



THE SPECTRUM

DECEMBER 2011

AUTISM & HOLIDAY GATHERINGS

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Tips for relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism. This article appeared in the holiday 1999 issue of ASAP news (volume 3.5). The Autism Support and Advocacy Project and Potential Unlimited Publishing, and can now be found on www.ButtonsAndMore.com

Dear Family and Friends: I understand that we will be visiting each other for the holidays this year! Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful.

As you probably know, I am challenged by a hidden disability called autism or what some people refer to as a pervasive developmental disorder (PDD).

Autism/PDD is a neurodevelopmental disorder which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see but which make it difficult for me to adapt to my surroundings.

Sometimes I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: some may not speak, some write beautiful poetry. Others are whizzes in math (Albert Einstein was thought to be autistic), or have difficulty making friends. We are all different and need various degrees of support.

Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time, like you would if you landed on an alien planet and didn't understand how the inhabitants communicated. This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by ok. But if something, anything changes, then I have to relearn the situation all over again! It is very hard.

When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time. You might think I am ignoring you--I am not. Rather, I am hearing everything and not knowing what is most important to respond to.

Holidays are exceptionally hard because there are so many different people, places and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, it's very hard work and can be extremely stressful.

I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat.

If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting in one place for even 5 minutes is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people--I just have to get up and move about. Please don't hold up your meal for me--go on without me and my parents will handle the situation the best way they know.

Eating in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses in-

(Continued on page 2)



DEAR FAMILY & FRIENDS (CONT'D FROM PAGE 1)

involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky -- I literally cannot eat certain food as my sensory system and/or oral motor coordination are impaired.

Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable! Temple Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed with sandpaper. I often feel the same way in dressy clothes.

When I go to someone else's house, I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!) Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things -- just please be patient with me and understanding of how I have to cope...mom and dad have no control over how my autism makes me feel inside.

People with autism often have little things that they do to help themselves feel more comfortable. The grown ups call it "self regulation," or "stimming". I might rock, hum, flick my fingers in my face, flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to your world.

Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grown ups call this "perseverating" which is kind of like self-regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable, and I don't want to come out of that comfortable place and join your hard-to-figure-out-world. Perseverative behaviors are good to a certain degree because they help me calm down.

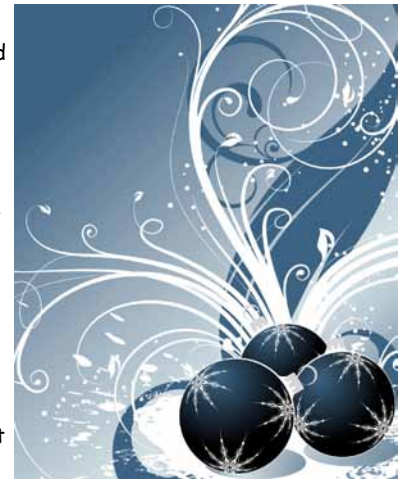
Please be respectful to my mom and dad if they let me "stim" for a while as they know me best and what helps to calm me. Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you neurotypical folk!) It hurts my parents' feelings to be criticized for being over-protective or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it's very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate, please remember that I don't possess the neurological system that is required to follow tippy rules.

I am a unique person--an interesting person. I will find my place at this celebration that is comfortable for us all as long as you'll try to view the world through my eyes!

STORIES WANTED!

Do you like to write? Do you have a story to tell other families? Has your son or daughter experienced a success-big or small? Do you have parenting tips to offer? Sibling stories? At ASC we really believe parents learn best from each other, and we would love to see your stories. Please send to Susan Gilroy at sgilroy@ne-arc.org or Gloria Castillo at gcastillo@ne-arc.org.



Check our
Facebook page
for program
updates



SUPPORT GROUPS

Acton

ASC Sponsored; Target Group: Mandarin-speaking parents.

