

The Sun

Newsletter

January-March 2010

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Start Planning Now – Summer Will Be Here Soon

Deep into January with a dreary fall behind us and that most awful month of all—February— ahead of us, the holidays are over and summer seems like a beach-filled dream that's so far in the future it's unimaginable. Oh for those lazy, hazy days of summer with no school. No School? NO SCHOOL!!! OMG! OMG! OMG! Suddenly that pleasant dream is a nightmare! How are we going to fill those weeks when school is out???



20 recreation and disability organizations in the fall, and we will be sharing some of our key events across the disability community and asking other groups to share their events with us. If we want a community that is open to our members, then we need to offer a community that is open to others, so from now on, Autism

Whether your child is mainstreamed and has the entire summer to fill, or is in the DAP and has only a few weeks to fill, those can be very long weeks. And as far away as June seems, it will be here in a heartbeat. This issue of The Sun focuses on recreation so that you as a parent can plan ahead and be ready to have a great summer with all your children exploring new things, learning new skills, and most of all, having fun. We will bring you tips from other parents for having fun, lists of summer camps, and highlight the things you need to be thinking about now. In January our speaker meeting will actually be a "Recreation Fair," held on January 19 at the Brennen School. Come meet representatives of some of the organizations that provide summer opportunities and learn more about what is out there for your child. We'll invite representatives from the YMCA, Boys Club, Camp Fairlee Manor and many others. Learn more about the fair on page 9.

Delaware will be opening our movies and skating parties to the rest of the disability community. We are looking to other communities to open some of their events to us as well.

We are also creating a Rec4All webpage that will highlight activities that the entire disability community can share, and we will continue to update our information about the variety of summer camps available for children on the spectrum. Look for an enhanced webpage to come by February 1, 2010 that will better address what individuals and families need across the ages.

Our families have cited recreation as one of their most important priorities for Autism Delaware. We are working hard to step up to the plate to ensure that our members and entire community have more opportunities throughout the state. Some will only be for the disability community, and hopefully more will be open to us all but aware of the need for accommodation that our communities have.

This is part of a larger effort for Autism Delaware. With dwindling resources across the state, we all need more low cost and no cost events. Heidi Mizell and Pat Swanson are heading an effort that we are calling Rec4All. We hosted two meetings with about



Our Mission

Autism Delaware is a community of people with autism, their family members and friends, and professionals who work in the autism field.

Our mission is to improve the lives of people with autism and their families. We will educate, advocate and raise public awareness in order to promote lifelong opportunity and acceptance for people with autism in their communities.

We serve the entire state of Delaware.



The Sun

A publication of Autism Delaware

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Director's Column

By Theda Ellis, Executive Director

I love the midwinter quiet. The fall and the spring are both filled with events, but this is the time to slow down and reflect about what has been and what is to come. It's particularly important to me now because I'm thinking about my own future. The board is allowing me to start a graduated step down to my retirement in three short years. So, come July, my work week will be reduced to four days. I have visions of working in my yard, cooking, and reading, reading, reading. (The stack of books by my bed is getting higher.) That extra day will also be spent thinking about what I want to do in full retirement. How will I stay connected to others? What opportunities for me are out there? It's my own transition time.



Autism Delaware will also be going through a transition. We have been thinking about how will we meet our expanding needs in these challenging times? How will POW&R move downstate? What should we look like in Kent and Sussex? Should we provide clinical services? How do we secure the future? These are questions we have been asking during our strategic planning process.

One thing is clear. We cannot continue to do more with less, and we need to strengthen our infrastructure to prepare for the future. For all these reasons the board

has decided to move forward with succession planning. Step one was our strategic plan, which is being completed this month. Then we will hire an Associate Director in the late winter or early spring. This person will work with me to learn and understand all of Autism Delaware's operations, and will take the lead in some of them.



Additionally, we will grow internal leadership. Both Katina Demetriou and Heidi Mizell will be enrolling in UD's management certificate program to learn nonprofit management. We are also looking at

moving some part time staff to full time status as we are able. And, we are working hard to strengthen our volunteer base, adding capacity by recruiting, training and recognizing the value of our great volunteers. My role as director will also be evolving in the next three years to one in which I will be more involved in future planning and direction and less involved in day to day operations.

We are lucky at Autism Delaware to have such a talented and diverse group of people with unique skills that have come together to make us a strong voice for autism. I'm excited to think about our future, and very grateful to be part of it. So, let's stick around and see what the new chapter looks like.

A Service of Autism Delaware



PRODUCTIVE OPPORTUNITIES
FOR WORK AND RECREATION

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Downstate News...

Autism Expo 2009

By Trina Cale-Rosario (mother)
and Shirley Cale (grandmother)

My mother and I teamed up to attend the Autism Expo 2009 in Columbia, Maryland on October 10, 2009 to learn what we could do to help my six year-old "TJ"—aka Tito Rosario, Jr. This expo was hosted by parents Randy and Lynn Gaston who wrote *Three Times the Love*; a book on finding answers and hope for their triplets with autism. The book is filled with practical advice, an extensive resource list, and an essential guide for any family touched by autism. The Autism Expo focused their mission, which is to arm other parents with the kind of information, guidance, and support they were so desperately looking for when their boys began to regress.

