



The Sun

The Voice of Autism in Delaware

Detachable Monthly Calendar

September 2006

Autism Society of Delaware

(302) 472-2638

www.delautism.org

| Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|--------|---------------------------------|---|-----------|----------|--------|------------------------------------|
| | | | | | 1 | 2 |
| 3 | 4 Labor Day Office Closed | 5 | 6 | 7 | 8 | 9 |
| 10 | 11 | 12 Parent Coffee Hour 9 a.m. | 13 | 14 | 15 | 16 Mom's Night Out 7 p.m. |
| 17 | 18 | 19 | 20 | 21 | 22 | 23 |
| 24 | 25 | 26 ASD Annual Meeting 6:30 p.m. | 27 | 28 | 29 | 30 |



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Sunday

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| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8 | 9 | 10 Parent Coffee Hour 9 a.m. Dads Night Out 7 p.m. | 11 | 12 | 13 | 14 |
| 15 ASD Fall Festival 1 p.m. | 16 ASD Chapter Meeting 7 p.m. | 17 N.C.C. Support Group 7 p.m. | 18 | 19 | 20 | 21 Autumn Auc- tion for Au- tism 6:30 p.m. |
| 22 | 23 | 24 | 25 | 26 | 27 | 28 |
| 29 | 30 | 31 |  <p>Taking the High Road Autism Walk</p> <p>Coming April 28, 2007 www.delautism.org</p> <p>Sponsored by: Autism Society of Delaware & High Road School</p> | | | |



The Voice of Autism in Delaware

The Sun

The Autism Society of Delaware Newsletter

www.delautism.org

September/October 2006

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Our Mission

The Autism Society of Delaware is a chapter of the Autism Society of America. We are 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.

Landmark Autism Registry Legislation Marks Two Year Anniversary

By: Marcy Kempner

In 2004, the Autism Society of Delaware, led by Advocacy Chair Rob Gilsdorf, was instrumental in getting legislation passed to establish a registry of people with autism in Delaware. This landmark law, the Autism Surveillance and Registration Program, sponsored by Representative Dick Cathcart, was modeled after similar legislation in West Virginia. It will make it possible for the first time in Delaware to get a true count of people with autism. The information collected in the registry will also start us down the road to answering many of the unanswered questions that surround autism, according to epidemiologist Craig Newschaffer, Ph.D. Dr. Newschaffer, who is Director of the Autism and Developmental Disabilities Monitoring (ADDM) project at Johns Hopkins, as well as an Autism Society of Delaware member and ASD Advisory Board member, points out, "When there are still big questions about causes for a condition, good, basic descriptive information is key. Creating a registry has been an important tool in advancing understanding and research of other conditions, most notably cancer, and replicating that success is the goal of the autism registry. You can get an idea about basic disparities across different groups that can help us figure out causes. It's also important to really understand the impact that autism is having in the community. There won't be any estimating of numbers or information. That is important for informing and

creating policy to help this population."

Ironically, Newschaffer's ADDM project, which is funded by the Federal Centers for Disease Control, was originally approved to include Delaware and would have provided crucial information about not only numbers, but trends across autism cases in the state. The ADDM project's method for collecting data is different from that of a registry. It involves studying health and education records of children, and while the federal regulations regarding privacy for accessing health records (HIPPA) are very specific about making it possible for accredited researchers to use the information, the regulations surrounding access to education records (FERPA) are more ambiguous. Though at least ten other states, including Maryland and New Jersey, have interpreted FERPA to allow access to education records for these legitimate and important research efforts, Delaware's Department of Education ultimately denied Newschaffer's team access to the records they needed. The Autism Registry was originally intended to supplement the ADDM project's information in Delaware, but now it will provide the only real data about autism in the state. While the Delaware Autism Program records can show the number of children enrolled in the DAP, they will

(Continued on page 3)

Contributions for this newsletter provided by:





The Sun

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The Director's Chair

By: Theda Ellis

ASD has a vibrant community that is the foundation for our many activities. Over the past few years, Artie Kempner and I have taken turns asking our members to step up and volunteer. We're thrilled to say that many of you are stepping up to the plate and we would like to recognize you and your efforts.

Public Awareness Committee—this committee has all new members that are doing some very important work – getting the word out about autism! Chaired by Dwayne McMahan, Dwayne has offered his help in a number of ways, including bringing ice cream to events. Joining Dwayne on this committee are Jen Nardo, Colleen Grier and Tim Ireland. Jen is writing our press releases; Colleen is heading the library awareness campaign which will be happening in October; and Tim, who is new to Delaware, is sharing his experience as a journalist to help us revise and update our strategies in working with the press.

The Sun—it's hard for anyone who is not involved to know how much work goes into this newsletter. The committee identifies what the articles should be, writes articles, and proofreads. At least three people read *The Sun* up to three times before it goes out. *The Sun* is comprehensive, and it takes time. We want to welcome new member Brenda Holsey in addition to Jen Nardo. Both Brenda and Jen have offered their assistance in other areas as well, so we're very excited about these new volunteers.

Social Activities—longtime member Nicole Curran is taking this committee back under her wing with the able assistance of new(er) members, Robin Delaney and Stacey Parfait. Robin also chaired the trophy subcommittee for *The Drive*, and all three will be involved with our *Taking the High Road Autism Walk*. Social events are a key activity of ASD, so this group has many events on their plate. Look for the Fall Festival in October, and the holiday party in December. If you are looking for something to do, this is a great way to get your feet wet and join in with the folks who are dedicated to having fun!

Taking the High Road Autism Walk. Many of you have been requesting a walk for years. We are pleased to announce that ASD is joining High Road School to introduce a walk in April. The *Walk* is headed by Lisa Albany and Robin Delaney with able assistance of long time members, Judy Hedrick, Nicole Curran and Karen Tuohy; and new members, Colleen Grier, Stacey Parfait, Rebecca Perry, and Michele Cornwall. It is a great opportunity for partnership between ASD, High Road School and the community.

We also would like to welcome Beth Bourett to the auction committee, and Monica McMahan who is heading *Mom's Night Out*.

Volunteering empowers us to make a difference, and we have many ways to use volunteer efforts. If you have the desire, we have the work. Contact any one of us in the office and we can help you find a place where you fit.



