

***Pipeline* . . . direct from the state . . .**

Ohio Department of Mental Retardation and Developmental Disabilities

Ted Strickland, Governor

John L. Martin, Director

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1. April Rally Focuses on Key Legislative Actions

Senate Bill 79

(MRDD Name Change, sponsored by Senator Jimmy Stewart),

House Bill 118

(MRDD Name Change, sponsored by Representatives Deborah Newcomb and Debbie Phillips),

AND

House Bill 8

(Insurance Parity/Autism, sponsored by Representatives Ted Celeste and Nancy Garland),

Move Through Legislative Process

On April 1, 2009, the West Lawn of the Ohio Statehouse hosted more than 200 individuals with autism and other disabilities, activists, families, and state legislators, rallying to support Senate Bill 79, House Bill 118, and House Bill 8. HB 79 and HB 118 would strike the words 'mental retardation' from the name of the state and county entities overseeing services to people with developmental disabilities. For example, the Franklin County Board of Mental Retardation and Developmental Disabilities would be re-named the 'Franklin County Board of Developmental Disabilities,' as the bill currently is written.

House Bill 8, introduced on the same day as the rally, mandates that health insurance policies providing basic health care coverage must include coverage for the diagnosis and treatment of Autism Spectrum Disorders (ASD).

The rally, co-sponsored by The ARC of Ohio, the Autism Society of America - Central Ohio Chapter; Autism Speaks; and, the Autism Society of Ohio, and People First of Ohio, among

others, provided a cross-section of support for raising awareness of specific issues faced by families who have members with developmental disabilities, including ASD. The federal Centers for Disease Control report that the incidence of autism in the United States is 1 in 150 children, and there are more than 10,000 families in Ohio affected every day.



Rally attendees enjoy a sunny but chilly and windy day on the West Lawn of the Statehouse.



ODMRDD Director John Martin (left) addresses the group from the perspective of being a parent of a young adult with disabilities, as well as a member of Governor Strickland's cabinet.



Self Advocate, Michael Groleau, reinforces the call to action, encouraging rally attendees to talk with their legislators about issues that are important to them.

For more information about legislation noted in this article go to www.ohio.gov



April is Autism Awareness Month and Alcohol Awareness Month

2. Roller Coaster Ride to Acceptance of a Family Member's Autism – One Family's Lessons Learned Speak to Many



The Autism Ribbon visually depicts the broad range of individuals affected, as well as the puzzling nature of yet-to-be identified causes or contributors to Autism Spectrum Disorder.

While clinical studies and speculation abound, what's important is individual people and how they learn about and cope with life issues. We focus on that perspective here.

Type the words 'autism' or 'Autism Spectrum Disorder' (ASD) into any internet search engine such as *Google*, and you see that there is no shortage of information on the subject. The lives involved can be easily lost in the shuffle from one technical resource to another, and yet sharing the human element is how the most important lessons can be learned. An article appearing in *The New York Times*, and reprinted in *The Washington Post* titled, "Roller Coaster to Acceptance of a Son's Autism" is a perfect example.

In the article, the mother indicates that her son, Jonah, who is now 25, was diagnosed at around age three, at which time he did not appear all that different from his peers. She tells of years of focusing constantly, every single day, on making the most of every learning opportunity for Jonah, including work on reading, speaking, and social interactions. They tried everything they could think of to 'bring his development along.' She states,

"We introduced communication boards and arranged sensory integration therapy. We had him wear headphones to 'normalize' his hearing, and tried other 'snake oil treatments' that no thinking person should consider! But each hope was followed with disappointment."

She relates it became clear after many years, that although they had been trying desperately to teach him, they had to concede that Jonah was 'no student.'

"What we wanted him to do had little to do with what he did. If he didn't want to do something, he would drop to the ground and refuse to budge. So we decided to back off and began taking cues from him."

The family did the same activities with Jonah as in the past, but without a checklist of goals. Until then, for example, his mother observed that he had never been able to really enjoy the

sensory pleasures of his beloved food magazines, “...without our subjecting him to a monologue about what he was looking at.” He finally was free to enjoy things for their own sake.

