



ASGC Newsletter

From The President's Desk

Dear ASGC Members,

These are truly exciting and dynamic days for the Autism Society of Greater Cleveland. We continue on our journey of forming a strategic plan, and the process has been moving along well thanks to your help. We held two forums this week with the help of our friends at the Independence Library. One was for parents, and one was for service providers. Both were well-attended, providing us a bounty of useful information. Please feel free to chime in on our website survey at www.asgc.org as well. Your feedback is so important to us!

Mark your calendar now! We are thrilled to announce that we will be the beneficiary of the Rev It Up for Autism Car Show on Saturday, September 9. It will be held in the parking lot of Best Buy in Macedonia on Routes 82 and 8. It will be an all day event, rain or shine. A huge ASGC thanks to Best Buy, Epson Printers, coordinator Karen Hale and the many classic car enthusiasts that make these events so special. Contact us at support@asgc.org or at (216)556-4937 for more information.

ASGC Meeting Time & Place

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 August 2.

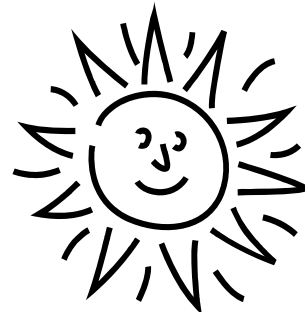
Anyone who is affected by, has a loved one affected by, or just wishes to learn more about autism or autism spectrum disorders is welcome to attend.

Thanks go out to our friend Joe from Fieldstone Farms for a great presentation at our July meeting. Our August meeting will feature a very special guest, so make plans now to join us at 6:30 pm on Wednesday, August 2 for a Presentation by Author Sondra Williams. Sondra is an adult with high-functioning autism, a mother of four children diagnosed with ASD and the author of numerous poems and the book *Reflections of Self*, released in 2005. We hope to start promptly at 6:30 and as always, child care for your autistic or typical child is available from our good friend Jennifer Might and her staff from STEPS of Olmsted Falls. All we ask is that you please call or e-mail us at least two days before our next meeting date and let us know how many children you will be bringing.

Have a great month and, as always, thank you for your support on our mission to make the Greater Cleveland Area the best place to live for those with ASD.

Sincerely,

Gus Gallucci
and
Rory McLean



Autism Society of
Greater Cleveland

August 2006

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Work & Family: Rulings clarify rights for special-needs caregivers

By Sue Shellenbarger
The Wall Street Journal

As a human-resources executive for a consulting firm, Debra Shafer was a heavy hitter -- until her 6-year-old son was diagnosed with autism.

Her career was soon history as Ms. Shafer, of Newtown, Pennsylvania, struggled to get her son to five weekly therapy sessions, plus testing and evaluations, while scurrying to cover her bases at work. Her supervisor asked, "OK, we understand this is a crisis. When is the crisis going to be over?" she says of the incident a few years ago. The only response Ms. Shafer could give, she says, was "I don't know." Left increasingly out of the loop, cut out of emails and excluded from meetings, she wasn't surprised when she was soon laid off, says Ms. Shafer, now a special-education consultant.

Employees who care for children and other family members with disabilities face acute work-family hassles. Until recently, little attention was paid by courts and enforcement agencies. But amid an increase in lawsuits and questions from the public, new, in-depth guidance on caregivers' rights is emerging on several fronts, from court rulings to Equal Employment Opportunity Commission advisories. Chris Kucyznski, assistant legal counsel for the EEOC, sees "more interest in this area in the courts," including rulings that delve more deeply into the issue of caregivers at work. The rulings promise fairer treatment for working parents, and clearer guidelines for employers in how to manage them.

In a 2004 survey of 349 parents of children with emotional or behavioral disorders, 27 percent said they'd been fired at some point because of work disruptions arising from their children's special needs; 48 percent had quit jobs to care for their kids, say researchers at Portland State University in Oregon. In focus groups with 28 mothers of such children, the women said they lived in fear of negative performance reviews and regularly worked extended hours to make up for job interruptions because of their children's crises or appointments, say Julie Rosenzweig and Eileen Brennan, professors at Portland State, and other researchers involved in the study.

Under current law, these parents aren't entitled to special accommodations. While the Americans with Disabilities Act outlaws discrimination against caregivers to the disabled, it doesn't require employers to change schedules or job duties to oblige them. In April, a federal appeals court in Cincinnati ruled in a case called *Overley v. Covenant Transport* that caring for a disabled daughter didn't entitle a truck driver to miss a regular weekend shift that she had worked in the past without providing an acceptable excuse or a backup driver to fill in.