Autism Registry

(Continued from Cover)

not capture the students with high functioning autism who attend their local school, student who are home schooled, or those who have transitioned out of the DAP, etc.

The first two paragraphs of the law read as follows:

1.1 Autism is a severe neurodevelopmental disorder whose prevalence appears to be increasing in Delaware and across the United States. An Autism Surveillance and Registration, or an Autism Registry, will enable the Department of Health & Social Services (DHSS), Division of Public Health (DPH) to collect basic descriptive information on the individuals with autism, to track changes in prevalence over time, to inform the planning of service delivery to children with autism and their families, and to facilitate autism research.

1.2 The purpose of the Autism Registry is to provide an accurate and continuing source of data concerning autism to provide information to Public Health officials to help to ultimately decrease the autism morbidity burden associated with the disorder. The Autism Registry will gather data to assist with: prevalence estimation, cluster investigation, risk factor identification, and outcome assessment.

In addition, the law contains the following privacy protections:

6.1 No report of a diagnosis or treatment of confirmed autism received by the Division shall be disclosed in such a way as to identify the child who is the subject of the report, or as to identify the child's family. However, patient-identifying information may be exchanged

among authorized entities as approved by the department and upon receipt by the department of satisfactory assurances by those entities of the preservation of the confidentiality of such information. Those entities will maintain the confidentiality of any information exchanged for the purpose of delivery of program services, evaluation, early intervention and epidemiological investigation.

6.2 No individual or organization providing information pursuant to these regulations shall be held liable for divulging such information to the Division.

(Full text of the law can be found at www.state.de.us/research/AdminCode/title16/4000/4100/4109.shtml)

Some practitioners who treat children with autism have expressed concern that some of the language in the law can be misleading, and have also expressed doubts about privacy protections. While the Autism Society of Delaware supports the Autism Registry and feels confident that the wording of the law was made available for public comment (at a public hearing in January of 2005 some changes were made to improve the wording and clarify the bill), now that the law has been in practice for a year, the experience of practical application could provide ways to improve the overall effectiveness of the registry.

ASD urges all parents to support the Autism Registry, to encourage your health care providers to submit your child's information to the Division of Public Health as specified in the law, and, if you have concerns, to please contact the ASD office and offer to work with those involved to make this registry as successful as possible. As Dr. Newschaffer sums up, "If registries are set up properly with information available while pro-

tecting privacy, they can be an important tool for doing research and can even serve as a draw for researchers to come to Delaware."

A Very Special Thank You...

Dear Kathie Cherry,

You collected literature, you took time from your busy schedule, you traveled to our sons' summer preschool and trained the teaching staff about autism and how to best interact with our special children. You then answered a ton of questions, and shared your own experiences. For this we are extremely grateful.

Kath, you are the best!

With heartfelt thanks,

Dafne Carnright &
Kate Stomieroski
Mommies to Dylan & Jack



Our most valuable resource is each other.

-C.K.

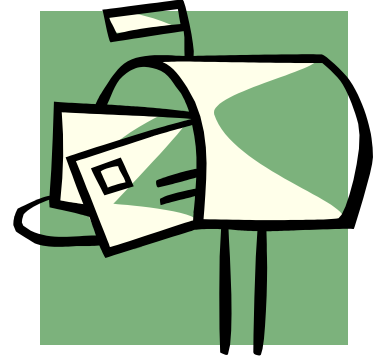


Please welcome the following new members to ASD...

Tonya Bowman-Davis
 Jennifer & Wayne Brandl
 Psyche Cherry
 Jennifer Cornell
 Trina Evans
 Carol Howard
 Suzanne Hurt
 Michael & Susan Jones
 Johane Joseph
 Robin and Michael Kane
 Charlene Lindsey
 John and Barbara Muenze
 Steven M. Nieblas
 Rebecca & David Perry
 Michelle Rosend
 Robert & Roberta Schroeder
 Twanna Winchester
 Paul & Tammy Zoppi

Letters to Sam Dr. Dan Gottlieb

September 12, 2006
 Bowman Center, Bank of
 America (formerly MBNA)
 Route 4 & Route 273
 Newark, Delaware
 Doors open at 6:00 p.m.



Tickets are \$5 each
 First 100 reservations will receive a free copy of
 Dr. Gottlieb's book
 Call (302) 831-3632 to RSVP or
mhess@udel.edu

Dr. Gottlieb is the host of "Voices in the Family," a call-in radio show aired on WHY 90.9 FM, Philadelphia's public radio station. He has recently published *Letters to Sam: A Grandfather's Lessons in Love, Loss and the Gifts of Life*, dedicated to his grandson, Sam, who has Pervasive Developmental Disorder, a form of autism.

ASD Options Policy

All information provided or published by the Autism Society of Delaware (ASD) is for informational purposes only. Reference to any treatment or therapy option or to any program, service or treatment provider is not an endorsement by ASD.

You should investigate alternatives that may be more appropriate for a specific individual. ASD assumes no responsibility for the use made of any information published or provided by ASD.

The Second Tuesday of Every Month

PARENT'S COFFEE HOUR

Crossroads Restaurant, Route 7 & Kirkwood Hwy, Wilmington.

Moms, Dads, Grandparents or anyone with a connection to autism is welcome to attend. Little ones not in school? No problem, bring them along, too.

Just Show Up at 9 a.m. and Ask for the Autism Table. Coffee is on US!



Next Deadline for Submissions to The Sun:
 September 29, 2006

Want to share a story? Have an idea for an article? Send it to ASD today!
delautism@delautism.org. Or mail it to us, (address on page 2)
 Let Your Voice Be Heard!



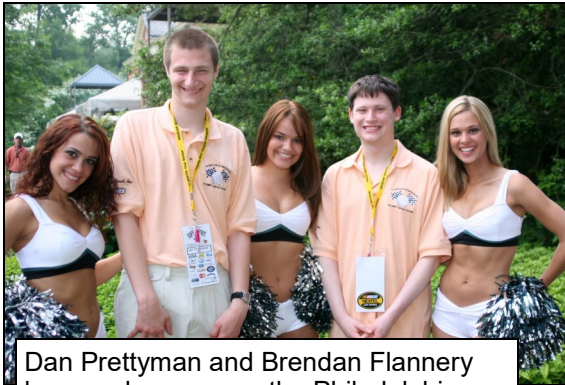
ASD reserves the right to edit for space and content.