Acton Memorial Library, 486 Main St (Rt. 27) Acton; bi-monthly meetings TBA

Parent facilitator: Wen Li

Contact ASC 978-777-9135 or asc@ne-arc.org

Danvers

ASC sponsored; Target Group: Grandparents

6 Southside Road, Danvers; 3rd Mondays, 10-11:30 am

Contact facilitator Susan Gilroy 978-624-2302 or email sgilroy@ne-arc.org

Danvers

ASC/AANE sponsored; Target Group: Adults (over 18) with Asperger's syndrome

6 Southside Road, Danvers; 3rd Wednesdays, 7-8:30 pm

Contact facilitator Gail Kastorf at 617-393-3824 ext. 42 or gail.kastorf@aane.org

Danvers

ASC Sponsored; Target Group: Parents of children with ASD

6 Southside Road, Danvers; 3rd Wednesdays, 7-8:30 pm

Contact facilitator Scott Buchanan at 978-624-2347 or sbuchanan@ne-arc.org

Danvers

ASC/AANE sponsored; Target Group: Parents of Adults with Asperger's syndrome

6 Southside Road, Danvers; 2nd Thursdays, 6:45-8:15 pm

Contact facilitator Gail Kastorf at 617-393-3824 ext. 42 or gail.kastorf@aane.org

Lawrence

ASC sponsored; Target Group: Spanish-speaking parents of children with disabilities

Greater Lawrence Family Health Center, 700 Essex St, Lawrence; 3rd Friday, 9:30-11:30am

Contact facilitator Gloria Castillo 978-624-2301 or gcastillo@ne-arc.org

Lowell

ASC sponsored; Target Group: Parents of children with ASD

DDS Lowell Area Office 325 Chelmsford St. Lowell; 1st Tuesday, 10:00 to 12:00

Contact facilitator Whitney Ryan 978-624-2305 or wryan@ne-arc.org

Newburyport

ASC sponsored; Target Group: Parents of children with ASD

Newburyport Public Library, 94 State St, Newburyport; 2nd Thursday, 6:30-8:30pm

Parent facilitator: Nancy Lucier

Contact ASC for more info 978-777-9135 or email ASC@ne-arc.org

Reading

ASC /EMARC sponsored; Target Group: Parents of children with ASD

Location: Reading Public Library, 64 Middlesex Ave, Reading; 7pm Date to be determined.

Contact parent facilitator Kim Gargano 781-526-9171 or kimgarqs@yahoo.com



The PAPC (ASC's advisory board) will meet on Tuesday January 9th at 10 am. If you want to know more about serving on the board, contact Susan Gilroy at 978-624-2302.

Chair-Kathleen Moline; Vice-chair-Nancy Lucier.
Other members:
Chris Curtin,
Debbie Bashaw,
Renee Williams,
Greg Candage,
Judy Doherty, Pina Hayes, and Annie Pulaski. Provisional members are Kristine Nicholas, Christine Romaides, and Christine Kelly.

FREE FEDERATION WORKSHOPS

Federation workshops are free and open to the public.

You may register for workshops by either calling the Federation at 617-236-7210 or in Massachusetts toll-free at 800-331-0688. OR go to <http://fcsn.org/pti/workshops/home.php#schedule> to register online.



December 2011

12/1 Andover, An IEP for My Child, Professional Ctr. for Child Development, 32 Osgood St, 6:30-8:30pm

12/1 Wilmington, Basic Rights, Wilmington H.S. library, 159 Church St, 7-9pm

12/8 Dracut, Understanding my Child's Learning Style, Dracut High School library, 1540 Lakeview Avenue, 7-9pm

12/8 Medford, Understanding my Child's Learning Style, Andrews Middle School, 300 Mystic Valley Parkway, 7-9pm

January 2012

1/12 Cambridge, 504 Plans, location TBD, 6:30-8:30pm

1/12 Tewksbury, Effective Communication and the IEP, Wynn Middle School, TSEPAC office, room 204, 1 Griffin Way, 7-9pm

1/25 Westford, MCAS, Access & Achievement in Special Education, Chrisfulli School, 2nd fl. library, 13 Robinson Rd, 7-9pm

SENSORY-FRIENDLY MOVIES

Join AMC Theatres and the Autism Society special showings of the following movies. Movies will be shown at 10 a.m. local time in participating theatres nationwide.

December 3 - The Muppets

January 7 - The Adventures of Tin Tin

February 25 - The Secret World of Arrietty

March 10 - Dr. Seuss' The Lorax

April 7 - Pirates! Band of Misfits

AMC **Dartmouth** Mall 12, 140 North Dartmouth Mall North Dartmouth, Mass. 02747

AMC **Framingham** 15, 22 Flutie Pass, Framingham, Mass. 17014

AMC **Tyngsboro** 12, 440 Middlesex Road Tyngsboro, Mass. 01879

AMC Loews **Methuen** 20, 90 Pleasant Valley St. Methuen, Mass. 01844

AMC Theatres (AMC) and the Autism Society have teamed up to bring families affected by autism and other disabilities a special opportunity to enjoy their favorite films in a safe and accepting environment on a monthly basis with the "Sensory Friendly Films" program.

