



# ASGC Newsletter

## From The President's Desk

Dear Members,

Fresh from the Autism Society of Ohio's Bi-Annual conference, your ASGC officers bring a wealth of new information and contacts to share with its membership. We extend our gratitude to ASO President Barbara Yavorcik and her support staff for all of their efforts in putting together an outstanding and very informative conference. We look forward to sharing details of the conference with you at our next meeting.

We would also like to thank Mary Beth Koss from the Achievement Center for an excellent presentation at our October meeting. Speaking at our November meeting will be renowned physician Dr. Derrick Lonsdale.

A former professor of Biochemistry at Cleveland State University and Genetics at Case Western University, Dr. Lonsdale was also head of the Section on Biochemical

Genetics at the Cleveland Clinic. He is a member of the DAN group of researchers and physicians that have continued to build on the original research on autism of Dr. Bernard Rimland. He also heads the Autism Research Institute in San Diego. We are pleased and honored to have Dr. Lonsdale as our featured speaker at this month's meeting.

The ASGC continues to build and grow. We are encouraged by our increased attendance at our monthly meetings, the support we receive from our membership, the quality of our presenters and our ever increasing inter-chapter network. We thank you all as we continue on our mission to make the Greater Cleveland area the best place to live for those with ASD.

Sincerely,

Rory McLean, President

Gus Gallucci, Vice President

**APRAIS**, a coalition of disability-related groups including TASH, ARC, etc., has created this publication re: what parents can do when their kids' schools are using abusive behavioral "treatments" and techniques, including physical restraints, time out rooms, aversives.

It is a very good publication and should be in the hands of every parent of a kid w/a disability who attends a publicly-operated school, class, program, as well as private special ed schools.

<http://www.tash.org/publications/parentguide/inthenameoftreatment.pdf>

## Meeting Time and Location for ASGC

The ASGC meets the first Wednesday of every month at 6:30 pm in room 8 of the St. Basil Parish Center in Brecksville. The next meeting is November 2.

Anyone who is affected by, has a loved one affected by, or just wishes to learn more about autism or autism spectrum disorders is welcome to attend.

Autism Society of Greater Cleveland

November 2005

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Autism Society of Greater Cleveland Officers

Rory McLean  
President

Gus Gallucci  
Vice President

Maureen Ferfolia  
Secretary

We can be reached at:

## ASA Attends National Summit

BETHESDA, MD — September 26, 2005 — The Autism Society of America (ASA), the nation's most widely-recognized and largest grassroots organization serving the entire autism community, attended the Alliance for Full Participation Summit 2005 in Washington, D.C., the first-ever gathering of over 2,000 persons with developmental disabilities, their families and supporting communities, to create a national agenda for full participation. ASA Board Chair Cathy Pratt, Ph.D., chapter leaders and ASA staff were on-hand to represent ASA and the autism community at this groundbreaking event.

"It is important for ASA to get involved in partnerships with broader disability organizations such as this on behalf of the autism community," said Pratt. "Individuals with disabilities, their families, advocacy groups; we're all in this together. Coming together for the Alliance for Full Participation Summit is a good first step toward a united front for those with developmental disabilities. The hope for this summit is that each state will begin to put together a comprehensive plan to address their individual issues. ASA chapters and members must be part of that process if we are to serve and represent our community."

ASA President & CEO Lee Grossman sits on the Board of The Council on Quality and Leadership, one of the 11 founding organizations of the Alliance for Full Participation. "ASA is stepping to the plate to collaborate with organizations both inside and outside the autism community," he said. "As a member of The Council's board, we felt it was important for the disability community to work together to facilitate a dialog and create an action plan to ensure that those with developmental disabilities can fully participate in communities of their choice. We look forward to more Alliance events in the future."

The Autism Society of America (ASA) is the leading voice and resource of the entire autism community in education, advocacy, services, research and support. The ASA is committed to meaningful participation and self-determination in all aspects of life for individuals on the autism spectrum and their families. ASA accomplishes its mission through close collaboration with a successful network of 200 chapters, and hundreds of thousands of members and supporters.

For more information about autism or ASA, visit the ASA web site, [www.autism-society.org](http://www.autism-society.org), or call toll-free, 1.800.3AUTISM (1.800.328.8476).