ASD Summer Fun and Fundraising!

The Drive for Autism Research

On June 1, 2006, ASD hosted The Drive for Autism Research Celebrity-Am Golf Outing at the Brantwyn Mansion at the DuPont Country Club. Over 250 golfers and guests showed up for ASD's largest golf outing yet. Over \$350,000 was raised that will be used for autism research and local programming. Many thanks to all of our sponsors and to the golf committee. We would also like to thank all of the volunteers who came out to help make this event a huge success. We couldn't do it without you! -Cheryl Kelley, Event Coordinator.



Dan Prettyman and Brendan Flannery keep a close eye on the Philadelphia Eagles Cheerleaders.



Nick Graham and Mom Lucy pose with NASCAR Driver Kenny Wallace.



Drive volunteers Robin Delaney & Kirsten Landon hop a ride in from the field with Dwayne McMahan.

ASD Annual Beach Party Picnic

On August 20, 2006 over 180 people gathered for ASD's Annual Beach Party Picnic at Cape Henlopen State Park in Lewes. Great food, ice cream, train rides, an obstacle course and a beautiful beach filled the day.

Special thanks to Nicole Curran, Theda & Warren Ellis, Rob & Robin Delany, Kim Siegel, Heidi Mizell, Karen Tuohy, Art Frampton, Dwayne & Monica McMahan & Margie Rowles for all of their help!



Monica McMahan dishes out ice cream to some hungry customers.



Colleen Grier along her daughters Tara & Maura and son Conor test the waters before going in.



Cameron Curran takes a dive off of the obstacle course slide.



Autumn Auction for Autism Unmasking Autism

Saturday, October 21, 2006
Greenville Country Club

Show Stopping Live & Silent Auction!

Magical Oils!

Featuring Music by *The Quake!*

Tarot Card Readings!

Great Food!

Black Tie—Formal Costumes Optional!

Honorary Chair
Former Philadelphia Eagles
Kevin Reilly

A true champion who overcame a serious disability, giving him a unique understanding of what it takes to fight back and win.

Please RSVP by October 13, 2006.

Patron—\$2,000, table of eight (Includes 1/2 page ad in program and newsletter, *The Sun*)

Friend—\$1,000, four people (Includes 1/4 page ad in program and newsletter, *The Sun*)

Supporter—\$500 per couple

Advocate —\$300 per couple

Individual — \$125 per person

**For ticket information,
please contact the
Autism Society of Delaware
5572 Kirkwood Highway
Wilmington, DE 19808**

**(302) 472-2638
delautism@delautism.org**

www.delautism.org



Autumn Auction Raffle

Trip for 4 to Orlando, Florida.
7 days, 6 nights at the
Residence Inn, Lake Buena Vista.
Includes airfare and 4
Disney one-day hopper passes.

Drawing will be held at the Autumn Auction on
October 21, 2006. Need not to be present to win.

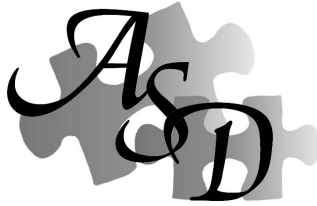
Only \$10.00 a chance!



Return with payment no later than October 13, 2006.



Inside The



There is never a dull moment here at ASD. Take a moment to read about what's going on.

Task Force for Adults with Adult Spectrum Disorders Service Needs

Rep. Bill Oberle introduced House Resolution No. 89 to create a task force to address the needs of adults who are on the spectrum but who are not eligible for any services or supports from the State. The task force is charged with completing a report by May 31, 2007 that has these components:

- clarify what the autism spectrum is and what it includes
- estimate the number of individuals in Delaware who are on the spectrum but who are not receiving services
- identify currently existing public and private resources in Delaware and any limitations they may have
- review services that are needed for this group to be successful, and determine how services can be delivered in a cost-effective manner

Members of the task force will include Rep. Dick Cathcart, Rep. Terry Schooley, Dr. Joe Keyes for Developmental Disabilities Services, Steve Dettwyler, Director of Community Mental Health for the Division of Substance Abuse and Mental Health, and Harline Dennison for the Division of Vocational Rehabilitation. Additionally there will be our own member, Craig Newschaffer for ASD, and parents Kent Riegel, Robert Facinelli, and Kathie Cherry.

We'll keep you informed as the work of this group progresses.

Teen Night Out!

ASD sponsored a monthly teen night out for young teens during the spring. We would like to thank Shara Simpson and Amy Ribblett for facilitating this group. Attendance ranged from 9 to 17 teens. Member Heidi Mizell organized the sessions and met with interested parents while Shara and Amy met with the kids. A highlight of the night, like any teen group, was eating pizza and cookies. The teens spent their time playing cards, board games, and having fun. They created their own rules and guidelines for participating in the group and brainstormed about what they would like to do in the future. ASD is now considering how to continue these groups; such as seeking sponsorship or the possibility of charging a fee. We hope to offer them again in late fall or early winter and will let you know as soon as we know.

Creative Gift Giving

Raising money is always a challenge so we really appreciate the unique ideas that some of you have exhibited over the past few years.

Member Bob Rausch and his lovely new wife, Julie Good, celebrated their marriage and ASD by naming us as the recipient for their wedding gifts. Congratulations to them on their recent nuptials as well as a big thanks! In a similar vein, Liz O'Neill and Karen Bashkow have honored us with 50th wedding anniversary parties for family members over the past few years (no, neither Liz nor Karen have reached that anniversary yet!) Friends and families gave gifts to ASD in lieu of gifts to the anniversary pair.

Young Missy Mizell and Emma Skilton had a joint birthday party and donated their birthday gifts to ASD; and Matt Kempner has assisted us by raising money through his Sunday school for a worthy cause. My personal vote for the most creative, James Grier's office mates at CSC paid \$5 each in order to dress down one Friday this past spring with half the money coming to ASD. His company allows members to pay to dress down with the funds going to local organizations.

Please let us know if you have a creative idea that you would like to share. We appreciate all your efforts!

Fall Elections and Annual Meeting

The ASD Annual Meeting is September 26, 2006. It's that time of year when we elect board members, review the ASD budget and expenses for the year, as well as review our accomplishments and get information from the membership about what you want to see the organization take on. This is a membership organization, so it's important to attend the meeting, share your thoughts, observations and opinions, and most of all, VOTE!