The Expo provided invaluable advice ranging from educational programs to legal issues to a comprehensive assessment of the therapies and alternative biomedical strategies and interventions that have worked for their three unique children. Lynn and Randy are noted advocates for autism awareness who have been featured on *Good Morning America*, *Today* and many other television shows and newspaper articles.

The Expo featured more than twenty autism experts and about thirty exhibitors, along with doctors who follow bio-medical protocols (formerly known as DAN). There were so many choices that it was hard to decide which ones focused most on things we needed to know for TJ. We started with Dr. Janelle Love, who outlined what children with autism experience as their bodies adjust to biomedical factors ranging from environmental toxins to food allergies. (Please note that Dr. Love will be a featured Autism Delaware speaker on March 20 in Dover, DE.)

We were thrilled to learn that TJ's physician, Dr. Richard Layton, was giving a presentation. TJ started biomedical therapy in September 2009 so it was encouraging to hear Dr. Layton's presentation on allergies, treatment procedures he uses and some success stories. We were amazed

What is a mand?

The mand is verbal behavior whose form is controlled by states of deprivation and aversion; it is often said to "specify its own reinforcer." What this means loosely is that the function of a mand is to request or to obtain what is wanted. So if a child says "Cookie," and it is functioning as a mand, it means the child is requesting the cookie. Think of mand as short for "demand" or "command." The way to reinforce a mand is to deliver the item manded for. So if a child says "Cookie," you'd give him a cookie. This positive consequence (reinforcement) of the mand will make it more likely that the behavior will occur again. For example, that the next time the child wants a cookie, he will say cookie. So you can equate a mand with a request. We mand for a great many things every day without really thinking of them as mands: Desired items ("I want pizza for dinner"); information ("What time is it?"); assistance ("Can you help me"); missing items (given a bowl filled with cereal and milk, the child says "I need a spoon"); actions ("Play with me"); attention ("Mommy, look what I did"); negative reinforcement (removing something undesired/aversive) ("Turn off that loud music!"), etc., etc., etc. Manding is typically a first step in teaching language because it's based in the child's motivation. Manding typically increases language in general because, through the positive reinforcement delivered as a consequence for the mand, the child comes to associate the sound of his/her own voice with positive consequences.

<http://www.christinaburkaba.com/AVB.htm>

by Dr. Vincent Carbone – a Board Certified Behavior Analyst from the Carbone Clinic in New York, who has researched Verbal Behavior and Applied Behavioral Analysis, working with various universities. He discussed the manding technique (see box) and showed videotapes that were amazing, including some things we would like to try with our son. To learn more about Dr. Carbone, you can see his lecture at: http://www.childnett.tv/videos/lectures/vincent_carbone_verbal_behavior

Ellen Callegary Esq., a special education attorney, talked about non-discrimination and special education laws. And finally, I found a swim instructor for TJ from Martar swimming safety school who teaches special needs kids to swim and can prep them for various Olympic events.

And then there was the shopping! There were exhibitors with all sorts of great products for our children. I found a swing for my son that cost considerably less than the swings in therapy books and holds up to 300 pounds. Wow! I also ordered a shirt that says, "I am autistic, what is your excuse!" from the Autism Shoppe, which it turns out is located right here in

Delaware.

We were so impressed with the conference; the next goal is to see who wants to do an Autism Expo here in Delaware, to get more DAN doctors in Delaware!

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If you have a newly diagnosed child and live in the Kent or Sussex area, give Dafne a call today for information and support.

We can help!

Call for Nominations for Volunteer Awards

We are fortunate in Delaware to have a strong and vibrant autism community across the state. That happens because a few good people step up and do the work that makes our state and community a more welcoming place. To acknowledge all that good work that makes a difference, every spring Autism Delaware awards members and community leaders for their good work. Over the past six years we have recognized a wide number of people who have helped Autism Delaware specifically, and the autism community in general. We also like to recognize employers who hire adults with autism for their contributions.

Please help us to recognize those folks who do this great work to make the entire community better for our individuals and families. Tell who you think should be this year's recipients of awards in these categories:

**Outstanding
Autism Delaware Volunteer**

**Outstanding
Leader in the Community**

**Outstanding
Employer**

To make a nomination you must be a member of Autism Delaware. Nomination forms can be downloaded at www.delautism.org and must be submitted by February 28, 2010.

Thank you!

Thank you to the following businesses and people who made the 11th Annual Auction for Autism such a success- the event raised over \$100,000!