## Tri-C Offers Swim Lessons to Special Needs Children

The Recreation Department at Tri-C, Western Campus, is offering Adapted Aquatics for Children with Special Needs. Instructors, who are Red Cross certified, will teach these classes. The method of teaching is student-centered, not instructor based. This allows for the skills and information to be based on the needs of the student. Our instructors will enhance learning through the use of routine and visual aids.

All lessons are private. The fees are:

Six, 30-minute lessons \$98

Six, 45-minute lessons \$147

Six, 60-minute lessons \$196

An information packet must be completed and returned prior to the first lesson. Anyone wishing additional information may contact Nancy Balluck or Rita Shearer, the Recreation Coordinator, at (216)987-5456. E-mails may be sent to: [nancy.balluck@tri-c.edu](mailto:nancy.balluck@tri-c.edu) or [rita.shearer@tri-c.edu](mailto:rita.shearer@tri-c.edu).

## OCALI Posts Job Openings

The Ohio Center for Autism and Low Incidence is seeking an Autism Consultant-Speech Language Pathologist, Autism Consultant-Occupational Therapist and an Autism Administrator.

The Ohio Center for Autism and Low Incidence (OCALI) is a statewide federally funded project under the direction of the Ohio Department of Education, Office for Exceptional Children (ODE-OEC)

More information is available at:  
[http://www.ocali.org/oi\\_aboutocali.html](http://www.ocali.org/oi_aboutocali.html)

# Disability Community Asked to Support Federal Direct Support Worker Bill

The Federal Direct Support Worker Bill, H.R. 1264 would amend title XIX of the Social Security Act to provide funds to states to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities under the Medicaid program. The website listed below provides an easy form email that can be used to contact your federal representative.

While not specific to autism, this bill would affect many of our population currently receiving Medicaid services. Please take a moment to read the information below and support this legislation. For more detailed information, visit <http://thomas.loc.gov/> and enter bill number "HR 1264" in the search box.

## BACKGROUND

Earlier this year, Representatives Lee Terry (R-NE) and Lois Capps (D-CA) introduced the Direct Support Professionals Fairness and Security Act of 2005 (H.R. 1264). Reps. Terry and Capps recognize the inadequate wages paid to hundreds of thousands of direct support professionals who struggle daily to enhance the lives of people with disabilities while at the same time struggling to provide income security for their own families. H.R. 1264 represents a first step in bringing an unfair situation to the attention of Congress and the nation.

For millions of people with disabilities of all ages, direct support professionals are the key to living successfully in their home communities. Direct support professionals are often personal care assistants or home care aides who assist people with severe disabilities with medications, preparing and eating meals, dressing, mobility, personal hygiene and handling daily affairs.

Direct support professionals face many difficult challenges throughout their careers. Unfortunately, these difficulties have led to high turnover and ongoing vacancies, which can place people with severe disabilities at risk. Annual turnover rates for direct support professionals range to more than 75 percent.

The lack of adequate and well-trained direct support staff for people with disabilities continues to threaten the quality of services provided for people with disabilities;

undermines their choice to live and work in the community; and chips away their ability to control their own lives.

## STATUS

The Arc, United Cerebral Palsy, the American Network of Community Options and Resources (ANCOR) and the Lutheran Services of America are participating in a national campaign to highlight this important issue and gain support for H.R. 1264.

Currently, the following members of Congress sponsor and co-sponsor H.R. 1264:

Rep. Lee Terry (R-NE) - sponsor  
Rep. Lois Capps (D-CA) - sponsor  
Rep. John Duncan, Jr. (R-TN)  
Rep. Bob Filner (D-CA)  
Rep. Ray LaHood (R-IL)  
Rep. Carolyn Maloney (D-NY)  
Rep. Tom Osborne (R-NE)  
Rep. Nick Rahall (D-WV)  
Rep. Tammy Baldwin (D-WI)  
Rep. Howard Berman (D-CA)  
Rep. Shelley Moore Capito (R-WV)  
Rep. Michael Doyle (D-PA)  
Rep. Michael McNulty (D-NY)  
Rep. Ed Pastor (D-AZ)  
Rep. Peter Visclosky (D-IN)

## TAKE ACTION

Representatives Terry and Capps cannot make this bill become law without the support of the disability community. You know the difference that quality direct support workers make. Now, it is time for you to help make a difference. Make it happen today!