In order to provide a more accepting and comfortable setting for this unique audience, the movie auditoriums will have their lights brought up and the sound turned down, families will be able to bring in their own gluten-free, casein-free snacks, and no previews or advertisements will be shown before the movie. Additionally, audience members are welcome to get up and dance, walk, shout or sing - in other words, AMC's "Silence is Golden®" policy will not be enforced unless the safety of the audience is questioned.

PLEASE CHECK WITH YOUR LOCAL THEATER TO CONFIRM DATE AND TIME.

Tickets are \$4-6 depending on location and can be purchased on the day of the event. **PLEASE CONTACT YOUR THEATRE TO CONFIRM SHOW TIMES AND PRICES.**



SKETCH-A-SPACE CONTEST

Share your creative ideas, dreams, skills and employment interests in this special online competition. Enter your design for a chance to win up to \$3,000!

Easter Seals is hosting its second annual Sketch-A-Space contest, supported by Google SketchUp. This online design competition is meant to draw attention to the employment needs of people with autism. Use the free Google SketchUp 3D modeling software to design a space that represents your dream job, career interests or plans for the future. Enter your design for a chance to win up to \$3,000.

And, the competition offers people with autism, those interested in learning more about autism, or those who have someone in their lives with autism an opportunity to celebrate the unique and critical contributions people with autism make to our nation's workforce. Help us spread the word about autism and employment. Because when individuals with autism have access to the supports they need and engage in work that capitalizes on their strengths, the result is meaningful employment. Isn't that what we all strive for?

http://www.easterseals.com/site/PageServer?pagename=ntlc8_sketchaspace



REAL LOOK AUTISM

Real Look Autism was founded by a former TV news anchor who has a daughter with autism spectrum disorder. The website aims to share information and encourage discussion while attempting to present different therapies and strategies using video in a very focused and thoughtful way. Video stories will only be a few minutes in length and will be partnered with an article on the same topic written by a parent or specialist...or both!

For more information, visit *Real Look Autism* at <http://www.reallookautism.com/>.

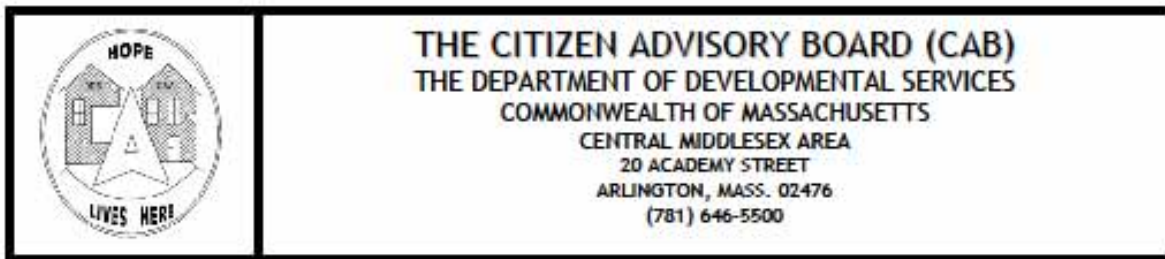
LOOK BACK, PLAN FORWARD

Institute On Disability Launches New Online Person-Centered Planning Tool

Planning for and providing support to a loved one who is aging or living with a chronic illness or disability is a common experience for almost everyone at some point in life. The process, however, can be arduous and presents a number of challenges that prevent individuals from living as they choose. The path to navigate the maze of medical and community supports can be complex and time consuming. Individuals and families often struggle to define and create a network of supports, and service providers frequently experience significant time and funding constraints.

With the help of [Look Back, Plan Forward](http://www.lookbackplanforward.com/), a new website from the UNH Institute on Disability, individuals with disabilities and people who are aging have a place to record and reflect on important life events in a web-based timeline. This online record can prove invaluable for understanding and focusing on the individual's desires and preferences when it is used by family caregivers and services providers as a framework for planning tailored services and supports. <http://www.lookbackplanforward.com/>

"Look Back, Plan Forward is an internet-based tool that makes it easy for you to record your personal history"



Invites You To Make a Difference As a Community Volunteer

The Citizen Advisory Board (CAB) of the Department of Developmental Services (DDS) seeks a few new members. The current CAB comprises 14 members who volunteer a few hours each month to advocate for persons with intellectual and developmental disabilities and to assist, monitor and advise the Area Office in providing quality support for all individuals it serves.