The article notes several tries and failures along the way, and the roller coaster of family emotions is clear. What makes the story especially worth sharing is this memorable moment the mom describes:

“Not long ago, I came across an old copy of ‘Cinderella.’ It reminded me of a time when he was five years old, when I tried to read it to him. Well, not read, exactly -- Jonah has always had a low tolerance for traditional reading, and stories must be sung or recited rhythmically.

So, as I sang ‘Cinderella,’ he rolled on the floor, seemingly oblivious to the story. Still, I clung to the idea that I might be able to engage him, so I left a sentence for him to complete.

**“The clock struck 12,” I sang off key, “and Cinderella ran down the palace steps, leaving behind a glass ...” He continued rolling while I waited to hear him say ‘slipper.’
At last he finished the sentence for me. ‘Of milk,’ he said.”**



She finishes, “I smiled, and I’m smiling still. Jonah had made a student of his teacher. I would never again be able to read or think of ‘Cinderella’ without seeing a glass of milk on the palace steps. Jonah turned 25 last fall, and when I look at him I can’t help wondering if the past years weren’t some heaven-directed scheme meant to humble us and teach us the value of acceptance. Understanding that we couldn’t change him had changed us. He remains a man of few words. But though it took us years, we have finally learned there was something to hear in his silence.”

Pipeline acknowledges, “Roller Coaster to Acceptance of a Son’s Autism” by Annie Lubliner Lehmann, the author of “The Accidental Teacher: Life Lessons From My Silent Son.”

Support and resources for Ohio families after they receive a diagnosis of autism are available at www.autismohio.org. Click on “local chapters.” Also an excellent resource guide may be found at www.ocali.org

From a national perspective, resources and information can also be found at sites including www.autism-society.org, www.autismspeaks.org, and www.nichcy.org.



Pipeline Feedback

Thanks to those who contacted feedback@odmrdd.state.oh.us regarding the calculation used in measuring the incidence of Autism Spectrum Disorder (ASD) reported in the April 1 issue of *Pipeline*. The incidence is reported at 1 in 150, as measured by the Centers for Disease Control (CDC). A description of how to arrive at the calculation was incorrect.

3. Alcohol Awareness Month Spotlights Fetal Alcohol Syndrome

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe the broad range of effects that can occur in an individual who has been exposed to alcohol in the womb. According to the FASD Center for Excellence, each year approximately 40,000 U.S. babies are born with FASD, costing the nation about \$4 billion. In Ohio, Department of Health officials estimate that FASD affects one in 100 births at a cost to taxpayers of nearly \$300 million annually -- for providing special services for education, juvenile justice, medical and mental health services, foster care, and unemployment.

Prenatal exposure to alcohol remains the leading preventable cause of birth defects, mental retardation, learning disabilities, attention deficits and behavior disorders.

The FASD Center for Excellence aims to raise awareness that no amount of alcohol is safe to consume during pregnancy, and that help is available for those families already affected. It is important to note that while many pregnancies are unplanned, and the possibility of a mother-to-be drinking any amount of alcohol during the early stages of pregnancy is likely, *as soon as the pregnancy is known, alcohol consumption by the mother should cease for the remaining duration of the pregnancy.*

Emphasizing the importance of education and information on the subject, Ohio Department of Alcohol and Drug Addiction Services (ODADAS) Director, Angela Cornelius Dawson, states, "Healthy children are Ohio's most important resource. When we bring attention to FASD, we increase compassion for those individuals and families already affected, and hope to minimize further effects, thereby ensuring healthier communities across the state."

In the MRDD community, families and caregivers of women who have developmental disabilities and are of child-bearing age/are sexually active, should help to ensure the good health of all involved, and make this message clear:

No amount of alcohol should be consumed during pregnancy.

If you know someone who is pregnant and continues to consume alcohol, it is critical to refer the individual to medical and informational resources as quickly as possible.

Visit <http://www.fascenter.samhsa.gov/> for a great deal of helpful information on the subject.

A Pro-Active Approach in Wood County

For more than 50 years, board members of the Arc of Wood County have advocated for the human rights, personal dignity, and community participation of individuals with mental retardation and other developmental disabilities. They have accomplished this through legislative and social action, information and education, and support to individuals and their families.

