Department of Mental Health
- Ohio Department of Education
- Ohio Department of Job and Family Services
- Ohio Department of Health
- Ohio Department of Mental Retardation and Developmental Disabilities

The IWGA's Threefold Purpose ...

As a group comprised of various state agency partners and priorities, the IWGA centers its work on three prominent functions. These include:

1. Acting as a catalyst to operationalize an action agenda around autism issues;
2. Serving as a vehicle to assure coordination among state partners;
3. Providing an avenue of communication for the state agencies to assure a reciprocal flow of autism related information to and from families and the field, so work is based on real issues and workable solutions.

A Work Plan serves as a launching point ...

Through thoughtful discussion, with a combination of differing perspectives, the IWGA drafted a Work Plan in October 2008. The Work Plan was built upon the focused effort behind the 2005 OAT Recommendations. The Plan is organized around six guiding priorities, and a set of short term deliverables with target dates for completion. State agency leads are identified to facilitate the work. The leads are charged with accomplishing results through active partnership with state agencies, and the families, advocates, and providers who care for Ohioans with autism. In difficult economic times, the work plan offers the state attainable activities that can achieve positive results in the short term with little financial expense through: building more coordinated state and local partnerships; capitalizing on already existing services and supports statewide; and assuring more effective communication.

The IWGA Work Plan is simple...it is about making and keeping connections. The Plan has served as a launching point -- action to keep momentum and focus on critical issues affecting many Ohioans on the autism spectrum and their families.

~ View the Work Plan in Appendix A ~

Six Priorities frame the IWGA Work Plan ...

The IWGA determined that in order to keep focused on lifespan issues, the work plan should encompass priorities spanning from early identification to adulthood. The six priorities established by the IWGA include:

1. Develop a statewide system of early identification of autism and other developmental disabilities;
2. Support evidence-based, high quality, cost-effective models for intervention services;
3. Build the number of qualified professionals serving individuals with autism;
4. Increase support for caregivers and service providers through information exchange about autism spectrum disorders and the service delivery system;
5. Promote the development of “regional hubs” that are affiliated with the university and medical community and serve as the foundation of effective service and support delivery for individuals with autism and other developmental disabilities;
6. Promote successful models for transitioning throughout the lifespan.

**A set of Core Values guides
the IWGA in its work:**

Some help and hope for all;
Services where they ought to be;
Good stewardship of
limited resources;
Quality outcomes through a
combination of people and process; and
Partnerships with stakeholders for
positive results.

Interagency Strategies are built around these priorities ...

The state partners have identified actions to begin addressing these priorities – tasks that can be accomplished through better cross system communication and activity. The strategies revolve around coordinating better links between already existing state programs and efforts, such as the early developmental screening activity found within Ohio’s Help Me Grow system, the Ohio Children’s Health Improvement Partnership, and the Autism Diagnosis Education Pilot Project. Other strategies center on improving the dissemination of autism-related information across systems to assure that information reaches a wide variety of disciplines and audiences for general information, continuing education, and professional development. And yet other strategies call for investigating and exploring new ways to respond to service needs, like the development of a concept for a New Futures (Medicaid) Waiver for children with intensive behavior challenges.

Feedback from families and the field has been an integral part of the IWGA’s activity ...

The Work Plan, disseminated in late October 2008 across the state, generated much input that indicated support for the IWGA’s direction. Apparent themes from the feedback included: lack of resources and information in rural areas of the state; the need for increased involvement of higher education in autism-related work; and the need for improved and timely communication from the state agencies. Resulting from this feedback, the IWGA established a more formalized communication link with Ohio’s Autism Coalition, which has opened up dialogue with advocates representing a host of organizations such as: the Autism Society of Ohio; The Autism Society of America local chapters; Autism Speaks; Milestones; Beyond Us, and others (Ohio currently has over 70 identified parent advocacy and support groups specific to autism). Regional coaches recently hired by the Ohio Center for Autism and Low Incidence (OCALI) to assist regions in building their capacity in the areas of autism, low-incidence disabilities and assistive technology, have begun to increase communication and dissemination of information among educators and professionals across the state. Additionally, OCALI’s growing connection with professionals in the higher education arena, and development of ASDU.org has begun to address a vision for certification programs in ASD.

So, what work has been completed?