Currently, meetings are held on the first Monday of each month from 6:15 p.m. to 8:15 p.m. at 20 Academy Street, Arlington, MA. The Board includes self-advocates, family members, business and area community people, and working and retired people. The goal of the CAB is to maintain the availability of required services, to assure the overall quality of life, the protection of rights and the achievement of individual potential for the people served by DDS. DDS Commissioner Elin Howe appoints board members for three-year terms.

Key activities include the review of DDS budgets, comprehensive services and other matters such as quality assurance, human rights issues, assessment of DDS services and supports, legislative advocacy by informing and advising legislators and community leaders about issues related to individuals with intellectual and developmental disabilities; education for caregivers, guardians, families and the public; and visits to group homes and day programs to conduct citizen monitoring.

If you are interested in attending a monthly meeting or if you have any questions regarding membership, please contact Rick Camara 781-646-5500.

Communities Served: Acton, Arlington, Bedford, Boxboro, Burlington, Carlisle, Concord, Lexington, Lincoln, Littleton, Maynard, Stow, Wilmington, Winchester and Woburn

Members: Laurie Brennan, Catherine Carpenter, Rob Cutler, Sean Donnelly, Suzanne Morse-Fortier, Liz Hopkinson, John Kramer, Donna Murphy, Laura Noble, Jennifer O'Leary, Patricia Quatieri, Rob Salzer, Edwina Spillane and Susan Wilkins

Stumped for a gift for a loved one in your life?



Give the gift of FUN this year!

Northeast Arc Recreation Gift Certificates

Use them for all your favorite Northeast Arc Recreation programs!

Ways to purchase:

- 1. Come into the Recreation office and pick one up**
- 2. Mail in a check or money order and we will mail you a certificate back
(please include the recipient's name and the address where you'd like the certificate returned.)**

You can determine the amount!

Some ideas: Give the gift of a Saturday outing, 8 weeks of an activity program, or an entire year of Movement Therapy. It's up to you!

For a complete list of programs go to:

<http://ne-arc.org/familyservices/recreation.htm>

If you have any questions please contact the Recreation Department at

978-624-2308 or recreation@ne-arc.org

The fine print: All Gift Certificates expire June 30, 2012 (no exceptions). No processing fees added to the certificate unless purchased with a credit card. Valid only for Northeast Arc Recreation programs, not valid for other departments or programs.

Upcoming Recreation Events

ArcWorks Guest Artist Workshop: Block Printing Holiday Cards, December 7, 2011 6:30-8:00pm

Winter Solstice Dance for Teens/Young Adults December 16, 2011, 6:30-8:30

Coming In January:

Recreation Session 3 starts January 3, 2011

Music Therapy: Ages 3-12, 6 Weeks beginning January 23, 2012

Creative Movement: Ages 3-13, 6 weeks beginning January 28, 2012

Monthly Drumming Circle, Date to be Determined

Call Rec Dept: 978-624-2308

ART CENTER CLASSES ANNOUNCED

Classes for Kids, Teens, Adults, Seniors

All abilities

Sign up soon, they will sell out!

After much anticipation, **ArcWorks Community Art Center** (in Peabody) is proud to announce the arrival of our Fall/Winter Class Schedule. Whether you have little ones, teenagers, are an adult who wants to learn something new, or are a senior who is looking for a fun class, we have something for you! Our classes are inclusive and are offered to all North Shore residents. For more info, please click on the section titles.

<http://arcworksns.org/KidsClasses.aspx>

<http://arcworksns.org/AdultClasses.aspx>

<http://arcworksns.org/TeenClasses.aspx>

<http://arcworksns.org/SeniorClasses.aspx>

Once you have made your decisions, please contact [Beth Mazzetta at 978-624-2555](mailto:Beth.Mazzetta@978-624-2555) or bmazzetta@ne-arc.org to sign up!

SIBSHOPS

Where: Peabody Institute Library of Danvers, 15 Sylvan St, Danvers in the Gordon Room off the Children's Library

When: Saturday, December 10th; 9:30am–1pm

Cost: \$15.00 per child - includes lunch; **Ages:** 8-12 year olds

Your child's spot will be reserved once we receive your check no later than December 5, 2011. For more information contact Sibshop facilitators: Marguerite Roberts or Mary Dean Calnan at 978-354-2660 or mroberts2@partners.org mbdc45_60@hotmail.com

Sibshops are provided through the Family Resource Center at MassGeneral for Children at North Shore Medical Center and held at the Peabody Institute Library in Danvers.