Sponsors

Peggy & Edgar Woolard
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Kevin Reilly
Rigby's Bar & Grill
Salt Air Restaurant
Sharon Salzstein
Seafood Shack
Seymour Cleaners
Sherif Zaki Salon and The Oasis Spa
Sherri Ciancutti Portraits
Don & Kay Shuey
Kim Siegel
Sound of Tri-State
Sugar & Spice Cake Creations
The Learning Station
The New Candlelight Theatre
Town & Country Salon
W.L. Gore & Associates, Inc.
The Hon. Tom Wagner
Wilmington University
Yo-Yo Joe's Toys & Fun
Young Chefs Academy
Alan & Peggy Zugehar

*also donated items

What's Up in Legislative Hall

Insurance Coverage of Autism Treatments

We have been working on insurance legislation to cover ABA therapy for children with autism up to age 21 for almost a year. We are wrapping up final revisions and meeting with potential allies, and expect that our lead sponsors, Sen. Liane Sorenson and Rep. Quinn Johnson will introduce it this winter. Thanks to Autism Speaks, Autism Delaware member Chris Flannery, and Disability Law Program attorney Brian Hartman for their extensive assistance in drafting and revising the bill. This legislation is written to cover individual and group policies, which is broader coverage than in other states. Look for some talking points to come out when the bill is introduced.

Adults and New Graduates

Once again, funding for day services for new graduates is on the chopping block. Delaware will have 77 special school graduates in 2011. Of these, 21 have autism. Another 29 students with autism will graduate in 2012. If these students are not funded, they will go home when school is over to no day program and no job. Someone will have to stay home with them.

Adult services in general may be in trouble as well. There have been no increases in rates for seven (7) years so day programs have already absorbed the big increases in oil and electricity that we've seen as well as the increases in health insurance. This means there is less money for staff. Now that there is a very real possibility that these seven year old rates will be cut, it's very possible that day program staff will be laid off or salaries will be cut, and these

are things that can impact the safety of participants. While Autism Delaware expects to weather this crisis should it come, other programs more dependent on state funding may suffer these consequences. Cuts in community programs that are maintaining people in their own homes and communities can wind up costing the State more in the long run because some of our folks will be forced to move to unnecessary and more expensive long term care facilities. According to figures provided by DelARF, the cost of serving the 77 grads in day programs for one year is the same cost as sending three individuals to Stockley Center.

What Can You Do to Advocate for People with Autism?

Join the efforts of LDAF and Autism Delaware on the Legislative Committee. Contact Denise Bradley, chair of the Legislative Committee, at DenisePete@msn.com. We'll be organizing testimony for Joint Finance Committee hearings.

Call and e-mail your local legislators with your priorities. Yes, the state is in dire straits, but our children should not suffer because of the economy, and insurance coverage for therapies will lead to real improvements for many children.

Autism Delaware will post legislator contact information and talking points on our website. Make appointments with your representative and senator. You may want to invite your legislator to your home to



meet with you and other families affected by disabilities in your district. Make sure your children are there.

Legislators need to know and understand the pressures on the families of children and adults with disabilities. They respond to local needs, so getting to know your legislator is more critical than ever before.

Did You Know?

Here is how you can find out who your legislators are:

Visit www.congress.org or call your county Department of Elections:

New Castle County: (302) 577-3464

Kent County: (302) 739-4498

Sussex County: (302) 856-5367

Let your voice be heard. Call up your legislators and let them know about your concerns and thank them for all of their support!

What does an Autism Delaware membership get you?

Your membership with Autism Delaware strengthens our mission to enhance the quality of life for individuals with autism and their families. You also can get:

- Free or discounted Autism Delaware Events (One to two events can pay for your membership!)
- Free childcare at Autism Delaware meetings or Speaker Series
- Access to conference stipends up to \$250!

Membership dues also help support family services like parent mentoring, great information, support and resources! In these times when every dollar counts, this has to be the best bang for your buck! For more information on membership, you can visit our website at www.delautism.org and join or call us at (302) 224-6020 or simply fill out the application found on the back of this newsletter.

PARENT PARENT

written by parents for parents

Summertime Recreation

by **Melanie Matusheski**

It may seem almost impossible to imagine now but, summer's coming!!! Really, it is! And what's summer supposed to be about? You and your family doing fun activities – cook-outs, sports, picnics, swimming, hiking, going to movies, going to the beach! Unfortunately, too many of us see only obstacles when we think about family activities. These obstacles stop us from seeing some very important facts.

First, the obstacles can not only be overcome, but used as teaching tools. You can use a trip to the beach to teach your son to make a list of what he needs to take to the beach, or what interesting things he will see on his trip, or of appropriate behaviors at a restaurant. A family cook-out can be used to teach food preparation or to learn more about which foods your daughter likes and dislikes.

Second, besides having fun, our kids get enormous benefits from participating in recreational activities. Recreational activities improve not only physical well-being, but can decrease stereotypical behavior. One study found that following moderate aerobic activity, children with autism may experience increases in attention span, on-task behavior, and level of correct responding. Recreation providers at Easter Seals say providing special needs children with social and recreational activities gives them the chance to gain confidence, discover new abilities and experience the joy of accomplishment. The recreation providers believe that special needs children learn much more when they are out in the community.

Summer provides a lot of opportunity for water sports. Many autistic children have benefited from aquatic therapy. It's a unique and fun activity that has not only physical benefits but also social and cognitive benefits. Many of our children have sensory issues that cause them to be easily distracted and over react to stimuli in the environment. Aquatic therapy provides them with a safe and supported environment that many children find soothing and calming. Water provides an environment in which body weight is decreased, which decreases stress

on the body and relaxes muscles. Many studies have found that water is the ideal medium for exercise or rehabilitating the body.