The ASD Board of Directors works very hard to ensure the continuity and growth of this organization, and they have provided a great deal of leadership over the past eight years to get us where we are. This is a great time to talk with them about where you want to go, and to share your observations on how we are doing. Mark your calendars for the Annual Meeting at 6:30 p.m. September 26 at the Concord Presbyterian Church.



Legislative Issues



Family Support Waiver Is Not Funded

It is not often that ASD takes on an initiative that isn't successful; particularly when we work in partnership with other organizations such as the Arc of Delaware and the Lower Delaware Autism Foundation. Unfortunately, despite the leadership of these and other advocates, the letters we wrote and phone calls we made, the Family Support Waiver did not go through this year.

All is not lost because the Family Support Waiver did get some attention. The epilogue to the budget bill calls for the Office of Management and Budget to examine the costs of funding the Waiver (see sidebar). Many of us in the disability community think the State should not restrict itself to reviewing just the costs. We think the question should really be: What are the costs if we do not fund the Family Support Waiver? Why are we only looking at the cost side? These are the really important reasons to fund the waiver.

Flexibility.

The waiver will offer greater opportunities for choice and flexibility to adults with disabilities and their families because it gives them both control and responsibility. It allows for those who choose, to plan their services and supports and control the funds available to them. With an approved plan and budget that meets appropriate guidelines, it improves accountability, and as shown in other states, it can reduce the costs.

Savings to the State.

There are currently more than 1000 adults with disabilities who live with their families, sometimes until the parents reach their 70s and 80s. By giving a little more support to these individuals and their families, the likelihood that they remain at home is stronger. If an adult cannot live with family and does not have the skills or ability to live independently, the State must find and pay for a place for them to live. This might be a group home, a skilled nursing home, foster care, or even the state institution. All of those options cost much more than living with mom and dad, who also help pay for food, transportation, medical appointments, respite care, and so on.

The family support bill would add \$4,000,000 in state dollars that would be matched with \$4,000,000 in federal dollars to increase support to 1,053 families. Even a low cost residential program can be as much as \$40,000. You can see that it wouldn't take many folks entering a group home to eat up that \$4,000,000 the State "saved" by not funding the waiver.

What can you do?

Write the Governor about why this program is important and what it means, or will mean, to your family. She needs to hear from all of us about why this waiver is important.

*Governor Ruth Ann Minner
Tatnall Building
William Penn Street, 2nd Fl
Dover, DE 19901*

Develop a relationship with your legislators. They respond to people they know, and they become

educated about our issues when they get to know us. They need to hear from all of us by e-mail, letter, or phone. Many have regular meetings for breakfast or coffee, so find out if your representative or senator has a meeting and attend.

Think Positive!

There are many of us who are working on this systems issue. The Division of Developmental Disabilities Services will be asking for these funds again next year. Let's work together to ensure that funding for the waiver is in place.

Epilogue—Family Support

Section 209.

The State of Delaware has taken the initiative to expand Medicaid, to optional populations and services beyond the federal guidelines. With the recent inflationary increase in health care costs and rising eligible population, the State continued to fund discretionary Medicaid services without interruption. It is the intent of the General Assembly and the Administration to analyze the costs of adding services and populations beyond those currently offered. The Department of Health and Social Services, the Controller General's Office and the Office of Management and Budget shall collect information and examine the costs associated with the Family Support Waiver.

You never really
lose until you quit
trying.

- Mike Ditka



Girls Just Wanna Have Fun... Mom's Night Out!!

When? September 16, 2006, 7:00 p.m.

Where? Casablanca's Moroccan Restaurant 4010 N. DuPont Highway.

How?

Call Monica McMahan for details and to RSVP at (302) 235-2101 or email: m.mcmahan28@comcast.net



Dad's Night Out

October 10, 2006

Time and Location TBA (They always wait till the last minute to plan things!)

Who can go? Dads, Uncles, Grandfathers or Friends of those living with autism. Interested?

Of course you are!

Contact:

Mark Frampton (302) 998-1466

Or

mark@designbycher.com



ASD Fall Festival

October 15, 2006 1-4 p.m. The Barn at Bellevue State Park

Hayride, Scarecrow Building, Pumpkin Painting
Light Refreshments Provided

Please contact the ASD office (302) 472-2638
Or delautism@delautism.org to RSVP no later than October 5, 2006



ASD Roller Skating Party

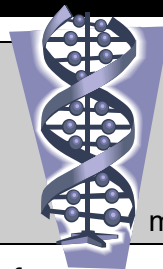
November 11, 2006 - Christiana Skating Center, Newark
5:15-7:15 p.m.

Free Admission, \$2-3 Skate Rentals, Snack Bar is Open. Closed to the general public. Autism friendly lights and music. No RSVP is needed. Just show up with family and friends and have a good time!





Research Headlines



Children with Autism Found to Have Specific Memory Problems that May Underlie Aspects of Disorder

Differences in spatial working memory and complex visual, verbal memory may contribute to problems with social interaction, information processing

Source:

www.apa.org/releases/autism011506.html

January 16, 2006

Washington, DC—If children with autism can't see the forest for the trees, that may be partly because the burden of processing all those trees at once makes it harder to lock in the scene. Researchers at the University of Pittsburgh School of Medicine and Veterans Affairs Pittsburgh Healthcare System have found that children with autism differ from other children in two specific memory capabilities. The research is in January's *Neuropsychology*, which is published by the American Psychological Association (APA).

Researchers including neurologist Nancy Minshew, MD, studied 76 children from ages 8 to 16. Half were verbal individuals with autism, half were normal controls matched for age, IQ and gender. The diagnosis of autism reflected social and communication impairments of the autistic type along with restricted interests and patterns of behavior.

First, the children with autism, compared to the matched controls, had poorer memory for complex information (many individual elements or one complicated element) in both word and picture form. In essence, the children with autism

found it hard to remember information if they needed a cognitive organizing strategy to aid recall or if they had to detect such an organizing element in the information itself.

The authors speculate that, "People with autism don't have the automatic cross talk between brain systems — the reasoning and the memory systems—that tells their brain what is more important to notice or how to organize it thematically."