What are Sibshops?

Sibshops are for siblings of children with special needs. The Goals of the Sibshop Model:

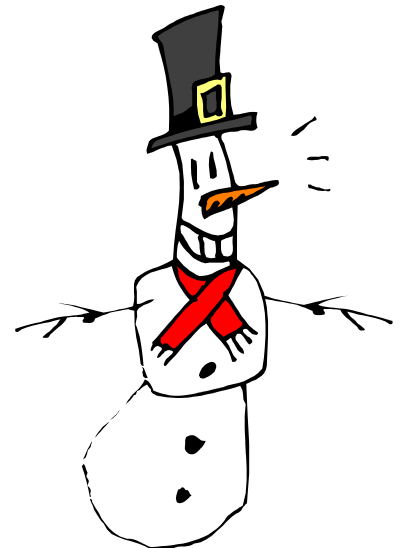
Goal 1: Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.

Goal 2: Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

Goal 3: Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.

Goal 4: Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.

Goal 5: Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.



FAMILY LEADERSHIP SERIES

The Mass. Families Organizing for Change **Family Leadership Series** focuses on supporting families and individuals to live in their communities as naturally and typically as desired. Applications from families with children or adult family members of any age with any disability are encouraged. The MFOFC Family Leadership Series is currently sponsored annually in five different areas of Massachusetts by the regional chapters of Massachusetts Families Organizing for Change. The MFOFC Family Leadership Series has a two-fold purpose. The first is to offer information about "best practices" for people with disabilities. The second is to assist families in creating a vision for their family member and a process to achieve the vision by incorporating that information. The MFOFC Family Leadership Series is organized into three (and in some regions, four), two-day workshops. Deadline for applications is December 30, 2011.

Dates:

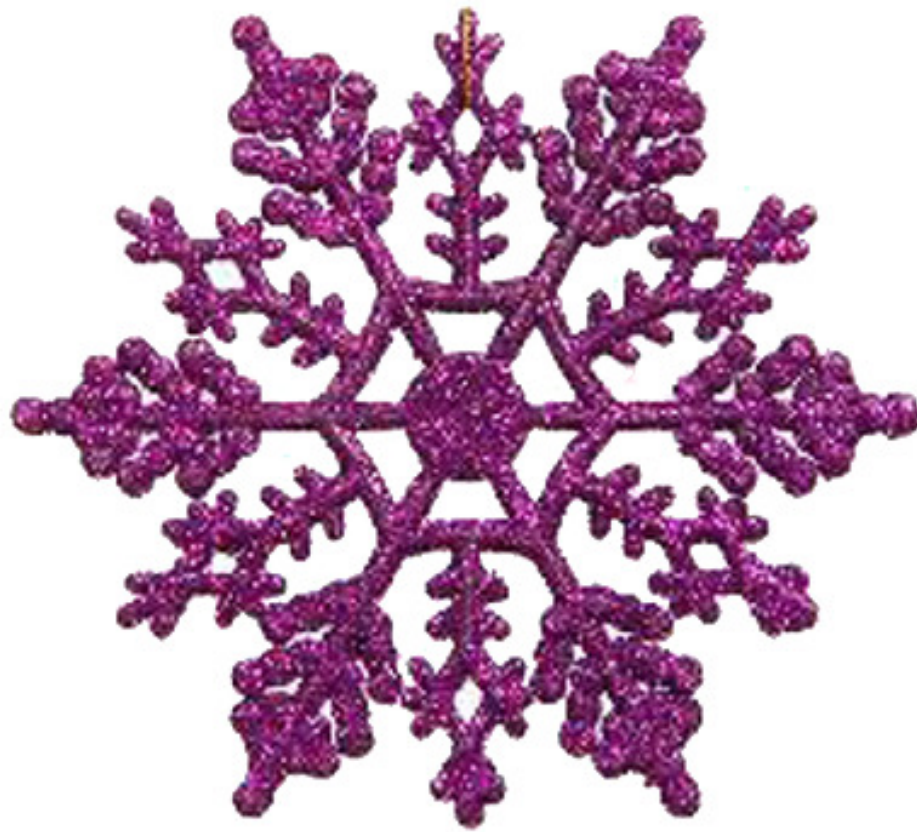
Friday and Saturday, January 20-21, 2012; Friday and Saturday, March 2-3, 2012