The last fact I want to point out is – We all need more fun in our lives! Yes, a family member with autism does make family activities more challenging. Autism makes just about everything more challenging, but that's no excuse for spending the summer indoors doing the same old things you did all winter. Recreation is at the heart of everyone's ability to enjoy life, develop important life skills, and deepen relationships.

The following websites were used for this article and can provide additional information:

- www.recreationtherapy.com
- www.easterseals.com
- www.palaestra.com/autism

Also, The National Center on Physical Activities and Disabilities website has a very useful section on considerations and guidelines for recreational and physical activities for people with autism. Just go to www.ncpad.org and click on Autism.

Summer Camps in January??

By **Jen Nardo**

We all just had a long winter break with our kids. Did you notice if your child who



has autism did the same thing every day? Did he or she watch DVDs non-stop or click around a favorite website for hours? I know my son will do just that if left to his own devices. Sometimes it's convenient when he is doing an activity that brings him lots of happiness, and I can make dinner or call a friend but, is it really the best way for him to spend his time? As I watch him, I think that there has to be more out there for him to experience and enjoy in life.

I also have a very typical 13 year old who, like most typically developing kids, has no problem making friends or finding something fun to do. He also has the entire summer off of school. Each year, he likes to go to day camps. Some favorites include football camp and anything at the Brandywine Valley Association (outdoor survival skills, spelunking, fishing, camping, etc.). Because of his camp experiences, I realized quickly that the most popular camps fill up fast, and I mean fast!

My son who lives with autism, like
(continued on page 7)

We have so many new additions to our recreation list that we had to move the list online. You can find the list by visiting our website at www.delautism.org and looking on our home page under "Find the Services You Need" and click on Recreational Resources. Or you can call our office to request a printed copy mailed to you.

INSIDE Autism Delaware

Strategic Planning

This fall was dedicated to creating a strategic plan for the coming three years. Members from around the state joined Marcy Kempner in this effort, meeting for three Sunday sessions. Additionally we did a member survey, met with the Advisory Council, Board and staff. Thanks to the 91 members who completed the survey. Here are highlights of things the board is considering:

Parents of Young Children. Autism Delaware does a number of things for young families, but we need to be more accessible and more supportive to young families. Our approach needs to cover the entire lifespan.

POW&R. Families in Kent and Sussex Counties are asking for POW&R services. POW&R is an expensive program to start due to its individualized nature. In a challenged economic environment, how can we expand this program and maintain our financial viability?

Web Presence. Because more and more folks are going to the web rather than making phone calls, we recognize that we need to update our information more often and more effectively and to categorize some information by age groups.

Clinical Services. Are they needed and if they are, are we positioned to think about providing them?

We also need to advocate for additional services across the lifespan to individuals who have Asperger Disorder. School

systems are struggling and there are few to no adult services, so this is a growing area of need.

We would like to thank all the members who participated in this effort including Dr. Suzanne Bagas, Lisa Poyta, Liz O'Neill, Pat Swanson, Judy Smith, Susan Patel, and Angie Sipple along with board members Marcy Kempner, John Fisher Gray, Rob Gilsdorf and Pat Murphy.

Changes in the Board

Lisa Albany is rotating off the board after serving 11 years. As an initial board member, Lisa served as treasurer when that meant writing the budget and paying all the bills. More recently, she has chaired the Walk for Autism and co-chaired the strategic planning process for the current plan. During all of this time, Lisa also worked and is mom of four children. Fortunately for us, she is continuing to chair the Walk. Thank you Lisa, for all that you have done.

Mike Graci also decided to step down from the board, and like Lisa, he is remaining with us. During the past eight years Mike has served as Vice President, Legislative Chair, and Investment Chair. Mike created Autism Delaware's investment policies and oversees investment strategies. This has been a critical factor in our ability to fund the start-up of POW&R, and remains a factor as Autism Delaware expands its programs across the state. Like Lisa, Mike is going to continue to work with Autism Delaware as Chair of the Investment Committee. Thank you, Mike, for your many efforts for us over the years.

While we are sad to see old friends rotate off, we also want to welcome our new board members. Pat Murphy will be staying with us for his final term and continuing in his role with the Golf Committee and Membership. We are happy to welcome Lisa Poyta and Annie Woolard-Provine as new board members. Lisa will bring a fresh look to Autism Delaware's activities and programs as the mother of a younger child. She is also active on the Insurance Committee and has taken the lead with our insurance bill advocacy.

Annie is also the mom of a child on the spectrum. She brings a different experience of having a child who was diagnosed after he entered school. Annie has extensive experience serving on boards and working in the non-profit arena so we look forward to her participation in governance and development.

Even in these difficult times, our future is bright. We were lucky this year to have a wonderful slate of candidates and will be working with both Nina Bunting and Tony Gangemi as we move forward to increase services across the state for individuals with autism spectrum disorders. Nina is chairing our Founders' Circle and will be recruiting additional circle members and helping with legislative advocacy. Tony will become more active later in the year once he earns his Master's degree.

Asking applicants to step up to serve on a board is no small request. We are honored to have so many talented board applicants and we want to thank you all.