Send an e-mail today to your member of Congress and urge him/her to co-sponsor Rep. Terry and Capps' bill, H.R. 1264. A sample e-mail has been provided to help you.

To take action, visit <http://capwiz.com/thearc/issues/alert/?alertid=7898841> and enter your zipcode in the box labeled "take action now".

## Easter Seals, NEFE Encourage Parents to Financial Plan

With Open Arms: Embracing a Bright Financial Future for You and Your Child is a new financial guide for parents of children with disabilities and other special needs.

Please log into [www.easterseals.com](http://www.easterseals.com) to access free downloadable versions of With Open Arms. Not a registered user? Sign up to access free downloadable versions of With Open Arms!

Caught up in the daily responsibilities of caring for a child with a disability, parents often push financial planning to the back burner. Postponing financial planning is understandable when a child's daily needs are more pressing, but this lapse can result in someone else choosing a child's future, should parents become unable to oversee his or her care.

Easter Seals and the National Endowment for Financial Education® (NEFE®) have collaborated to create a 72-page financial planning booklet for parents, caregivers, grandparents or others involved in the care of a special needs child. Included is information on estate planning, finding the right lawyer or knowledgeable financial planner, wills, special-needs trusts, government benefits, savings options insurance plans and other available resources. Easter Seals and NEFE encourage families to start financial planning when their child with a disability is at a young age.

The Denver-based National Endowment for Financial Education is an independent, non-profit foundation committed to educating Americans about personal finance and empowering them to make positive and sound decisions to reach financial goals. NEFE accomplishes this mission in part through unique collaborations with other national non-profit organizations to develop tailored financial literacy materials.

To order a printed copy of this free booklet, send a \$5.00 check for shipping/handling, payable to Easter Seals. Mail to: With Open Arms/Easter Seals, 230 W. Monroe, Suite 1800, Chicago, IL 60606.

### The answer to the most frequently asked questions regarding the autism waiver are as follows:

1. The autism waiver was approved in the recently enacted state budget bill (HB 66)
2. Currently, the waiver is under development. The earliest it will be available is fall, 2006 - unfortunately, it may take longer.
3. Check back frequently for updates.

Your child with autism may be eligible for benefits and assistance through programs offered by the Bureau for Children with Medical Handicaps (BCMh). Please contact the public health nurse at your county Health Department for qualifications and criteria. Also, contact your county Department of Jobs & Family Services (JFS) to inquire about Medicaid eligibility requirements for your child with autism and/or family. Finally, contact your county Department of Mental Retardation & Developmental Disabilities (MRDD) to inquire about qualifications for the Level One Waiver. Your child with autism may qualify for benefits based on your level of income. Note that a set number of waivers are allocated to each county and there will likely be a waiting list (definitely put your name on any waiting list). You may also contact Bill Shackelford for additional information about available services:

Bill Shackelford  
Senior Policy Advisor  
Division of Medicaid Policy  
Ohio Department of Mental Retardation & Developmental Disabilities  
Phone: 614-752-8469  
Fax: 614-752-5303  
[bill.shackelford@dmr.state.oh.us](mailto:bill.shackelford@dmr.state.oh.us)

Contact information for your county can be found online as follows:

Visit <http://odmrdd.state.oh.us/CountyBoardsDoc/countyboards1.htm> for your local County Board of MRDD.

Visit <http://jfs.ohio.gov/county/cntydir.stm> for your local County Department of Jobs & Family Services (JFS).

Visit <https://odhgateway.state.oh.us/LHDDirectory/NetMgr/NetMgr.aspx> for your local Department of Health.

### PECS Training Will Be in Columbus

Pyramid Educational Consultants, Inc. is sponsoring the two-day **Picture Exchange Communication System (PECS)** training workshop in **Cincinnati, Ohio in December 2005**. The training workshops are appropriate for all educators, speech/language pathologists, OTs, PTs, social workers, parents and caregivers of individuals with autism and related developmental disabilities.

Pyramid Educational Consultants, Inc. is a source for services designed to enhance the lives of children and adults with autism and related developmental disabilities. For an updated workshop listing, please visit our website at [www.pecs.com](http://www.pecs.com).

## A Word on the Autism Waiver

The Autism Waiver, approved in June under Ohio HB66, is currently under development. We will be posting updates to our website regularly, as things change and develop. If there is no new information posted or no new email updates from ASO, things are still under development.