Second, children with autism also had poor working memory for spatial information, or remembering over time where something was located once it was out of sight. Although working memory for verbal information was fine, a "Finger Windows" subtest of recall of a spatial sequence easily distinguished between children with and without autism. Spatial working memory depends on a specific region of the frontal cortex that is known to be dysfunctional in autism.

Despite these two impairments, the children with autism did not have global memory problems. They showed good associative learning ability, verbal working memory and recognition memory. Because their memories differed in only two specific ways, memory in autism appears to be organized differently than in normal individuals—reflecting differences in the development of brain connections with the frontal cortex.

Says Minshew, "If the brain does not, from the start, automatically identify and store key information, that seriously impairs the capacity to interact, communicate and solve problems. Children with au-

tism can be easily overwhelmed by the complex information in more every experiences."

She explains how these memory

problems can affect behavior. "Typical people automatically notice and focus on what's important or relevant," she says. "But because people with autism focus on details instead, they can't recall or respond to what most people think is important."

Let's say some teenagers see a poster for a new movie about a small-town romance. They talk about going to the movie and joke about the love story. One boy, though, interrupts with how great it will be to see a football film. Hearing this seeming *non sequitur*, doesn't understand why they aren't interested in what he is saying. He was responding to what he saw — not the larger-than-life stars embracing, but the small background detail of a man in a football jersey.

Minshew and her colleagues believe that a growing appreciation of memory deficits and their impact on social function in autism will extend research beyond the traditional diagnostic triad of the social, language and reasoning problems. The Pittsburgh group has, in prior studies, found autism-related problems with motor, sensory and balance systems. "With autism, there seems to be a widespread problem with how the brain copes with or processes all types of information," Minshew says. Thus, she urges scientists to look more broadly at the brain in autism to find whatever causes such widespread involvement.

Article: "The Profile of Memory Function in Children with Autism," Diane L. Williams, MD, University of Pittsburgh School of Medicine; Gerald Goldstein, MD, University of Pittsburgh Medicine and Veterans Affairs Pittsburgh Healthcare System; Nancy J. Minshew, MD, University of Pittsburgh School of Medicine; Neuropsychology, Vol. 20, No. 1.

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Childcare is available at all regular ASD chapter meetings. Please contact the office at 302.472.2638 or delautism@delautism.org two days in advance.

ASD Chapter Meetings

- ▶ **September 26, 2006** — ASD Annual Meeting — 6:30 p.m. Concord Presbyterian Church, 1800 Fairfax Blvd., Wilmington. Guest Speaker: Mr. Ben Shamberger, Social Security Administration. This session will highlight SSI and other Social Security benefits for children and adults with disabilities.
- ▶ **October 16, 2006** — ASD Chapter Meeting — Brennan School (DAP), 7:00 p.m. Guest Speaker: Dr. Rhonda Walter of A.I. Dupont Hospital for Children. Dr. Walter will talk about medications and the latest research on effective medications.
- ▶ **November 2006** — ASD Chapter Meeting — Dover. Exact date and Location TBA. Guest Speaker: Dr. Laura Donnelly on sibling issues.
- ▶ **There is no Chapter meeting in December.**

Social Events, Public Awareness & Fundraisers

- ▶ **September 12, 2006** — Parent Coffee Hour, 9:00 a.m. Crossroads Restaurant, Route 7 & Kirkwood Highway. Coffee is on us!
- ▶ **September 16, 2006** — Mom's Night Out, 7:00 p.m., Casablanca Restaurant, Route 13, Wilmington. Please contact Monica McMahan to RSVP. (302) 234-2101 or m.mcmahan28@comcast.net.
- ▶ **October 10, 2006** — Dad's Night Out. Exact time and location TBA. Contact Mark Frampton, (302) 998-1466 or mark@designbycher.com.
- ▶ **October 15, 2006** — ASD Fall Festival. 1-4 p.m. The Barn at Bellevue State Park. Hayride, scarecrow building, pumpkin painting. Light refreshments provided. Please contact the ASD office (302) 472-2638 or delautism@delautism.org to RSVP by October 5, 2006. More information on page 9.
- ▶ **October 21, 2006** — 8th Annual Autumn Auction for Autism—Unmasking Autism. 6:30-11 p.m., Greenville Country Club. More information on page 6.
- ▶ **November 11, 2006** — ASD Roller Skating Party, 5:15—7:15 p.m. Christiana Skating Center, Newark. No RSVP needed. Free admission. More information on page 9.
- ▶ **April 28, 2007** — Taking the High Road Autism Walk. Bellevue State Park. More information coming in next issue of *The Sun*.

Support Groups

Parents/caregivers of an individual with an autism spectrum disorder are welcome. (Autism, Asperger's Syndrome, PDD-NOS). The New Castle County evening support group meetings are held on the third Tuesday of every other month.

- ▶ **October 17, 2006** — ASD's N.C.C. Support Group. Facilitated by Kathy Hupp. Meetings are held at 7 p.m. at the ASD office, 5572 Kirkwood Highway.

Other Events

- ▶ **September 26, 2006** — Pyramid Educational Consultants (PECS) is holding a one day introduction to The Pyramid Approach to Education. University of Pennsylvania, Perelman Quadrangle on Walnut Street in Philadelphia. Speaker: Andy Bondy, Ph.D. For more information: www.pecs.com or (302) 368-2515.
- ▶ **October 13, 2006** — Parent Information Center of Delaware's Annual Conference "Surviving the Social Mindfield." Cosponsored by the Autism Society of Delaware and Lower Delaware Autism Foundation (LDAF). A day-long conference for parents, teachers and professionals working with children who have social skills challenges. Delaware Technical and Community College/Terry Campus, Dover. 8:30 a.m.— 3:30 p.m. For more information: www.picofdel.org or call (888) 547-4412.
- ▶ **November 4, 2006** — 2nd Annual Most at the Coast Conference: "Challenging Behaviors and Fads in Autism: What Works and What Does Not." Dover Downs Hotel, Dover, DE. 7:45 a.m.— 4:30 p.m. For more information visit: www.ldaf.com/Events/2006conference/info.html.



Parent 2 Parent

written by parents
for parents

Helping Kids with Asperger's Syndrome learn the Social Map of Emotions By: Jane Miller

For people with Asperger's Syndrome, understanding and expressing emotion are tools they lack, but which are critical to succeed in life.