(continued from page 6)

most kids in the Delaware Autism Program, attends school year round. So, it would seem that his need for summer camps is non-existent. But, is that the case? Since camps are the summer "thing" for most kids, why not Jake?

Now really is the time to look into available camps that occur during those weeks in June and August that school is closed. Wouldn't camp at a local farm be fun?

How about swimming lessons? Would Jake enjoy some craft camps at the local art center? I know the library has ongoing programs for kids all year long actually. Let's try something new.

Since our kids have specific weeks off, and combine that with the "competition" from the rest of the world, January is not too soon to start planning for the summer. Our kids need those real experiences to put them into social situations so that they

can learn how to react. The more they are exposed to, the more comfortable they will become in new situations which will then open up new doors to new opportunities.

As all new things, starting camp may be a challenge, but don't give up! Call ahead and discuss your child's special needs. You'd be surprised at the many people out there who are willing to make camp available to our kids and who want to see our kids succeed. Call now, I am!

Dr. Temple Grandin Conference

by Shannon Liew

When I signed up to hear Dr. Temple Grandin in October, I asked myself, "Do I attend as a Physical Therapist or as a Mommy?" My son is only 6 ½, and Temple's presentation, "Positive Outcomes for Individuals on the Autism Spectrum" was aimed towards older individuals with autism. In the end, I decided to be a mom and learn from her vast experience in the employment world.

Temple spoke of her childhood in the 1950's when life was simpler and autism was a quieter diagnosis...unknown, underdiagnosed, and untreated. Most children were sent away with a diagnosis of mental retardation. Temple had all the quirks and eccentricities that made her autism shine. With the loving help of her strong willed mother, teachers, and her own will, she honed her quirks and skills into employable ones. She told us to focus on what our folks like to do and what they are good at. Her advice –turn your skill into employment.

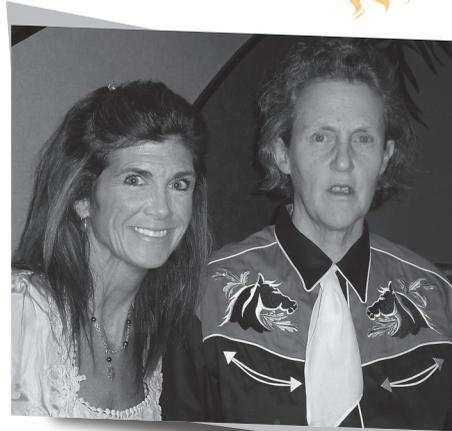
Dr. Grandin gave valuable information about the environment we live in and how Sensory Integration Disorders (SIDs) can affect individuals with autism in the work place. She spoke frequently about

the importance of physical activity (at least 20 minutes of structured, vigorous activity every day) to calm and refocus the brain/ body connection.

She also touched on the "type" of learner you may be. For example, if you are a visual learner, you need to be taught to "STOP" at the street corner when there is a stop sign, when there is a stop light, and when there is a "No Crossing" white line on the road. She calls this "Bottom Up Thinking". Jobs for Visual Thinkers might be: Industrial Designers, Computer Network Specialists, Graphic Artists, Auto Mechanics, Equipment Designers, Photographers, Animal Trainers and Architects.

If you are a "Pattern Thinker", you might excel in math and music. Good job placements might lead you into the jobs like Statistician, Math/Science Teacher, Chemist, or Music Teacher.

Finally, she spoke of drugs like SSRIs – Selective Serotonin Reuptake Inhibitors. Prozac, Lexapro, Paxil and Celexa focus



on depression, and Respirodal, Geodan, Zyprexa and Abilify work on anger. She said we should read the ingredients, know how our body responds to these drugs and take the least amount of prescribed pharmaceutical and alternative supplementation

interventions as needed. (Side note: she swears by CLO – Cod Liver Oil – Omega 3s!!!).

Finally I purchased her newest book, *The Way I See It* and got a photo with her. But mostly, I had the extremely gratifying experience to delve into the thoughts of an individual who is living the life of an adult with autism in the world as we and our children know it today. She gave valuable insight about the gifts autism has brought to the world (Einstein, Tesla), and the strengths we have yet to uncover in our children and young adults with autism in the coming employable future. A fabulous and incredible woman! Thank you for this opportunity Autism Delaware.



Autism Delaware Seeks Corporate Sponsors, Teams, and Walkers for the 4th Annual Walk for Autism on April 10!

In 2009, over 1,000 people raised \$100,000 at the Walk for Autism, and **on April 10, 2010, we're going to do it again!** The Walk, Autism Delaware's largest community fundraising event, will once again be held at the Hunter Barn in Bellevue State Park, and will feature music, exhibits, games, food, and crafts, turning the event into a day of family fun.

How can YOU be a part of it? By being a...