One current initiative is their Fetal Alcohol Spectrum Disorders Task Force (FASD), a collaborative group comprised of nine local social service agencies with the goal of educating the community about the risks and dangers of alcohol consumption during pregnancy. A key tool in this effort is the Fetal Alcohol Syndrome Teaching Research Awareness Campaign (FASTRAC) originated in Riverside, California -- a peer training program where eight to ten Junior High

School students are provided information and trained, and then in turn, speak to their peers on the subject.



Wearing bright red NineZERO T-shirts, local high school students visit Rossford Junior High School to educate peers. The slogan NineZERO stands for 'nine months, zero alcohol.'

According to Margie Harris, executive director of the Arc of Wood County,

“Wood County has ten school districts, and some picked up on it and some didn’t. We’ve been doing this for a few years, and Rossford School, in particular, has been very successful with the program. We’ve also done things like have beverage coasters made with the slogan, *NineZERO*, that means for *nine months, zero alcohol*. We had several restaurants and bars use these, and that was one way the kids thought we could get the word out.” She added,

“The main thing in the junior high schools is to get the appropriate message out to students early in their lives.”

Thanks to Rob Spence and Margie Harris, Wood County MRDD and The Arc of Wood County.



4. Systems Innovation and Technical Assistance (SITA), Update

During the past several months, the Office of Systems Innovation and Technical Assistance (SITA) has completed the process of changing from a Regional Consultant service model for technical assistance, and implemented other strategies for assisting the field, most specifically, County Boards of MRDD.

According to Kevin Aldridge, Assistant Deputy Director, Community Services, “Due to the reduced budget, we needed to find different ways to get the job done. We have been committed to creating as few disruptions as possible in this process, and to developing new strategies for providing technical assistance, while encouraging our stakeholders to work with us to help us meet their needs as effectively as possible.”

In the MRDD services environment, the need for technical assistance never goes away, and SITA has been the long-time centralized point of technical assistance, through the work of regional consultants. So, in order to maintain and ultimately improve the flow of information and assistance, ODMRDD has worked to integrate technical assistance into the review and accreditation processes, and then analyze specific remaining technical assistance needs.

Briefly, here are some of the results:

- We have worked with the Division of Medicaid Development and Administration (MDA) to create increased technical assistance capacity for Medicaid-related issues *at the source*. Two formerly Regional Consultant positions are now MDA Field Consultants. Having technical assistance on Medicaid issues within MDA creates system efficiencies and helps minimize confusion.
- SITA will concentrate on specific operational aspects of implementing Departmental policy initiatives in the areas of *employment; children and families; early intervention; individual service planning; and, special populations* including dual diagnosis, autism, housing, and interagency collaboration.
- The Certification Unit within SITA has unified the staff certification and provider certification functions under a single reviewer. This helps us to stay on top of the certification process and minimize any negative effects caused by decreased capacity due to budget constraints. We also are looking at unifying all certification processes, including the certifications of Instructors, Trainers, and Certified Medication Administration Personnel.

In line with our over-riding ODMRDD Five Goals*, we are working to streamline operations and simplify processes that provide technical assistance needed by individuals, families, and providers of services to the MRDD community, statewide. According to Kevin Aldridge,

“It is our responsibility to create positive change, and lay a firm foundation for more prosperous times.”

** The Five Goals are on page 2 of the ODMRDD Primer at <http://odmrdd.state.oh.us/about/docs/ODMRDD-Primer09.pdf>*



5. Accessible Shelter a New Reality in Franklin County

The Franklin County Board of Mental Retardation and Developmental Disabilities (FCBMRDD), in collaboration with the American Red Cross of Greater Columbus, has developed a Red Cross Shelter designed and staffed to accommodate persons with developmental disabilities in the Central Ohio area.

It is thought to be the first Red Cross Shelter in the nation that will be equipped and staffed to accommodate the needs of persons with developmental disabilities and their families in the event of a disaster that requires temporary shelter and assistance.