Rep. Jon Peterson was instrumental in getting the waiver into legislation, but he is not responsible for developing the details of it. Please DO NOT contact his office for further information - he has done his job and is working hard on other recommendations. Rest assured that ODMRDD, ODJSF and others, including ASO, are working very hard to make the waiver happen. ASO WILL post updates as changes occur and send out alerts - so please check back to the ASO website at [www.autismohio.org](http://www.autismohio.org) or the Ohio Autism Taskforce website at [www.ohioautismlegislation.org](http://www.ohioautismlegislation.org).

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## For Deep-End Families, Lack Of Hope Can Kill By Peter Bronson for the NY Enquirer

There's a name for the toughest cases in the mental health system: "deep-end kids." It fits their families, too. Parents of children with autism, bipolar disorder, schizophrenia, severe retardation, or a witches' brew of other syndromes and disorders can barely tread water. They struggle to keep their heads up, running out of breath and patience as they watch their families slowly drown. Many spend themselves into bankruptcy and find out health care plans that cover "normal" diseases and injuries don't cover bills to treat mental illness. They miss work to care for their children and lose their jobs. Neighbors complain. Cash runs out. Their other children are emotionally neglected as mom and dad worry constantly that someone will get hurt.

The future is a bleak horizon of rough water and no life raft, far from shore without rescue or relief. Some mentally ill kids turn to drugs or wind up in jail. Some attack or abuse siblings, neighbors or parents. Most are kept at home like a dark secret, soaking up every spare second from frantic, stressed-out, sleepless parents who are beat down by debt, depression, divorce and disintegrating families.

Jane Naylor of Springdale went under in the deep end on Sept. 29, and shot her 27-year-old autistic daughter, Sarah, to death, then set her house on fire and shot herself. Officially, it was a murder-suicide. Unofficially, they died of hopelessness. A single mother at the end of her rope was so bereft of hope she could not leave her daughter behind alone.

"I guess she finally decided this was the way to go," said Springdale Police Lt. Mike Mathis. "Families have a lot of difficulty finding the help they need."

Several mental health providers and advocates - local, county and state - said the same thing. They described parents with two mortgages and three jobs; desperate moms and dads who know the schools are not equipped to care for their unmanageable children, but have nowhere else to turn.

"It becomes a dire situation. They go through horrible times," said Susan Shelton, board member on the National Alliance for the Mentally Ill and the Junior League, which supports mental health awareness.

All of the families suffer. But Shelton and others agreed that middle-class families suffer most. They can't afford private care and can't qualify for Medicaid help. Some give up custody of their child to the state, just to get adequate care and save the remains of their family.

"The only way it happens is if they think it's the only avenue to save the life of their child," said Terre Garner of the Ohio Federation for Children's Mental Health. "It's devastating. The child is already emotionally unstable, and then there is emotional abandonment."

Ohio doesn't know for sure how many families have done that, said Dora Sterling of the Ohio Department of Mental Health. But state and county mental health agencies are working to make it less likely.

The answers can be simple. Families need respite care, to escape for a few days or a weekend. They need help to care for a difficult or violent child. They need transportation and medications. They need someone to listen.

A survey by Ohio State University found that 74 percent of children in their sample were at risk of going into state custody without such services. Nearly half of the parents had lost a job or significant income in the past year; and many felt like the fragmented system blamed them, failed to answer questions and added to the stigma of mental illness.

More than \$1.2 billion is spent on mental health by federal, state and local programs in Ohio, Sterling said. But the most important part for deep-end families may be a \$4.2 million sliver called FAST (Families and System Team). It has the funding flexibility to keep families together, so children stay at home, not in more costly state custody and foster care. Ohio should expand FAST immediately.

Jane and Sarah Naylor's heartbreaking headline fit the sad story the "system" knows well. Jane was fired from jobs, in debt, in trouble with neighbors because Sarah wandered and could be violent. They were alone, barely treading water. And then they went under.

We can do better to rescue deep-end kids and their sinking families.

# Every Child with Autism Wishes You Knew These 10 Things

By Ellen Notbohm  
South Florida Parenting

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute, the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it.