- ...**Sponsor:** sponsoring the Walk is a great way to get exposure to your company or organization. There are sponsor levels for every organization budget (\$100 to \$10,000), and many include opportunities to feature sponsor names on brochures, T-shirts, posters, etc.
- ...**Captain:** Captains lead and build Teams through recruiting, encouraging Walker fundraising, and serving as a liaison between their Team and Autism Delaware.
- ...**Walker:** Walkers raise money for their participation in the Walk, which gets the word out about autism and Autism Delaware with every request for a donation. Walkers who raise at least \$100 will be eligible for prizes for their success.
- ...**Volunteer:** there are lots of volunteer opportunities before and on Walk day! Contact Colin Barratt at colin.barratt@delautism.org for more information.
- ... **Exhibitor:** Setting up a table at the Walk is a great way to reach out to the hundreds of families at the Walk. There is a fee of \$25 for nonprofits and \$100 for businesses to exhibit.

For more information on becoming a sponsor or exhibitor, call Autism Delaware at 302-224-6020 or email delautism@delautism.org. To become a Captain or individual Walker, please contact us at the same number or address with your name, Team name if you have one, mailing and email addresses, phone number, and number of Walkers you are requesting materials for. We'll begin mailing Team and Walker packets in late January.

N.C.C. Family Bowling Night

Join us every Wednesday night at AMF Price Lanes at Prices Corner on Kirkwood Hwy, Wilmington, 5:30 pm.

RSVP required by the Monday before.

to Mark or Cher Frampton at (302) 998-1466. No commitments. Pay after you play. Play as many or as few games as you like. Bumpers, ramps and special discounts available. Game room and snack bar open. Parents, siblings, and friends are welcome to bowl.



Milford, Lewes & Dover Coffee Hours

January 12, Lewes Coffee Hour, 9 - 10 am
at McDonald's - Rt.1 in Lewes. Meet in the play place area.

February 19, Milford Coffee Hour, 9 - 10 am
at Georgia House Restaurant, 18 S. Walnut Street, Milford.

March 17, Dover Coffee Hour, 9 - 10 am
at the Holiday Inn Express, N. DuPont Hwy,
Dover (behind the McDonald's).



Recreation Fair

January 19th from 6:30-8:30PM at Brennen School
144 Brennen Dr. Newark DE, 19713.

The recreation fair provides opportunity for families to explore activities such as sports groups, camps, art, dance and therapeutic programs. Recreation service providers will have the opportunity to share information about their services and many will be available to answer questions. Contact Heidi. Mizell@delautism.org if you have any questions.

N.C.C. Parent Coffee and Conversation Hour



(302) 326-1130
(Restaurant)

Join us along with other parents or family members on the second Tuesday of every month at the elegant Prince on Delaware for coffee and conversation. Coffee is on us!

124 Delaware Street
Historic Old New Castle
(Across the street from the old court house near the Delaware River.)

Restaurant is closed to the public. Children are welcome. No RSVP needed.

Hope to see you there!

Sensory Friendly Movie

Save the date for this new and developing social opportunity...

Movie: The Princess and the Frog

NCC Regal Cinemas, People's Plaza - January 16
10:00 a.m. \$7.50 per person.

Speaker Series: Dr. Janelle Love

March 20, 2010 from 10 AM until noon. Place to be determined

Last year Dr. Love talked to us about "Autism Biomedical Treatments". She will be returning to talk about what's next and to update us on the latest findings in biomedical treatments. \$10 fee. Members free.

Supporting community organizations is one way WSFS Bank has been strengthening the core of Delaware for more than 175 years!

**We
Stand
For
Service**

in our community!

WSFS Bank is especially proud to support Autism Delaware.



www.wsfsbank.com

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Milford Skating Party

Milford Skating Center 5:30 -7:30pm

February 19, 2010

Free admission. No RSVP needed. Family and friends welcome. Rinks are closed to the public. Autism friendly lights and music. Snack bar is open, and skate rentals are available (\$2-3).

Parents may wear sneakers on the floor to help aid younger children while learning how to skate.

Don't miss out!



CALENDAR of EVENTS

If an event has a page number in parentheses after it, visit that page for more details.

January

January 1- AD & POWR Office Closed, New Years Day

January 6- NCC Family Bowling Night, 5:30PM at AMF Price Lanes at Prices Corner (see page 9 for more info).

January 12- NCC Parent Coffee and Conversation Hour, 9:00AM Prince on Delaware on 124 Delaware St., Old New Castle. Coffee is on us, children are welcome! We meet the second Tuesday of every month. No RSVP required.

January 12- Lewes Parent Coffee & Conversation Hour, 9-10 am at McDonald's - Rt 1 in Lewes. Meet in the play place area. Join us along with other parents, caregivers, and grandparents and enjoy informal conversation. Coffee is on us! RSVP Requested but not necessary.

January 12- Adults with Asperger's Support Group, 7:00-8:30 PM at the Autism Delaware office. Pilot support group for individuals with Asperger's Syndrome. RSVP requested but not necessary. Contact Heidi Mizell (302) 224-6020 for more info.

January 13- NCC Family Bowling night, 5:30PM at AMF Price Lanes at Prices Corner (see advertisement page for more info).

January 15- Tween/Teen game night, 6:30-8:15PM at 774 Christiana Rd. in Newark. Cost is \$10 per night. Call Deanna Principe for details (302) 224-6020.