Court rulings leave room for reasonable people to disagree, however, on how much disruption at work is too much.

A 2004 ruling by a federal appeals court in Chicago, *Larimer v. IBM*, maps out areas where employers are vulnerable to charges of discrimination against caregivers to the disabled. For example, parents can't be fired, demoted or harassed simply because they're "somewhat inattentive" at work. Employees who are distracted by family needs, but who still manage to get the job done without accommodations, are protected, the court held.

But employees and employers may disagree on whether the job is getting done. When Sidney Chen's 3-year-old son began having developmental problems, Mr. Chen's workday as a marketing director for a Silicon Valley firm was sometimes interrupted by the need to attend doctor or therapist appointments. "I thought I had it covered" by forwarding calls home and continuing to work there during the day and after hours, he says. But when "I wasn't in my cube, people would stop by "and think, " he's not here?" He was soon laid off, largely because he wasn't in the office enough, he was told.

Although Greg Long, a Mount Vernon, Michigan, single father, had a good track record as an advertising and sales executive, he says he has been pressured to quit two managerial jobs since his daughter was diagnosed 10 years ago with Rett syndrome, a neurological disorder. He tried to make things work; if his daughter had a 10 a.m. hospital appointment, "I'd be working until 10 at night to make up for it," he says. But at one company, his boss complained he felt "like I'm running a social-services organization." In the second, a fellow executive demoted him, saying, "You've got to deal with your kid." Such incidents suggest a need for working caregivers to nail down job objectives with employers in clear, measurable terms.

In the past courts have shied away from dealing with workday issues such as employee scheduling, but a 2005 ruling suggests that even revoking a parent's flexible schedule can be illegal under some circumstances, such as when he or she is caring for a child with special needs. Chrissie Washington, a secretary for the Illinois Department of Revenue, had been working a 7 a.m.-to-3 p.m. schedule so she could get home to care for her son, who has Down syndrome. But after she filed formal charges of race discrimination against her employer, she was ordered to work 9-to-5.

Ms. Washington claimed in a lawsuit that withdrawing her flexible schedule constituted illegal retaliation for filing the racism charges. A federal district court in Springfield, Illinois, ruled in the department's favor in 2003. But a federal appeals court in Chicago last August overturned that ruling, holding that Ms. Washington's special vulnerability -- her son's medical condition -- meant that revoking her flexible schedule was "a materially adverse change for her." A department spokesman says, "We did not and do not discriminate or retaliate" against employees, and predicts the department will prevail in the suit.

**REV IT UP FOR AUTISM - A Charity Event
2nd annual car and bike show**

**Saturday, September 9
10:00 am - 9:00 pm, rain or shine
Best Buy Macedonia
470 East Aurora Road
(330)468-6850
Car and bike entrance fee is \$20**

Half of all entrance fees and all donations and raffle profits will be donated to the Autism Society of Greater Cleveland

For more info, email kikione1@cox.net

News Briefs

Don't forget to sign up on our Yahoo site for automatic updates on what's happening in the autism world.

To sign up use the following link:

<http://health.groups.yahoo.com/group/triautism>

Here is information on a local group for young adults with Asperger's:

This group just completed its first year! We have 6 male members (though it's also open to females), age 19 to 34, and have been meeting every two weeks at an office in Highland Heights (just South of Beachwood). The group covers many issues of concern to "high-functioning" people with autism, including social/family/dating, relationships, academic/vocational pursuits, emotional concerns, and a host of others. It's educational, supportive, therapeutic, and works to address any and every issue that members bring to the table.

Please call (216)751-0710 if you would like additional information.

NIH releases mental health lessons

A new, FREE NIH-sponsored curriculum supplement for middle school, The Science of Mental Illness, has been released. The six-lesson unit is designed to complement existing life science curricula and is consistent with the National Science Education Standards.

Lesson 1 - The Brain: Control Central
Lesson 2 - What's Wrong?
Lesson 3- Mental Illness: Could it Happen to Me?
Lesson 4 -Treatment Works!
Lesson 5- In their Own Words
Lesson 6-You're the Expert Now

The structure of the unit enables teachers to effectively facilitate learning and stimulate student interest by applying scientific concepts to real-life scenarios. Activities promote active and collaborative learning and are inquiry-based to help students develop problem-solving strategies and critical thinking.

To order this new FREE resource, contact:
<http://science.education.nih.gov>.