Without these social skills, they can experience extreme stress that can lead to anxiety, depression, anger, or withdrawal into isolated activities. Often, they become scapegoats for bullies. While they may achieve high marks in school, it is their social deficits that define them and ultimately determine their standing in work and society.

This is the view of Dr. Tony Atwood, an expert in Asperger's Syndrome, who has worked with thousands of children to help them learn social skills and better cope with people and situations they face in life.

In a one-day presentation for "Encouraging Social Understanding and Emotion Management" this spring in Philadelphia, Dr. Atwood explained his approach to teaching social skills and how it can be successfully applied.

His cognitive behavior therapy program is based, not just on what people need to learn, but on how they learn. And for people with Asperger's Syndrome, High-Functioning Autism, or Pervasive Developmental Disorder, that learning has to be positive, specific, and concrete. Because children who have Asperger's Syndrome view the world literally, it is important to teach them in ways they understand.

For people with Asperger's Syndrome, emotions are the polar opposite to the order and routine they prefer. Unlike math facts or Lego construction, emotions are illogical and mysterious, even threatening. To them, "tears are the equivalent of blood in emotional pain," he says, and if they don't understand how to handle that pain, they will suffer life-long consequences.

To make emotional concepts easier to understand and handle, Atwood has created two workbooks, "Exploring Feelings" that deal with anger and anxiety. In teaching these emotions, he ties all the thinking exercises to physical games or activities that form the contents of what will become a par-

"Because children who have Asperger's Syndrome view the world literally, it is important to teach them in ways they understand."

icipant's emotional toolbox. For example, children write what makes them happy or relaxed and then stand on different points of a rope to show how happy an emotion or situation makes them feel.

Participants always identify happy emotions first because they form the positive thoughts that can offset negative thoughts and deeds. Each child creates an emotional toolkit that contains activity, relaxation, social, thinking, and other 'tools' to fix problems around negative emotions. They include a happiness diary, a pleasures book of activities, relaxation pictures,

and cue cards of things that make them happy.

Only after participants have become comfortable with positive emotions do they turn to negative feelings and how to deal with them. When dealing with emotions, Atwood recommends this order: happiness, sadness, relaxation, affection, and anger. This helps children learn the different levels and language of emotion.

Using a drawing of an oversize thermometer, children identify situations that make them angry and place them in degrees of anger along the thermometer. Then they choose activities or tools from their emotional tool kit to reduce their anger.

Children may have an extensive vocabulary, but not the knowledge to use it. Atwood recalled a child who said he wanted to kill himself, but he was not suicidal. Those were the only words he knew to say he was sad. Another child used anger to express sadness. "Crying doesn't work for me," he told Atwood, "so I get angry."

Atwood also makes use of Carol Grey's social stories and comic strip conversations to show children how to think and act more appropriately in stressful situations they experience.

To offset the negative self-talk that plagues many children with Asperger's Syndrome, Dr. Atwood has them create an antidote list of positive thoughts that they can use for better self-control when difficult



Parent 2 Parent

(Continued from page 12)

situations arise.

Papers published in the *Journal of Child Psychiatry* and the *Journal of Autism and Developmental Disorders* document the effectiveness of his approach. He also recommends training materials available through www.cat-kit.com as well as the interactive CD ROM/DVD, "Mind Reading" that teaches more than 400 emotions (www.fhautism.com or www.tonyatwood.com.au). A new version of that DVD will be available in October.

Cheerleading for Parents

By: Dan Coulter

I've had a taste of acclaim a number of times in my life.

The first time that stands out was riding on the bus to an "away" basketball game in junior high school. The cheerleaders were doing that "Bill, Bill, he's our man, if he can't do it, David can..." thing where they go through the names of everyone on the team. Even though I was on the second string and the girl leading the cheer had to refer to the program at each name to make sure she didn't miss anyone, it was very heady stuff to hear, "Stan, Stan, he's our man, if he can't do it, Dan can! Dan, Dan, He's our man." Of course, it was only five seconds of fame, followed by the unsettling assurance that if I couldn't do it, the next guy down the roster could. Still for those few seconds, I got to hear my name chanted by a busload of cheerleaders and imagine I was the subject of hero worship.

Everyone could use that kind of positive reinforcement once in a while. Trouble is, we rarely get it when we most deserve it.

This week, I was reading an autism-related magazine and was really drawn into an article about parents who were devoting tremendous amounts of time and effort to helping their kids who are on the spectrum. I admired these parents. They really deserved to be written up, especially in a magazine that's read by people who can appreciate their situation.

It made me think about all the other parents of kids on the spectrum who are trying their best, but often get met with criticism or misunderstanding.

Raising a child who's on the autism spectrum is tough. To be fair, it's hard for anyone who hasn't been involved to understand just how tough it is. When my son Drew was in grade school, he hadn't yet been diagnosed with Asperger's Syndrome. We were working under the diagnoses of "communication handicapped" and "ADHD." I remember talking with a colleague at my office, describing his difficult behaviors. Her reaction was, "But isn't that just normal boy stuff?" No echoes of cheerleaders chanting my name in that conversation.

Because most people don't understand what's involved, we parents of kids on the spectrum have a smaller universe of people who can appreciate what we do. I was talking with Lori Sherry, president of the ASPEN support group, the other day about the things that special needs support groups have to offer. One of the things she mentioned was sharing our kids' accomplishments at meetings, "Other parents might say, 'Well, that's no big deal,' but it is,

it's a very big deal to us."

People who don't appreciate what's involved can't give us the positive reinforcement that can help us through the tough times. The more alone you are, the easier it is to doubt yourself or wonder if you're making the right decisions.

That's why I think it's important to be a part of a community of people who understand. While we're working to educate the world about our kids, it really helps to be in contact with people who already have a clue.

Support groups can be great. We're members of the ASPEN organization, the MAAP organization, and the local chapter of the Autism Society of America, among others. ASPEN and MAAP focus on higher-functioning conditions on the autism spectrum, such as Asperger's Syndrome, while the ASA addresses the entire spectrum.

Because we've been involved with ASPEN the longest, I'll say a few words about how it's helped us. We joined a local ASPEN chapter while we lived in New Jersey and kept our membership when we moved to North Carolina. In New Jersey, my wife Julie and I took turns going to the meetings so one of us could stay home with our kids. I remember how reassuring the ASPEN meetings were; especially right after Drew was diagnosed. Professionals came to the meetings to speak and answer questions. Later, parents could trade info and compare notes. Every time we realized we were doing something right, it helped lower our anxiety level.