Access is Everything in an Emergency

Through a grant from The Columbus Foundation, FCBMRDD has purchased and installed a heavy-duty electric generator at their West Central School location, allowing that location to be used as a shelter in the event of mass power outages. While working on the project, three facilities operated by FCBMRDD were identified and equipped to serve as potential shelter locations, and the West Central School site will be one of a very few shelter locations of any kind in Columbus equipped with electric generator capability.

The combination of the accessibility features at West Central School, along with the electric generator capacity, make this a unique community resource.

In addition to these facility-oriented accommodations, the Red Cross *'Ready When the Time Comes'* project has trained 70 staff members from FCBMRDD to serve as volunteers at the shelters. According to Jack Brownley at FCBMRDD, "These volunteers share a common commitment to respond to emergency needs of individuals with developmental disabilities, and bring with them the experience and special skills to support this population." He adds,

"A disaster simulation exercise will be conducted at the West Central School location, 1481 W. Town St. Columbus, Ohio, on Saturday April 25, 2009 from 9:00 a.m. – Noon. Individuals and their families have volunteered to participate in the activities and scenarios designed to simulate a disaster that affects their shelter and access to community supports. The shelter will be staffed by Red Cross leadership and FCBMRDD volunteers."

According to Brownley, because this is a unique partnership and because it responds to a major community health and safety issue, the FCBMRDD in encouraging other County Boards of MRDD to attend this disaster simulation event, to observe and ask questions. He notes, I'm pretty excited about the shelter and about the April 25 event – especially because I believe it's replicable in other communities. We can share information about how the grant funds allowed us to purchase the electric generator we needed, and how our collaboration with the Red Cross has worked out so well. It's been a great experience, altogether."

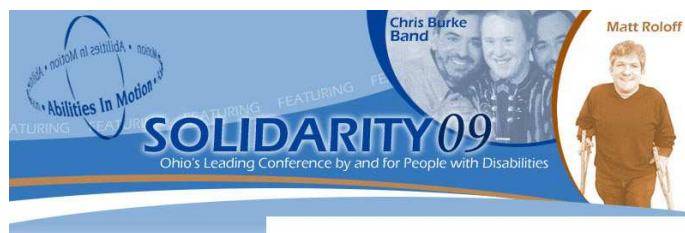
For more information about the disaster simulation event on April 25, or about the partnership between FCBMRDD and Red Cross of Greater Columbus, interested persons may contact Jack Brownley, Director of Schools and Special Programs at 614-342-5960 or jack.brownley@fcbmrdd.org



6. Solidarity's 10th Anniversary Draws a Crowd of Nearly 500

Despite a persistent and dreary drizzle, the crowd gathered around the registration desk was highly energized, as one of Ohio's leading conferences by and for people with disabilities' returned to the Hyatt Regency Hotel in Columbus yesterday -- opening to a crowd of nearly 500 people from across the state. The three-day event (April 14-16) celebrates *Solidarity's* 10th Anniversary and continues a tradition of bringing relevant information to people with disabilities, their friends and families, on issues important to the disability community.

Solidarity 2009 focuses on current information regarding legislation, advocacy efforts, and a long list of practical and topical workshops to improve daily life for people with all types of disabilities. On hand to lead these workshops are self advocates and organizations taking fresh approaches to helping people be successful, including the use of technology and improved networking opportunities.



Governor Strickland Addresses Relevant Issues

Governor Ted Strickland began the opening day luncheon with enthusiastic comments on Ohio's initiatives and targeted efforts to improve the employment scene for people with disabilities. He noted that the Medicaid Buy-In program, initiated last year, helps to create an environment where competitive employment opportunities are available, stating,

“This is critical to the dignity of individuals with disabilities, and to the economy of our state and our nation. Medicaid Buy-In is an important opportunity for Ohioans with disabilities, and it's the right thing to do. People with disabilities have the right to find and keep jobs without the risk of losing their medical benefits!”

The Governor's presence was greatly appreciated and duly noted by the luncheon's Keynote Speaker, internationally known disability advocate, Joyce Bender -- host of the international radio talk show “Disability Matters.” Her focus on employment for the nearly 60% of the disability population who are unemployed is no watered-down approach to getting the job done. She took the microphone enthusiastically, stating,

“Your Governor came here, in person, to speak to you! This doesn't happen in many other states where I speak. Sometimes a governor is supposed to be there and they send someone else. But

this is Ohio! This state has the ability and the interest in helping you – now you need to help them to help you. Tell your legislators what you need and what you want.”

