

The ALL ABOARD NEWS



A Quarterly Publication from the Advisory Board on Autism and Related Disorders

Volume XIV— Issue 3

Summer 2010

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Save the Date!

ABOARD's Fall Conference

DIR®/Floortime™ - Developmental-Relational Treatment of Autism & Sensory Processing Disorder

Thursday, October 21, 2010
8:00 AM - 3:30 PM

Regional Learning Alliance
850 Cranberry Woods Drive
Cranberry Township, PA 16066

Presented by Esther B. Hess, Ph.D., a developmental psychologist with more than 30 years of clinical experience. Dr. Hess specializes in the assessment, diagnosis and treatment of children with developmental delays and/or regulatory disorders including autism spectrum disorders utilizing the developmental/relational method known as DIR®/Floortime™

For more information about Dr. Hess, visit her website drhessautism.com.

Key Seminar Features & Highlights

- * The **6 stages of developmental capacities** and what "moving up the developmental ladder" really means
- * **Video demonstration:** real families struggling with the diagnosis of autism in their child and learn how relationships are the drivers of all future development
- * **Diagnostic classifications** of Childhood Disorders including interactive disorders, regulatory challenges and severe disorders of relating and communicating
- * Biologically based individual differences, family/community/culture and child-caregiver interactions that impact a child's developmental capacity
- * **Sensory integration theory** and the impact on a child's individual neurological differences
- * The developmental/relational approach known as DIR®/Floortime™ and learning to "follow a child's lead"
- * **Theory of brain plasticity** – a concept of brain development gives hope for children impacted by autism
- * Progress in **therapeutic interventions for autism**

Chairman's Message - AUTISM GROUPS WORKING TOGETHER-THERE IS MORE TO DO!

Dear Friends,

Recently, the Pittsburgh Post-Gazette ran a story and an editorial which outlined the impact ABOARD and others in the autism community have made. It is also a reminder of the work that still remains to be done. One article mentioned efforts being made by houses of worship to make children on the spectrum, and their families feel included in services. They have had to educate their congregants to be tolerant and accepting of these children.

That same week, a Hampton mother, Renee Georgi, wrote an editorial in response to an anonymous letter she received from a group parents who wanted her to remove her son from their children's classes. They felt the attention he needed (in their view) would affect the education of their children and their subsequent chances of getting into a good college. The Hampton School system has an excellent inclusion system and Ms. Georgi's son is an active and well-liked member of his classes.

In one case, we see our efforts to educate the public about children on the autism spectrum resulting in wonderful new programs in the community. In the other, we see how much more we have to do to overcome discrimination against our children.

Then, on June 16th in the Post-Gazette, there was an article about nonprofit mergers. The Multiple Sclerosis Service Society and United Cerebral Palsy Living and Support Services realize they shared similar missions and histories. Both were founded in the 1950's by families who wanted their loved ones to receive services to help them function more independently.

It strikes me that the MSS-UCP/CLASS merger is a good example to study for ABOARD and others organizations. ABOARD was started

by families that wanted their loved ones to receive services to allow them to function more independently. Our mission is to empower families to help their loved ones achieve their "maximum potential and maximum possibilities". Other organizations involved in the autism spectrum want the same thing, though their written mission statements may say it differently.

There are over 100 non-profit autism groups in Pennsylvania! If we looked at them all, it would be a safe bet that many provide duplicate efforts. All truly care about those on the spectrum. I suspect that each group feels that they have a "unique" perspective.

While ABOARD has always worked with other groups, the future warrants an active look at more strategic alliances among all the groups in the autism community. Funding is going to be difficult for some time. We need to reach out and cooperate more with each other. There are no enemies in our world of autism organizations! Our board of directors will continue to support partnerships and strategic alliances with other groups to insure those on the spectrum get the maximum help and benefits available to them.

We are saddened to hear that Dr. Stanley Greenspan passed away on April 27, 2010. As the world's foremost authority on clinical work with infants and young children with developmental and emotional problems, his work continues to guide parents, professionals, and researchers all over the world. Dr. Esther Hess, who spent numerous years training with Dr. Greenspan, will present at ABOARD's fall conference in October. Dr. Hess uses the highly successful "DIR/Floor Time" method of intervention based on the model of Dr. Greenspan.

Enjoy the summer!

Elliot Frank, Chairman of Board of Directors

WALK WRAP UP—Rain Drops were Falling on Our Heads!