I also subscribe to a number of online autism-related forums



Parent 2 Parent

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Autism & Asperger Conference

By: Psyche Cherry

where people share information, concerns and support. Online forums are great because you can access them from wherever you live.

So here's my pitch.

Let's all make it a point to compliment another parent every chance we get on what he or she is doing. I don't mean just when you see them do something outstanding. Look for something they're doing that you agree with or admire and let them know. Maybe you'll tell a support group leader you really appreciate her volunteering to organize and run meetings. Maybe you'll tell another parent who shared a difficulty that you appreciate how he dealt with the situation. Maybe you'll hug your spouse and say how much you appreciate his or her patience. But look for opportunities to give that jolt of encouragement and approval.

It costs us nothing, but it can mean the world. And praising others may just spark someone to tell you what a great job you're doing when you really need to hear it.

If the moment's really special, you may just capture that junior high school feeling of having a whole squad of cheerleaders chanting your name.

I bet you deserve it.

ABOUT THE AUTHOR: Dan Coulter is the producer of the INTRICATE MINDS series of videos that help students understand and accept classmates who have Asperger Syndrome and similar conditions.

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For more information: www.coultervideo.com

I recently had the privilege of attending the Autism & Asperger's conference held in Cambridge, Maryland. Before I attended this conference, I knew that there was a lot I already knew on both subjects because my brother has autism and I have Asperger's syndrome. However, I am pleased that I learned many things that I was not previously aware of and I am more than happy to share some of these things with you.

Dr. Temple Grandin was the first to speak and her central "theme" was the autism continuum. Temple herself did not learn to speak until she was around three or four years old; however, she has gone on to become a very successful speaker and even holds a Ph.D. One key point that she mentioned, which caught my attention, was to be happy with echolalia. Echolalia is repeating what someone else has said. She said that if a child is repeating people, commercials and videos, then the child will learn how to speak. When Dr. Grandin went over sensory sensitivities, a lot of what she said made sense to me. Before the conference I knew I was sensitive to bright lights, certain sounds, and often noticed smells that others did not. However, I could not explain why I do not like to be touched unless I initiate it. When she spoke about auditory detail being a problem, I felt as if a burden had been lifted off my shoulders. Before this conference, I was self-conscious about my hearing. I constantly have to ask people to repeat what they say to me, especially if they do not enunciate very well or if

they speak very quickly. The reason for this is that I hear what the other person is saying, but I need time to process the information. According to Dr. Grandin, it helps to enunciate the consonants when speaking. Dr. Grandin also covered the fact that many of us have little to no eye contact and may look at the other person's mouth. When I have a conversation I have a tendency to do both (although I look around much more often than at the person's mouth). Although I knew my eye contact was poor, I did not know why I would look at people's mouths. According to Temple, I do it because I am trying to figure out what people are saying.

To help minimize or prevent behavior problems, Dr. Grandin developed the rule system. The rule system consists of really bad things (i.e. murder, theft, etc.), courtesy rules (saying please and thank you, no pushing or cutting in line, etc.), illegal but not bad, and sins of the system. One thing she couldn't state enough was not to take away from our special talent when discipline is needed. The special talent can turn into a successful career someday. Instead of using the special talent as a form of punishment, nurture the skill. Another example she included was to use the talent in an area that the child may be poor at. When she said that, I thought of an example from my own life. Last year when I took algebra (which I am very poor at), my instructor learned of my love for writing. Together he and I developed formulas similar to the ones I use for my

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Who We Are

In each issue of The Sun we have been introducing you to a few of our staff and volunteers. This month we are featuring long time member Pat Murphy and the newest member to the ASD family, Kim Siegel, Development Director.



Pat Murphy

What do you do?

I am a Property Claims Supervisor for the Insurance Placement Facilities of Pennsylvania & Delaware. I also supervise the claims handling of the West Virginia Essential Property Association.

How long have you been with ASD?

My wife Lynne and I actively attended meetings after ASD was founded in 1998. While our son Patrick attended DAP, Lynne was active and attended CAC and PAC meetings.

In 2000 my brother-in-law had a golf outing and raised \$1,500 which was donated to ASD. At the following ASD monthly meeting I spoke to Artie Kempner about sponsoring

its own Golf outing. Shortly thereafter "The Drive" was born. Five years later our 2006 golf outing raised \$350,000, used two golf courses, was attended and supported by NASCAR and NFL celebrities, and has become one of the premier golf outings in the area.

I am a past Vice President of ASD, currently a member of the Board of Directors, active with the legislative committee, and a member of the Adult Issues Committee.

Why do you do this?

I do it for the children and adults with autism. They cannot speak for themselves and need ASD's support and advocacy to ensure that their needs in the future are met and that their rights are protected.

The two most important reasons I do this is for my sons. My oldest son Patrick is a 22-year-old adult with autism who now works at Chimes. My son Michael is an 18-year-old with a cognitive disability and now attends Networks Team Works after graduating from the Newark High School REACH Program this year.

It has been incredibly exciting and rewarding to be part of ASD and watch an organization of parents, teachers, grandparents, friends and family members become a respected voice in the state, the legislature and the disability community of Delaware.



Kim Siegel

What do you do?

I'm the new development director at ASD. My major responsibilities will be establishing and enhancing our relationships with Delaware businesses to attract more corporate funding; staffing the Auction; and managing two new fundraising initiatives, a mail appeal and a Walk. I'll also be working with the Public Awareness and Legislative Committees.

How long have you been with ASD?

Three months.

Why do you do this?

I've worked in other nonprofits addressing health issues, and while I still have a lot to learn about autism, I can empathize with families trying to care for their loved ones and make sure they have as many opportunities as possible regardless of what illness or disorder they have. During the interview process and over the short time I've been here, I've been amazed at how much ASD accomplishes through the efforts of staff and volunteers, and I'm very glad to now be a part of it.