Caregivers in Delaware find services lacking for adults with autism

By Hilary Corrigan

Inadequate housing, public transportation and solid employment options have grown into common complaints through the southern Delaware region.

For those with autism, though, the options narrow much further.

Millsboro resident Theodis Bowe searched for a group home for his two autistic adult sons, he told other parents at a May 23 meeting in Georgetown. He found crowded places with little privacy, members suffering from drug and alcohol addictions, time limits on kitchen and bathroom use.

"I don't think they should be forced to live in a place that you wouldn't want to live in yourself," Bowe said.

So, he rented an apartment for them. Tony and Michael can walk to their jobs and the grocery store. Bowe visits and checks in by cell phone.

"They had to live independently," he said, encouraging other parents to prepare for their autistic sons' and daughters' futures.

The Lower Delaware Autism Foundation hosted the gathering, part of an effort by the Lewes nonprofit to target the needs of area adults with autism, a neurological disorder that impedes development of social and communication skills.

While the Sussex Consortium educates autistic students until they turn 21, the area lacks continuing programs, such as activities, as well as needed services, including housing, parents complained.

Some autistic adults, such as 24-year-old Antuan James, live at home with family. The arrangement works now, said his mother.

"I'm not going to live always," Pam James-White added.

The Bridgeville resident showed up at the meeting to hear options. She would like to see Antuan live in a home with a small group of residents, supervised by trained staff.

Rehoboth Beach resident Terry Barnheimer wants the same for her 22-year-old son, David. She figures that transitioning him into such a setting would also help him avoid a sudden switch when she dies. A comfortable home, Barnheimer pictures, run by caring workers.

"Where you know that they're safe," she said. "That would be like glory."

The population of adults with disabilities across Delaware has been growing, as those living here age and as retirees relocate to the region from other states and bring disabled children with them, according to Roy Lafontaine, deputy director of the Division of Developmental Disabilities Services, part of Delaware Department of Health and Social Services.

The division partners with various private and nonprofit agencies to provide services -- including housing, employment and caregivers -- for those with disabilities.

Warren Ellis, director of the division's adult special populations program that serves 114 people with behavior problems, mostly autistic people, expects the need for services to rise as a larger population of autistic students grows up. But for now, more group homes for autistic people aren't warranted.

"Not that many people over the years have been requesting residential services," Ellis said.

That may change.

"There are clearly more people with autism who are needing services," Ellis said, noting a statewide increase. "Most of those people are still in school."

Starting more group homes and home care services requires enough applicants who meet state eligibility requirements and enough money for the state to meet costs, Ellis said.

Division officials have worked with the Delaware Department of Education to project the number of graduates in coming years. Along with advocates, they have presented findings to lawmakers in an attempt to prepare for the future.

"We're well aware of it," Ellis said of expected rises in the state's autistic adults. "We've been tracking this."

But, housing is not the only need.

Parents complained of a lack of transportation options and a small pool of available caregivers to hire when they need to work or travel.

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Caregivers in Delaware find services lacking for adults with autism

From page 4

Laurel resident Dorothy Thompson has been looking for a job for her 42-year-old autistic son, Kenneth, since 2002.

In caring for a friend's autistic daughter, Lewes resident Bonnie Zistl has trouble finding aides to watch 21-year-old Ashley Dinn.

"My biggest dilemma is, I work a full-time job," Zistl said. "You exhaust your friends getting them to babysit. They become not your friends real quick."

A community center or gym would help on weekends and evenings, since Dinn works weekdays. "Things that she would enjoy doing," Zistl said. "I'd be willing to pay for services."

Getting around the rural region presents another hurdle.

While Delaware Transit Corp. provides door-to-door service for \$2 per trip, Barnheimer refuses to rely on the state agency.

"Half the time, they don't show up, they're always late," she said.

The federal Americans with Disabilities Act requires public transportation agencies to provide the same transportation services for disabled people as it does for others.

DART's 52 buses for paratransit services completed 900,000 trips through the state last year, according to Darrel Cole, of Delaware Department of Transportation.

"It's a great service," Cole said, noting that the buses arrive within a 30-minute reservation window. "Transportation is there, is available, for anyone with any sort of disability."

Zistl also refuses to rely on the agency, after a driver returned Dinn to her workplace when she acted out with behavior that autistic people have trouble controlling.

While drivers train to help those with disabilities on bus rides, they do not qualify as medical aides, Cole said.