On May 22 the Highmark Walk for a Healthy Community took place at Schenley Park in Pittsburgh. The day looked cloudy from the start and, before the walk even began, the rain poured down. The rain stopped and started several times throughout the morning but it didn't dampen our spirits! It was so nice to see so many of you brave the weather and come out to support ABOARD. The 5k course wound through scenic Schenley Park and started and ended at Phipps Conservatory. Phipps provided free admission to the walk participants and many stayed and strolled through the many rooms and gardens of Phipps.

This year over 5,000 supporters from 58 health and human services organizations walked. Highmark underwrites the cost, so 100% of the money raised will be used to fund our family support services. ABOARD is proud to be a part of this important event and thank all of you that supported us.



THANK YOU TO OUR WALK SUPPORTERS!

Nancy, Jon and Alec Albinini	J. Dougherty	Renae Kutsum	Chandra Peterson
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A big thank you to Donna Enzerra, sister of Diane Catterall, for obtaining a generous donation of McDonald's salad coupons that were used as an incentive prize for the walkers at this year's Highmark Walk for a Healthy Community!



UPMC | University of Pittsburgh
Medical Center

The University of Pittsburgh Medical Center (UPMC) announces

CHARTS

Children with Hyperactivity and Autism Research Treatment Study
Funded by the National Institutes of Mental Health

The UPMC Center for Autism and Developmental Disorders at the Merck



Child Outpatient Clinic is conducting a research study to examine the use of an approved ADHD medication and parent training sessions for the treatment of over-activity, inattention, and impulsivity in children diagnosed with Autism Spectrum Disorders. The parent training sessions are intended to help families manage their children's challenging behavior.

The treatment phase of the study involves 10 weekly sessions. An optional 24-week follow-up involves monthly visits to our outpatient clinic located at:

*The UPMC Center for Autism and Developmental Disorders
Merck Child Outpatient Clinic
Franklin Building, 1011 Bingham Street
in the South Side of Pittsburgh*

There are no costs to participate in this research study. Evaluations, study visits, parent training sessions, and medication are provided free of charge.

Who is Eligible to Participate?

Children who...

- Have symptoms or a diagnosis of Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder (PDD)
- Have symptoms of ADHD: such as over-activity, inattention, and impulsivity
- Are between 5 and 13 years of age
- Are not on medication **or** are on medications that are not working well

For more information, please contact:

**Sarah McAuliffe-Bellin, M.Ed., Study Coordinator, at 412-235-5447
or mcauliffebellinsj@upmc.edu**

Thanks to our United Way Fall 2009 Campaign Donors

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A Special Thanks to our Supporters!

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Keith Johnson

\$100.00 Donation

Robert and Melissa Walls

\$50.00 Donation

Loretta M. Uhlmann
The Crock Family

Special Thank you to:

Liberty Tax Services of
Bedford, PA for hosting an
Autism Awareness Roadside
Party to benefit ABOARD.

Kappa Delta Rho National Fraternity Iota Alpha Chapter at the University of Pittsburgh at Johnstown for raising \$1,035.03 at their annual autism walk which was held on April 17, 2010, to benefit ABOARD.

Donators through The Bank of New York Mellon 2010 Community Partnership employee gift match campaign:
Vicki Ann Caldart
William G. Ramaeckers
Carol J. Schlott
Charles R. Schlott

Funding was provided to ABOARD by the Geraldine Kennedy Cooper Fund of The Pittsburgh Foundation.

Donation In Memory of
Mrs. Margaret Voytko and
Mrs. Josephine Colapietro
From Lori McMaster

In Honor of Evan Sasmore
8th Birthday from
Dorothy Sasmore.

**Thank you to
our Donors!**

In 2009 ABOARD

responded to over 3,700 information requests for guidance and support, gave support to 53 family support groups, distributed 1400 information packets and 750 publications from our lending library, and provided trainings to parents, paraprofessionals, and educators. It's a massive task made possible only by the considerable help of our neighbors!

Support Group Happenings

Central Susquehanna **Autism Support Group**

Susan Bolig

The last several months our group has been trying to find new ways to get our families together. For March and April, we watched the biopic of Temple Grandin. For May, we had a family get together (private party) at our local Bounce Funplex Place, a trampoline fun center. We had 36 attend and 24 jumpers! We have a bowling get together set for June and a swimming party in July. August we will meet for our regular meeting with a special guest speaker, a college student with aspergers.

Our attendance has been low for our regular meetings but our family get togethers have been great with 30-40 people attending. Our outings are for the whole family and everyone is encouraged to come, even if they only last 10 minutes!