January 16- *The Princess and the Frog*, sensory friendly movie. The movie starts at 10:00 AM at Peoples Plaza Regal Cinemas, \$7.50 per person.

January 18- POW&R Office Closed, MLK Jr. Day.

January 19- Recreation Fair, 6:30-8:30PM at Brennen School, 144 Brennen Dr. Newark DE, 19713. The recreation fair provides opportunity for families to explore activities such as sports groups, camps, art, dance and therapeutic programs. Recreation service providers will have the opportunity to share information about their services and many will be available to answer questions.

January 20- NCC Family Bowling night, 5:30PM at AMF Price Lanes at Prices Corner.

January 26- Friendly's Fundraiser Night, 5:00-9:00PM at the Friendly's on 896 near UD stadium and close to the I-95 entrance. A percentage of all eat in and take out orders go to Autism Delaware.

January 27- NCC Family Bowling night, 5:30PM at AMF Price Lanes at Prices Corner.

January 30- Milford Skating Party at Milford Skating Rink from 5:30-7:30PM. The event is sensory friendly. Parents can wear regular shoes on skate floor to better assist their children with learning to skate! Free entrance, \$2.50 skate rentals. Contact Dafne (302) 422-2255 for more information.

February

February 9- NCC Parent Coffee and Conversation Hour, 9:00AM, Prince on Delaware on 124 Delaware St., Old New Castle. Coffee is on us, children are welcome! We meet the second Tuesday of every month. No RSVP required.

February 15- AD Office Closed, Presidents Day.

February 19- Milford Parent Coffee & Conversation, 9-10AM at the Georgia House Restaurant, 18 S. Walnut Street, Milford. Contact Dafne (302) 422-2255 for more information.

February 19- Tween/Teen game night, 6:30-8:15PM at 774 Christiana Rd. in Newark. Cost is \$10 per night. Call Deanna Principe for details (302) 224-6020.

March

March 9- NCC Parent Coffee and Conversation Hour, 9:00AM Prince on Delaware on 124 Delaware St., Old New Castle. Coffee is on us, children are welcome! We meet the second Tuesday of every month. No RSVP required.

March 10- Autism Delaware meeting after the Charlton PAC meeting. 7:00 PM. at the Charlton School, Camden-Wyoming. Location is tentative.

March 12- Tween/Teen game night, 6:30-8:15PM at 774 Christiana Rd. in Newark. Cost is \$10 per night. Call Deanna Principe for details (302) 224-6020.

March 17- Dover Parent Coffee & Conversation Hour, 9-10AM at the Holiday Inn Express, N. DuPont Hwy., Dover (behind the McDonald's). Contact Dafne (302) 422-2255 for more information.

March 19- Tween/Teen game night, 6:30-8:15PM at 774 Christiana Rd. in Newark. Cost is \$10 per night. Call Deanna Principe for details (302) 224-6020.

March 20- Speaker series, Dover Dr. Janelle Love speaking on biomedical protocols for children with autism. This will be a follow up to her introductory lecture last year. 10am-12pm. \$10 fee, free to members.

March 31- Autism Delaware/PAC meeting at Capital School. 6:30 PM. Dover.

PSST! Did You Hear?

Some upcoming happenings that you may not have heard about.

Lego Club (once a week) an evidence based generalization of social skills program. We are working on this statewide.

Adults with Asperger's Social Group-social events and support for our individuals who have finished high school.

Game Night (once a month) for individuals who need more one on one attention in board game play. This game night will run with more support and for a shorter amount of time (6:30-7:30). We will be playing one game as a group and encouraging friendly play and communication. PECS and AAC devices welcome and encouraged. This group will be limited to four participants to start. For more details or to register please call Heidi Mizell at 224-6020 ext. 205.

Things we are planning:

Sexuality class for those across the spectrum.

Independent Living class: Basics for those who are going to college or are learning to be more independent.

Medicaid and Your Child by Theda Ellis

We recently invited a panel of state Medicaid workers to speak about Medicaid Eligibility. Learning about Medicaid programs for children with disabilities is a challenge and getting more challenging, so Autism Delaware offered to serve as a facilitator to help parents understand what they need to provide to Medicaid when applying for the **Children Community Alternative Disability** program. This is important because there are many programs under Medicaid. It's not unusual for eligibility workers to only know their own program, so they don't always steer applicants in the right direction. Also, it is not clear what kind of information you need to provide so that your child will become eligible based on his or her disability. Here is some information that we hope you will find helpful.

Eligibility for Children's Community Alternative Disability

This program is for children's whose disability is so severe that they are at risk of requiring institutionalization. The purpose is to support children to live at home instead of in an intermediate care facility (e.g. Mary Campbell Center), a skilled care facility (nursing home), an acute care hospital, a psychiatric facility or a mental retardation facility (Stockley Center).

The child may have some income, but that income may be no more than 250% of Federal Poverty Level, which is currently \$1,685 per month. Parental income is not counted to be eligible for this program.