"Our role is to transport folks in a safe manner," he said. "We're not capable of providing special needs."

Continuing care, Ellis' division aims to attract more agencies to Delaware to partner in providing services to autistic adults.

With limited resources, the division must prioritize, focusing first on disabled people who most need homes, who are poor, who lack caregivers or have been orphaned. While federal laws mandate education for disabled children, no such provisions ensure specific care for disabled adults.

"Many parents feel that it should be an entitlement," Ellis said of housing and services for autistic men and women. "Unfortunately, it's not."

That became clear to Lower Delaware Autism Foundation organizers at last month's meeting. "It's more bleak than I expected," Dr. Vivian Bush, a foundation board member and psychologist at the Sussex Consortium, said after hearing parents' comments.

For now, foundation leaders will consider expanding the programs and activities that they provide for autistic children to accommodate autistic adults.

But Charlotte Herbert, executive director of the group that formed in 2001, employs two workers, is run by an 18-member board and maintains a more than \$400,000 annual budget, plans further steps. She will seek state and federal money, along with grants and private donations, to boost housing projects. "There's things that just need to change," she said.

Autism Group to picnic on July 29

The Tri-County Autism Group will be going to Conneaut Lake Park on Saturday July 29. The park hours are 12 PM-10 PM and ticket prices for the park are \$17.95. If we get enough people there will be a picnic with an additional cost of approximately \$12.75 per person. Please contact Dennis Houghton if you are interested in attending or have any questions at (330)482-3954, or you can e-mail him at dennishoughton@sbcglobal.net.

There is a new national research study by Professor Jim Adams (recently on Dateline) to measure the level of toxic metals in baby teeth of children with autism spectrum disorders and typically-developing children (unrelated to those with autism). Baby teeth form during pregnancy and the first few years of life, so they measure the total exposure to toxic metals during that time. His pilot study (submitted for publication) found that children with autism had 2-3x as much mercury in their baby teeth as typical children. If you would like to participate, please go to www.eas.asu.edu/~autism for more information and an application form. There is a cost of \$200 to participate in the study for non-Arizona residents, but a limited number of scholarships are available thanks to the Autism Research Institute.

Helpful employment, advocacy information for adults with ASD

Partners in Employment is a free self-study course designed to help people with developmental disabilities find meaningful jobs and jumpstart their careers.

<http://www.partnersinpolicymaking.com/employment/index.html>

This six-hour, self-study course is designed to help people with developmental disabilities find meaningful jobs and plan a career. In this course, participants will create a resume or portfolio of their strengths, skills, and interests; learn how to network and identify potential employers; prepare for an interview; and understand the hiring process.

Partners in Policy Making is a self-study course designed to help people with developmental disabilities

Insurance coverage for Autism to be discussed in online Yahoo forum

Due to an overwhelming response to the need for discussions regarding insurance coverage for Autism, a new Yahoo group has been established to discuss related issues. It is located at:

http://health.groups.yahoo.com/group/autism_insurance_information/

This group is open to all members of the Autism community, professionals and service providers. The purpose of the board is information sharing, including providing ideas on working with the system of insurance provisions and ways of ensuring coverage is provided according to the laws that govern insurance, Medicaid and Tricare.

Sites may help teachers of ASD kids

Strategies for Accessing Curriculum for Students with Autism:

<http://www.teachernet.gov.uk/doc/6698/Full%20document.pdf>

Additionally, again developed in the UK, the following contains suggestions for mainstream teachers with ASD (Autistic Spectrum Disorder) students in the classroom situation.

Strategies for mainstream teachers of Students with ASD:

<http://www.simonmidgley.co.uk/support/asd.htm>

and their families create positive change through advocacy.

<http://www.partnersinpolicymaking.com/makingyourcase/index.html>

This three-hour, self-study course is designed to help people with disabilities and their families create positive change through advocacy. The course helps participants understand the legislative process and essential elements of good advocacy. Participants will learn to identify and research personal issues, then advocate for change as individuals and as part of larger community efforts. The course includes opportunities to put what has been learned into practice through a series of interactive exercises.

Caregiver Study:

You are invited to participate in a research study looking at the short-and long-term effects of receiving a diagnosis of an Autism Spectrum Disorder (ASD) in one's child. With your help, we can learn more about the process families go through to get a diagnosis of an Autism Spectrum Disorder for their child as well as better understand the different variables that can help a person adapt to his or her situation.