Lebanon County Autism **Spectrum Support Group**

Diane Grumbine

Sometimes you just want to go somewhere and hang out with people who get it. That's the purpose of our group in a nutshell. We aim to educate at our monthly meetings and through our email chain. The best times, though, are the family events that are held throughout the year. The kids enjoyed a trip to a nearby laser tag and indoor playground in April, parents could chat while their children were happily engaged. No one batted an eye at the one or two meltdowns, the one way

conversations or the mom shadow in the laser tag arena. We are looking forward to our family picnic this month. We are having a stuff swap at the same time. You bring your outgrown or unused games, DVDs or toys and take home something that's new to you. The Splash Party in July is always lots of fun and is a yearly favorite along with the hayride and bonfire in the fall. However, the best part of the group is the friendships gained and the support of people who care.

FBR Indiana

Amy Flickinger

During the months of January and February, FBR has collaborated with the YMCA on providing Crossroads at the YMCA. This program assists with enhancing children with ASD on social skills. The children complete craft, use the pool, and have gym time. The program was open for consumers 5-17 years old. Plans are to continue this program during the summer months.

FBR North Huntingdon & Monroeville

Eileen Saltzgiver

In regards to Monroeville:

The addition of our Asperger's group has been amazing. It is excelling at record speeds. The families are so excited to have a designated and structured time for their higher functioning children to be with other children to interact. The group recently had a movie night and just did a community outing to mini golf and the kids and their families had a blast. This month they will be going out together to go bowling. The children are leading the

group as to what they want to do and where they would like to go - the highest vote wins!

In regards to North Huntingdon:

The group has remained open forum for now as per request of the families. Taking some time to get to know each other again as some families weren't able to attend for a while given schedule conflicts. They have been very active in discussing topics, such as: school placement, school struggles, and summer activities. They have chosen to meet during the summer

FBR Uniontown

Brittany Winfrey and Kara Kaylor

So far, the support group in Uniontown has been fantastic!!!! We just started the group a few months ago. We've had speakers (educational advocate Barb Keefer and Parent to Parent rep., Nicole Zillij). We've had children/families from Fayette and Greene Counties. We've had nothing but positive feedback from the parents that attend. A lot of the children/families that come are not consumers of FBR. For the summer, we plan to continue with our group. We are going to have our next group at a local park.

FBR Robinson

Courtney Walsh

FBR Robinson's support group has been focusing on getting feedback from our area families to improve the support group experience to meet our family's needs. The past

Support Group Happenings—Continued

few months have been focusing on summer support and planning, fund-raising events coming up, and advocacy with insurance companies.

Columbia, Montour, Northumberland, Snyder, Union County CSIU Parent Support Group

Kathleen Stropnick

Our Local Autism Support Group in Danville does not meet in the summer at the DCDC, but we do have a Parent Roundtable at our Camp Emerge weekends. We had a very successful Camp Emerge Memorial Day weekend, with warm weather, great swimming and fishing, the balloon bouncer, crafts, dress-up in the tree house, animals to pet (including a Llama), and lots of talking and sharing of stories between families.

At the Parent Roundtable on Sunday, about 20 of us gathered to share information about our families and our trials and successes. We went around the group and said who we were, talked a minute or two about our families and identified a topic to be addressed. Some topics keep coming up, and we find interesting solutions, or at least someone who will listen! Topics discussed included Transitions from Elementary to Middle School, Puberty, and "Medicate or Not?" The great thing about support group is that we did not find any one answer, but lots of stories about what works, and information to bring home to try.

FBR North Hills

Teresa O'Brien

Our FSG is, for the most part, driven by the parents. After polling the families, their preference is to have open discussions regarding stressors in the schools (IEP, placements, bullying, etc.) and stressors in the homes (feeding/eating, emotion regulation, supporting siblings). Typically, I inquire about "hot" topics of interest for the group and try to accommodate needs (IEP questions /needs). We will try to get an advocate strong with autism knowledge to assist with questions. Again, for the most part, our group is parent driven with an open forum of sharing successes and providing support to each other. At our last group, the discussion centered on "de-stressing" and what each person does to assist with decreasing stress.

Southwestern Pennsylvania

ABOARD Adult Autism

Meet Up Group

Diana Dugina Riebling

The Southwestern Pennsylvania ABOARD Adult Autism Meetup Group started off its summer with the Bucco's at the Autism Awareness Day at PNC Park. And to add to that, we were certainly proud to see Marie Mambuca, and the entire ABOARD team featured before the game! We plan to go to another game at the end of season.