Solidarity attendees began making legislative visits during the conference four years ago, in an effort to affect and influence public policy, and will again visit the Ohio Statehouse during this year’s conference to speak with elected officials. *Solidarity* began in 1991, and was organized as *Solidarity Ohio*. In 1993, the group became the Disability Network of Ohio-Solidarity, Inc. (DNOS), and continues to host the conference every two years.

One thing for sure, attendees of *Solidarity 2009* will leave the conference with a lot more information and resources than they arrived with, and probably more than a few new friends!



People First of Ohio member, John Gillespie, knows his desserts – and proclaims this torte to be ‘positively delicious’. John attended the Solidarity luncheon on opening day, along with about 499 acquaintances and friends.

Solidarity 2009 sponsors include the ODMRDD, the Ohio Rehabilitation Services Commission, Ohio Developmental Disabilities Council, Buckeye Chapter of the Paralyzed Veterans of America, Invacare, Ohio Legal Rights Service, and others.

For more information visit <http://www.dnos.org>



6. Governor’s Council on People with Disabilities Accepting Advocacy Award Nominations

The Ohio Governor’s Council on People with Disabilities is seeking nominations for the ‘Advocacy Award.’ This award recognizes a person or group who has demonstrated outstanding contributions to people with disabilities, and recipients are honored for a *new initiative* or a *significant improvement to an existing program* that materially improves the quality of life for one or more individuals with disabilities. One or more of the following components also would need to be demonstrated:

- Positively impacting laws and/or regulations for the individual or population(s) with disabilities;
- Flexibility in design, addressing future needs or newly identified populations of individuals with disabilities;
- Having the potential to be taught or replicated across the State;
- Raising public awareness regarding issues related to disability.

News, government and disability-focused organizations from the following areas also are encouraged to apply:

- Newspaper, TV, radio and other commercial communication venues;
- Business Publications (examples: Business First, Columbus CEO, etc.);
- Ohio's local and state Chambers of Commerce and local governmental units;
- Members of the Ohio House and Senate, and Ohio members of the U.S. House and Senate;
- The Governor's Office;
- The Ohio Rehabilitation Services Commission; Statewide Independent Living Council; Ohio Legal Rights Service Commission; Ohio Developmental Disabilities Council; other agencies serving the state; and,
- Members and former members of The Ohio Governor's Council on People with Disabilities.

The Advocacy Award will be presented at the annual Governor's Council on People with Disabilities meeting *August 20, 2009*. Nominations must be postmarked by *May 15, 2009*.

For nomination forms, contact the Governor's Council on People with Disabilities at 1-800-282-4536, Ext. 1392, or visit the website at: <http://gcpd.ohio.gov/AdvocacyAward.asp>

Contact Person: Scott A. Hinton, Executive Director, Governor's Council on People with Disabilities, Office 614 438-1393, Fax 614-985-8967



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Pipeline Quarterly, Winter

Reports on winter 2008-'09



Toll-Free Hotline

ODMRDD Hotline for Reporting Abuse, Neglect, and other Possible Major Unusual Incidents (MUIs)

ODMRDD's toll-free hotline number to report abuse/neglect and other MUI's is **1-866-313-MRDD (6733)**. Please note that MUIs are to be reported to the local County Board of MRDD, however, it is

understood that there may be times an individual, staff member, or family member may feel it is a conflict -- or that, potentially, a County Board may be involved in the allegation. In those instances it is important to remember that the hotline number exists, and is to be used for reporting concerns in these situations.

Pipeline feedback ... direct from you to the state ...

Questions? Comments? *Pipeline* is an electronic publication of the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD), distributed approximately twice monthly to update and inform readers of time-sensitive, relevant information affecting MRDD stakeholders. Please share your questions or comments with us about *Pipeline* at feedback@odmrdd.state.oh.us , or contact Sherry Steinman at sherry.steinman@dmr.state.oh.us , phone (614) 644-0262.

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