ASD Anticipates Becoming a Support Broker

By: Theda Ellis

One thing is true in this life. At some point we become adults. The question is, if we have a significant disability and reach that magic age of 21, what's out there? That is what the Adult Issues Committee has been wrestling with over the past several years. In 2004 ASD was successful in getting funding for the *Best Practices Study for Adults with Autism*. Once the study was completed, the committee decided—with the blessing of the Board—to pursue services for adults that are a little different than services currently available.

The DFRC awarded funds to develop a plan, and with support from Michael Chapman of Chesapeake Resources, we looked at service options and decided that a “support broker” was the option to pursue. Over the past six months Karen Bashkow and Theda Ellis have visited programs in New Jersey and Maryland, reviewed programs on the internet, and ASD is currently developing an application to become a certified provider for the Division of Developmental Disabilities Services as a support broker and fiscal intermediary.

If we are successful in finding start-up funding for this project, ASD plans to work with 30 adults over a three-year period.

What is a support broker and fiscal intermediary?

This self-determination model uses the concept of “Money Follows the Person.” It means that the individual and his or her family control the resources that the federal government and state make available.

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Tell me more about the support broker.

The Support Broker is a facilitator.

He or she is responsible for making things happen in the person's life. This typically begins through the organization of and facilitation of the person's “circle of support.” Circle of supports can include, but are not limited to: friends, family members, neighbors, local merchants, clergy or other interested people in the life of the individual with disabilities. The goal of the circle of support is to bring to bear those resources that are necessary for the person to move towards and to achieve life goals. The results are summarized in a planning document (Essential Lifestyle Plan). Approved supports identified on the ELP are reflected in the approved budget.

The Support Broker is a negotiator. Acting on behalf of the person, the Support Broker identifies those local connections that will facilitate the implementation of the plan. Unlike traditional service programs that focus on “the place” (e.g. day program, sheltered workshop, group home) and rely on direct support staff to implement a plan, this service use friends, family, neighbors, college students or others to support the various goals of the person. For example, a college student may be hired for a period of 4 hours to support the person to go the movies, a restaurant, or a club meeting. A neighbor may support the person with learning to read the want ads and a job coach to learn a work skill. The Support Broker will ensure the person employs the right people to support their life goals as defined in the plan.

The Support Broker is a coach. Being an employer offers many challenges. The Support Broker will work with the person to ensure a good fit exists between the person and his/her employee. This includes not only “doing the job” but doing the job in the spirit in which it needs to be done – focusing on community, community connections, relationships, independence, productivity and full integration.

The Support Broker provides fiscal support. In this role, the Support Broker works with the person to understand the nuances of budgets and budget management. The Broker also supports the person in monitoring the budget and overall plan implementation evaluating each step of the process.



*Sunshine is delicious,
rain is refreshing,
wind braces us up,
snow is exhilarating;
There really is no such
thing as bad weather,
only different kinds of
good weather.*



- John Ruskin



Support Broker

(Continued from page 16)

The support broker works with a person and his or her family to develop a plan of supports and a budget for services. The person then sets his own goals and may choose to hire and supervise his own staff to provide services (in this case day services), or he may choose to negotiate for those services from a provider agency. The key is that the person controls the funds and the services.

The fiscal intermediary actually pays the cost of the supports. The fiscal intermediary provides accountability to the process, paying only for expenses that are in an approved plan and within the individual budget. The experience in other states is that people are very good at choosing services and supports and managing their budgets; and they are typically happier with the supports they receive because they have chosen them.

Autism Society of Delaware Support Broker Vision Statement and Mission

Vision Statement:

The Autism Society of Delaware envisions a world where all people live productive, fulfilling lives with dignity as integral members of their community.

Mission Statement:

The Project's mission is to create networks that connect individuals to resources that support their choices of how they live, work, and play in the community.

As ASD considers our future, we would like to hear from you. Are you interested in having your son or daughter served by ASD? We anticipate opening the doors for supports sometime during the next fiscal year, and would like to identify at least five families who would like to work with us to start this important new service. Please contact Theda Ellis at (302) 472-2638 if you are interested.

Key themes of a support broker:

- Individuals and families make informed choices about their own lives
- Individuals and families have control over these choices
- Individuals and families have individual budgets with which to make decisions
- Supports and services are designed to fit the preferences and desires of individuals and families
- The intent and outcomes of supports and services are determined by individuals and their families (and chosen advocates)
- Self-determination is about sharing power and control and negotiating relationships among individuals, families, advocates, providers and support coordinators

Autism & Asperger Conference

(Continued from page 14)

poetry and writing to be applied to some algebraic equations. I got my first B in math last year as a result. Prior to that I was lucky to get a C in math.

Dr. Grandin didn't surprise me when she said that thinking is usually in pictures and learning style is visual. All three speakers covered the similarities of ADD/ADHD & Asperger's Syndrome because attention span is an issue with all three. Because of that and other issues, it is easy to receive an incorrect diagnosis from well meaning professionals. With that being said, Dr. Grandin also covered which medications to take and which ones not to take if medicine is necessary. She stated that people on the spectrum usually need a much lower dose, and hat we all need exercise.

Editor's Note: Psyche reported on two other speakers that we are saving for a later edition. She reported that she enjoyed Temple's presentation the best, thus we highlighted this portion.

Artist Metin Bereketli's artwork honors the victims of September 11

Hollywood artist Metin Bereketli and the Autism Society of America (ASA) launched a new U.S. postage stamp series to benefit ASA and the autism community. The *God Bless America* stamp, a piece Bereketli created after the tragic events of September 11, 2001, is the first in a three-part series of postage stamps, which also feature Bereketli's *Jollification* and *Freedom*. The stamps are produced by Zazzle.com.

Order yours today by visiting: www.autism-society.org/stamps



Autism Society of America Membership Application

Please enroll me in the following category:

Student \$15 Individual \$30 Family \$40 Outside USA \$50 Professional \$100 Agency \$500
 Life \$1,500

I am a new member I am renewing membership

Name (s): _____

Address: _____

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

Employer or professional background: _____

I am joining through ASA's local chapter named the Autism Society of Delaware.

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 ASD'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 directly to ASD

Total amount enclosed (add both amounts).....

\$ _____
\$ _____
\$ _____

Date: _____

Please make your check payable to the Autism Society of Delaware to

aware (ASD) and send the check and application to

ASD, 5572 Kirkwood Highway Wilmington, DE 19808. All membership fees and contributions are tax deductible.

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The Voice of Autism in Delaware

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