As the designated lead for coordination of state agency autism- related work, and in partnership with member agencies of the IWGA, ODMRDD has completed the following:

- Facilitated sixteen monthly IWGA meetings and the development of a year long Work Plan organized around six guiding priorities. Action through the Work Plan is a launching point to guide the IWGA in establishment of long-term objectives;
- Completed thirty visits to autism specific programs and stakeholder groups to keep informed of the service and support networks statewide;
- Formalized communication linkage with key autism advocates across the state through Ohio's Autism Coalition, and connection with the Autism Society of Ohio, the Autism Society of America chapters, Autism Speaks, and other key autism advocacy and family support groups statewide;
- Reviewed and compiled a search of autism insurance parity legislation passed and/or introduced across the United States to keep state leadership informed of relevant legislative activity;
- Completed a review and comparison of other states' autism and child-specific Medicaid waivers approved or pending by the Centers for Medicare and Medicaid Services (CMS), in preparation for concept development of the New Futures Waiver for children with intensive behavioral needs;
- Coordinated and implemented a multi-agency Bridge Plan to address needed transition services for an identified group of families in Central Ohio who were at potential risk of unexpectedly losing needed services;
- Built the preliminary design and infrastructure for a website related to the work of the IWGA;
- Submitted comments to the federal Interagency Autism Coordinating Council (IACC) in response to a request to states to identify high priority issues surrounding services and supports for individuals with autism spectrum disorders, and the IACC's draft strategic plan for autism research;
- Participated in a National Autism Policy Conference which brought together 25 states to participate in guided discussions to learn more about other states' responses to autism-related funding and service provision issues;
- Completed statewide dissemination of an electronic flier in recognition of Autism Awareness Month in April 2009, including information on Ohio's Center for Autism and Low Incidence and Ohio's Parent Guide to Autism Spectrum Disorders.

Key multi-system activities that cross lifespan issues were also accomplished through the IWGA Work Plan ...

- The Ohio Child Health Improvement Partnership (OCHIP), the Ohio Department of Health, and Ohio's Autism Diagnosis Education Pilot Project developed a standard of practice for early childhood developmental screening to promote earlier identification of autism. Public awareness activities to address the value of early identification began with the development of concernedaboutdevelopment.org.
- ODMRDD submitted the New Futures Waiver concept paper to the Ohio Department of Job and Family Services and has begun preliminary dialogue with CMS in preparation for the formal waiver application submission.
- The full State Board of Education approved a Resolution of Intent to rescind current Autism Program rules governing the Autism Scholarship program, administered by the Ohio Department of Education, and adopt new rules with a targeted effective date of July 1, 2009.
- A transition pilot project, through a partnership with OCALI and ODMRDD was established to assist school districts to utilize a customized employment approach, developing or enhancing local Transition Councils and teaming with County Boards of MRDD, the Rehabilitation Services Commission, State Support Teams and others. The goal of the project is to promote employment for youth with developmental disabilities and complex needs, including individuals on the autism spectrum, who might otherwise be unemployed or transition to sheltered environments after high school.
- ODMRDD, in collaboration with the Ohio State University Nisonger Center, and in cooperation with Ohio's Developmental Disabilities Network, submitted a grant proposal to the federal Department of Health and Human Services, Administration for Children and Families. The proposed project would expand the Aspirations Program, currently existing at Nisonger Center, and develop a family support model to empower adolescents and young adults with autism spectrum disorders and their families, resulting in positive individualized outcomes, and promoting success at home and in the community.
- Collaborative efforts have begun to address a vision for certification programs in ASD for educators. OCALI and university partners are exploring sample syllabi for autism-related coursework. OCALI has developed the ASDU.org website to enable communication and information sharing among colleges and universities in Ohio.
- The IWGA joined other state teams from across the nation to participate in the Network of Autism Training and Technical Assistance Programs Conference. Strategies and solutions to address issues that all states face in the area of ASD were shared. IWGA members also participated in a panel presentation for the Conference to report on Ohio's efforts to coordinate state services and supports for individuals with ASD.
- Through the efforts of the Interagency Council on Homelessness and Affordable Housing and funding through Money Follows the Person, administered by ODJFS, work was begun to review the current state of Housing policy and funding, and a review of current Medicaid Waivers and the State Plan in order to make recommendations for a statewide Housing Plan in 2009.

See Appendix B for further Work Plan Updates

In Conclusion ...

The members of the Interagency Work Group on Autism have spent the last year learning from one another. They have explored what they each bring to the table with regard to services and supports... they have determined ways they can be more efficient in communicating with one another and the field about autism... they have worked together embracing a core value of “some help and hope for all”... they have found connections with key autism advocacy networks...and most importantly, have agreed that solutions for addressing the needs of individuals on the spectrum cannot be realized by creating a siloed “autism system”.

Much has been achieved by bringing together these state partners. Heightened attention has been brought to the strengths and challenges that Ohio’s service system faces as individuals are identified earlier and a growing adult population is on the horizon. State partners have agreed that Ohio’s service system can be better prepared to meet increased demands through improved knowledge and understanding of the complexities and gifts of individuals on the spectrum. To this end, the IWGA will continue to implement the activities of its Work Plan, with full recognition that long range strategizing is the necessary next step in moving forward.

Ohio’s developmental disabilities community is working together to address long-term collaborative opportunities, along with the fiscal sustainability of our system. The Interagency Work Group on Autism is an excellent example of agencies working through these challenges, and identifying the best possible use of available resources.

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Your comments or feedback about this Status Report are welcome and can be directed to autism-feedback@odmrdd.state.oh.us. All feedback will be shared with the Interagency Work Group on Autism.