Criteria for eligibility is:

- The child must be under age 19.
- The child may not have assets in his or her name worth more than \$2,000.
- The child must qualify **medically** for SSI (Supplemental Security Income) under Section 1614(a) of the Social Security Act. See the link below for more information: www.ssa.gov/disability/professionals/blue_book/childhoodlistings.pdf
- The qualifying disability is expected to last at least one year.
- The child requires a *level of care* (see box) but can be cared for safely in the community.
- Medical care received at home must cost less than the cost of care of the appropriate facility care.

Please note that children with autism are not automatically eligible. Eligibility depends on their *level of care* (see box) required. If your child has severe behavioral

and other health issues, she or he is more likely to be eligible.

Where do I apply?

Apply through your local Division of Medicaid & Medical Assistance (DMMA) offices. I called to test this out and found they were willing to mail the application to my home. Where you apply is based on your zip code and is listed below. Be careful that you do not apply through a State Service Center. They may not understand what you want or direct you to the correct place.

DMMA Office	Zip Codes it serves
16th & Thatcher St.	19703, 19732, 19735
910 E. 15th St. Wilmington, DE 19802, 577-2174	19703, 19732, 19735
Robscott Building 153 E. Chestnut Hill Rd. Newark, DE 19713 368-6610	19701, 19702, 19706, 19707, 19708, 19710, 19711, 19713, 19720, 19731, 19733, 19804, 19807, 19808
Smyrna SCC 200 S. DuPont Blvd., Suite 101 Smyrna, DE 19977 514-4560	19709, 19730, 19934, 19936, 19938, 19953, 19955, 19977
Milford State Service Center 11-13 N. Church Ave. Milford, DE 19963 424-7210	19901, 19902, 19904, 19941, 19942, 19943, 19946, 19950, 19952, 19954, 19963, 19960, 19961, 19962, 19963, 19964, 19979, 19980
Georgetown State Service Center 546 S. Bedford St. Georgetown, DE 19947 856-5379	19930, 19931, 19933, 19939, 19940, 19944, 19945, 19947, 19951, 19956, 19958, 19966, 19967, 19968, 19969, 19970, 19971, 19973, 19975

Required medical information

The application packet will contain forms for you to complete, however, it is also important for you to provide the following information, even though it is not initially requested. Medicaid has advised us that the application process will go more smoothly and the chances of your child becoming eligible will be greater if they have this information.

- Chromosomal Studies
- Therapy evaluations, treatment plans & progress notes

- Most recent IEP
- Psychological test results
- IQ test results
- Psychiatric and/or psychological reports
- Hospital discharge summaries (if applicable)

What services are provided under Children's Community Alternative Disability?

Medicaid provides comprehensive medical coverage. Benefits include:

- Private duty nursing services
- Emergency and Non-urgent Transportation Services
- In and Out Patient Hospital Care
- Prescribed Pediatric Extended Care
- Durable Medical Equipment
- Therapies (PT, OT, ST) (Note: Medicaid does NOT provide ABA therapies in Delaware.)
- Home Health Care
- Physicians Care
- Dental Care
- Pharmacy
- Vision Care

When do services end?

Children's Community Alternative Disability is available through the child's 18th year. Once the child reaches age 19, she or he will no longer be eligible; however, she or he should be eligible for SSI and Medicaid at that point. Be sure to apply for SSI when your child reaches age 18 so that there will be time to establish eligibility for SSI and Medicaid as an adult. This will keep services from being interrupted when your child turns 19.

If you have problems, please let us know so that we can assist you with advocacy and also to ensure that our information to you is correct. State Medicaid staff is working hard to do a great job for our families, but they are working under severe resource limitations, so the more prepared parents are during the application process, the more likely it will be that your child will be eligible.

Level of Care

The term, level of care, refers to the type, duration and frequency of nursing care and related services that are medically necessary to keep the child at the optimum level of functioning. A medical need or known diagnosis may exist, but, if no nursing services are required on an ongoing basis to treat the medical need then the child does not require a medical facility level of care. This decision is NOT based solely on diagnosis or type of condition or degree of functional limitation.

Autism Delaware Annual Membership Application

Please enroll me in the following category:

- Individual \$20 Family \$25 Professional \$50 Silver \$100 Platinum \$300 Lifetime \$500
 I am a new member I am renewing membership I was referred by: _____

Name(s): _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (h) _____ (w) _____ Email: _____

- I am a: Parent Family Member Service Provider Educator Medical Professional Individual with autism
 Other (please describe): _____

- Yes! Please add my name to the mailing list to receive Autism Delaware's newsletter *The Sun*.

(This is for families who do not receive *The Sun* through DAP Distribution only please.)

My membership fee is \$ _____

I would also like to contribute this amount \$ _____

Total amount enclosed (add both amounts) \$ _____

Becoming a Silver member or higher will make you a part of a select group of individuals who have demonstrated special leadership and a deep commitment to making a significant difference in the fight against autism. You will receive special recognition in our newsletter or other documents as a leader in the support of autism and autism research.

Please make your check payable to Autism Delaware and send payment and application to Autism Delaware, 924 Old Harmony Rd., Ste 201, Newark, DE 19713.

If you prefer to pay by credit card, please join on line at www.delautism.org or call Autism Delaware at (302) 224-6020. All membership fees and contributions are tax deductible.



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Newark, DE 19713

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Helping People and Families Affected by Autism