Friday and Saturday, March 30-31, 2012; Saturday, April 28, 2012 (One day only)

<http://www.mfofc.org/events/leadership-series.html>

DECEMBER 2011

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5	6 Lowell-group 10 am	7	8 AANE Parents of adults 6:45pm Newburyport group 6:30p	9 Spanish speaking group @ Danvers	10 Boston Rock Gym Event
11	12	13	14	15	16	17
18	19 Grandparents group 10 am	20	21 Danvers group 7pm AANE/adults	22	23	24
25 	26 Closed	27	28	29	30	31 



Holiday Open House

at ArcWorks Community Art Center

When: Thursday, December 1st, from 6-8PM

Where: 22 Foster Street, Peabody, Mass 01960

What: Holiday party featuring all sorts of **home-baked goodies to eat**, a **gift-basket raffle**, and a chance for you to **get started** on that **holiday shopping** in our **gift shop** featuring work by local artists and crafters!

Who: You!

For More Info: Please Contact ArcWorks Community Art Center Director, **Merritt Kirkpatrick** at **978-531-7146** or **mkirkpatrick@ne-arc.org**

We are Proudly Sponsored by:



The van Oosterloo Family Foundation



FAMILY SUPPORT SURVEY

As part of the development of a strategic plan for Family Support services, the Department of Developmental Services (DDS) created the attached survey to gather information from family caregivers about what helps them to support their family member at home. The survey also collects input about other ideas or thoughts they have about what's important to their family. The survey is intended for the primary caregivers of an individual with an intellectual or developmental disability who lives at home with them and for whom they have day to day responsibility for providing care. The individual may be a child or an adult. The survey is available online through "Survey Monkey" and the results are completely anonymous. The survey will be available for completion online until **Thursday, December 8th, 2011**.

In addition to the link being made available through the DDS Family Support and Autism Support Centers, we are asking for your assistance in having this link to the survey broadly distributed through your networks to reach as many families as possible. If there are family members who would like to complete the survey on paper, there is a PDF file attached above that allows a copy of the survey to be printed. This can be provided to anyone who cannot complete the survey online. It includes information about where to submit the completed survey.

Here is the link to the survey as well as an HTML code to place the link on your website.

Web link to survey: <http://www.surveymonkey.com/s/7V9Q5MG>



NEEDED: AFTERSCHOOL CARE

A family in Beverly is seeking an in-home provider of afterschool child care for an eight year old boy with PDD. Services are needed 2-4 days per week from 2:00-6:00. Must have experience.

Please contact the family at 978 927-5212

FAMILY ZUMBA



Zumba is an activity for all ages and abilities. ASC collaborated with the Salem YMCA to offer a family Zumba on a recent Sunday afternoon.

If you and your family would be interested in participating in the future, please let us know! Contact ASC at 978-777-9135 or asc@ne-arc.org

Zumba participants at the Salem YMCA.

Check our website!

www.NE-arcAutismSupportCenter.org

Center for Developmental Excellence

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E-mail: asc@ne-arc.org



THE SPECTRUM

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E-mail: asc@ne-arc.org

www.ne-arc-autismsupportcenter.org

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Anyone wishing to contribute information for this newsletter should send it to asc@ne-arc.org or to our mailing address above. Parent contribu-

tions are encouraged. *Announcements are included as space is available.*

NEWSLETTER STAFF

Susan Gilroy, Editor

Contributors:

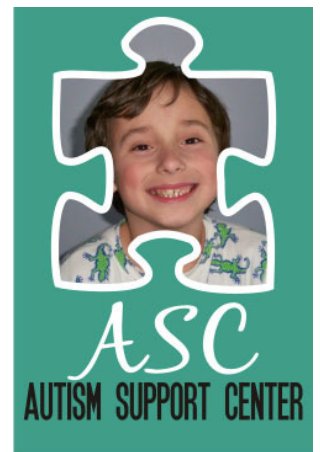
Gloria Ricardi Castillo

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Whitney Ryan

Stephanie Gammons

The Autism Support Center is celebrating **20** years of supporting and empowering families in northeastern Massachusetts.



NortheastArc
Life-Long Support for People with Disabilities