If you choose to participate, you will complete a survey packet now and again one year from now. The packet should take approximately 40 minutes to complete. You will receive a \$10 Wal-Mart gift card after completing each survey packet. All personal information will be kept confidential.

You are eligible to participate if:

Your child has been formally diagnosed with an Autism Spectrum Disorder (autism, Asperger's disorder, Pervasive Developmental Disorder, Not Otherwise Specified [PDD-NOS]) by a licensed clinical psychologist or medical doctor

This is your first child to be diagnosed with an ASD

Your child was diagnosed less than 6 months ago

You can complete the survey packet online at:

<http://mypage.iu.edu/~mlstuart>

Or, request a paper copy from:

Melissa Maynard at (317) 274-1091, mlstart@iupui.edu

NDC offers sibling support group

SIBLINGS WANTED!

For Sibling Support Workshops

Brothers and sisters of children with autism spectrum disorders (ASDs) now have a chance to meet and talk with others who have brothers and sisters with ASDs. They will have an opportunity to talk about the good and not-so-good parts of having a sibling with ASD. They'll also have fun!

The NeuroDevelopmental Center's (NDC) Sibling Support Workshops are an exciting new opportunity where siblings can share information, enjoy recreation activities, and most importantly, get support from other siblings in similar situations. The cost is \$90 for a two-day session. There will be two sessions this summer, Session 1: August 1st and 2nd and Session 2: August 3rd and 4th. Kids in the groups will gather in the NDC at 10:00 am and have a day full of activities lasting until 2:00 pm.

Brothers and sisters have many feelings that are difficult to express, even to a friend: sadness that a sister can't learn things that others take for granted, anger when a brother's behavior problems prevent the family from doing things other families do, or the special pride when a sibling with a disability learns a basic, but important life skill after months or years of practice. At the Sibling Support Workshops, siblings will share these feelings with others who truly understand.

Besides peer support, the Sibling Support Workshops will provide participants with an opportunity to learn more about their sibling's disability. Most important, the Sibling Support Workshop will be fun! Participants play new games and make new friends.

For Registration, please call 330-543-8050.

Directed by: Christine Golden, Ph.D. & Michelle DePolo, Psy.D.

Autism Society of America
Greater Akron Chapter
Serving Summit, Stark, Portage, Wayne and
Medina Counties

Presents:

**The Problem Solving Process:
Creating Interventions that Work!**

August 15 at 7pm

**By Chris Filler Lincoln Way
SERRC – Autism Consultant**

In this presentation, Chris will present an overview of the problem-solving process, which is based on the technology of applied behavior analysis (ABA). This process will assist parents and professionals to understand challenging behaviors based on why the behaviors occur. This understanding leads to the selection of appropriate interventions, strategies and supports that will teach new skills to replace the challenging behaviors. Behaviors of concern include those that interfere with learning, socialization, independence, or safety. An example case study will be provided, as well as worksheets for future reference. This process is a wonderful framework that could change your opinion on behaviors, as well as how you prefer to intervene.

**Location: Akron Children's Hospital, William
Considine Bldg, Bowery Street Parking Deck**

NO COST & NO RSVPs

Any questions? Please call 330-543-3955 or email us at
asagreaterakron@sbcglobal.net

www.asagreaterakron.com

Coalition for Healthy Communities to release report on mental health parity

A new report will be released by the Coalition for Healthy Communities entitled, "**Failure to Enact Mental Health Parity: Consequences for Ohio Businesses and Communities.**" This new report addresses the last unresolved issues regarding Mental Health Parity in Ohio. The leadership in the Ohio General Assembly asked for this information, and it is the hope of the Coalition for Healthy Communities that once this report is in the hands of all legislators, hearings will resume and parity advocates will see this legislation put to a vote.

Autism Society of Greater Cleveland

P. O. Box 41409
Brecksville, Ohio 44141

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

From Diagnosis through Adulthood.

The ASGC is a volunteer organization



Upcoming Autism Conferences

Wrightslaw Special Education Law and Advocacy Training

Tuesday, October 17
9:00 am - 4:30 pm

Featuring:
Pete Wright, Esq.
&
Pam Wright, M.A., M.S.W.

Marriott Airport Hotel
Cleveland, Ohio

For more information, call:
(440)478-8708

Critical Issues for Adolescents with Autism Spectrum Disorder

September 27th & 28th

Presented by:
Spectrum Training Systems, Inc.

Holiday Inn
Indianapolis, Indiana

For more information, email:
spectrumtrainingsystems@yahoo.com

www.spectrumtrainingsystemsinc.com