The child who lives with autism may look "normal," but his or her behavior can be perplexing and downright difficult. Today, the citadel of autism, once thought an "incurable" disorder, is cracking around the foundation. Everyday, individuals with autism show us they can overcome, compensate for, and otherwise manage many of the condition's most challenging aspects. Equipping those around our children with a simple understanding of autism's most basic elements has a tremendous effect on the children's journey toward productive, independent adulthood. Autism is an extremely complex disorder, but we can distill it to three critical components: sensory processing difficulties, speech/language delays and impairments, and whole child/social interaction issues.

Here are 10 things every child with autism wishes you knew.

**1.** I am a child with autism. I am not "autistic." My autism is one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)?

**2.** My sensory perceptions are disordered. This means the ordinary sights, sounds, smells, tastes and touches of everyday life that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you, but I am really just trying to defend myself.

**3.** Please remember to distinguish between won't (I choose not to) and can't (I'm not able to). Receptive and expressive language are both difficult for me. It isn't that I don't listen to instructions.

It's that I can't understand you. When you call to me from across the room, this is what I hear: "\*&^%\$#@, Billy. #\$\$%^\*&^%\$&\*" Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.

**4.** I am a concrete thinker. I interpret language literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is, "This will be easy for you to do." When you say, "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me, "It's raining very hard." Idioms, puns, nuances, double entendres and sarcasm are lost on me.

**5.** Be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused, but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation, or other signs that something is wrong.

There's a flip side to this: I may sound like a little professor or a movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits, because I know I am expected to respond when spoken to. They may come from books, television or the speech of other people. It's called echolalia. I don't necessarily understand the context or the terminology I'm using, I just know it gets me off the hook for coming up with a reply.

**6.** Because language is so difficult for me, I am very visually oriented. Show me how to do something rather than just telling me. And please, be prepared to show me many times. Lots of patient repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day planner, it relieves me of the

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# 10 Things Every Child with Autism Wants You to Know

From Page 6

stress of having to remember what comes next, makes for smooth transitions between activities, and helps me manage my time and meet your expectations. Here's a great web site for learning more about visual schedules <http://www.cesa7.k12.wi.us/newweb/content/rsn/autism.asp>

7. Focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough or that I need fixing. Trying anything new when I am almost sure to be met with criticism, however constructive, becomes something to be avoided. Look for my strengths, and you'll find them. There's more than one right way to do most things.

8. Help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply don't know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, I may be delighted to be included.

9. Try to identify what triggers my meltdowns. This is termed "the antecedent." Meltdowns, blowups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented.

10. If you are a family member, please love me unconditionally. Banish thoughts such as, "If he would just ..." and "Why can't she ... ?" You didn't fulfill every last expectation your parents had for you, and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you, I'm worth it.

It all comes down to three words: Patience. Patience. Patience.

Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. I may not be good at eye contact or conversation, but have you noticed I don't lie, cheat at games, tattle on my classmates, or pass judgment on other people?

You are my foundation. Think through some of those societal rules, and if they don't make sense for me, let them go. Be my advocate, be my friend, and we'll see just how far I can go.

I probably won't be the next Michael Jordan, but with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They had autism too.

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## First Responders Can Now Use A Child is Missing Alert System

The "A Child is Missing Alert System" is currently available to law enforcement agencies in the United States at no expense. The brochure does feature an incident where a child with autism was found with the utilization of this system. The website is [www.achildissing.org](http://www.achildissing.org).

The system utilizes phones and generates up to 1,000 calls in 60 seconds. This is a 24/7 service and has no jurisdictional boundaries to adhere to. A recorded message is created from the information a responding officer provides regarding a vulnerable individual's disappearance. To be effective, it should be activated as soon as possible, with accurate information.

Residents should contact their local police departments and ask that they utilize this system. Some departments have already created a policy that coincides with the Amber Alert policy and makes it much easier for officers to disseminate information as soon as possible.

For more information call 1-888-875-2246.

## Autism Society of Greater Cleveland

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Brecksville, Ohio 44141

Phone: 216-556-4937  
Email: support@asgc.org

From Diagnosis through Adulthood.

The ASGC is a volunteer organization



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## Upcoming Autism Conferences in Ohio

**"Behavioral and Inclusion  
Strategies for Home,  
School and Community"**

**Featuring:  
Maria Bird-West Wheeler  
and Dr. Paula Kluth**

**February 1-2, 2006  
Cleveland, OH  
Holiday Inn West**

**[www.spectrumtrainingsystemsinc.com](http://www.spectrumtrainingsystemsinc.com)**

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