Lately the group has been meeting at the South Side Beehive for board games. It has become quite popular, so we slated this activity as a quarterly

event. The running favorite is marathon length *Trivial Pursuit* tournaments. We'll be there again in August!

David Kwaczala is our movie scout. He posts the groups favorite movies and off they go! Recently, the group has seen *Shrek Forever After*, *Alice in Wonderland*. These events are part of our 'On Your Own' events, as the organizers do not generally attend. Thanks John for your commitment to the group.

Members of our group joined assistant organizer, Janice Nathan, her brother Sam Bushnick and Marie Mambuca as registered walkers at the Highmark Walk for A Healthy Community.

On Memorial Day the group met for its 3rd annual Picnic in Schenley Park's Camp David Lawrence pavilion. We had over 48 members and their friends or family attend. Everyone pitched in to bring their favorite picnic foods and the group would like to thank Caitlin Freeman for monitoring the menu items. Although the day wrapped with a quick down pour, the event was attended well and new connections between new friends and family were made and continue to grow.

For June, July and August it seems we're going to have to extend our once a month social event to include a few more excursions. June is slated for our annual Kennywood picnic. We stake our claim to one of the picnic shelters in the park so that we have camp "Chill Out" but for those in our

Continued on Page 8

Support Group Happenings—Continued

group who like to ride, it's just a good place to designate as a meet up.

Our group is quite interested in the Kayaking event in July through Venture Outdoors and we are planning a "Just Ducky Tour in July as well.

The Pittsburgh Renaissance Festival was a big hit last year, so the group expressed for it to be an annual event. Another popular request was for a day trip to the Rock n' Roll Museum and an organized trip to Laurel Caverns. As always in our fair town and with our friendly group, there is just so much to do and a swell of enthusiasm to join in!

While it is apparent that there is never a shortage of activities, the SWPA/HFA/AS Meetup do discuss many issues that face adults on the Autism spectrum. Two of the main items are employment and housing. Several of our group members attended the 2nd AHEADD Autism Awareness Day Conference at the Sheraton at Station Square. There, individuals learned about different job coaching agencies, and were able to participate in mock interviews. Next year we certainly hope to participate again. In the housing category, more and more discussion is being made on a fixed social center and an independent living complex for those adults who want to live independently but need additional support. Members, parents and partners have started preliminary talks: only the sky is the limit.

Discussion Group for Adults with HFA/AS

Rebecca Klaw

As is typical in the discussion group, we talk together briefly at the beginning and then split into smaller groups to talk. This small group discussion is guided by conversation starters which are provided by the group members. In May, we got to know each other by sharing favorite musical pieces. Once we heard someone's selection, we found one word descriptors of this music and put them on a board. Then the person who selected the music let everyone know if any of those description words applied to them as well. Interesting getting-to-know you exercise. Wendy Halley-McAllister also took a small group of folks who wanted to work on conversation skills into the smaller library room for both May sessions. We thank her for her time and energy!

Washington County HOPE4AUTISM

Patty Neil

I started this support group because my school's Special Ed Director used me as a point of contact for any parent in the school that may need help or guidance or just a friend. I'm able to do this and also offer a night to get together and just vent, talk or brainstorm about our kids. We had Marcia Laus from The Watson Institute speak to our group at the High School--we had teachers, aids, parents, grandparents, church peers attend. She spoke to the group on understanding what autism is and how it affects the chil-

dren. We have help meetings at the local park for the kids to have some social time. We keep our meetings very informal unless we have a speaker. The parents that attend decide what we discuss and there is always something to discuss! I try to attend as many seminars as I can to gather information to hand out. We share doctors, dentists, advocates and other information from our past experiences. We have babysitting services available at our meetings.

Biomed Buddies

Chrisoula Perdziola

The biomed buddies support group continued to review new advances in treatments for children and adults with autism during its support group meetings as well as review the basics of the Defeat Autism Now protocol for parents new to biomedical interventions. Biomed Buddies will be reviewing findings from the most recent DAN conference and will feature local naturopath, Dr. Heidi Weinhold, over the summer months.

ABOARD is the largest facilitator of autism support groups in Pennsylvania. We currently have 60 groups in 46 counties. ABOARD owes a big thanks to the facilitators, who volunteer much more than the 2-3 hours at a monthly meeting. We are so grateful for their help in providing education, advocacy and support to the families and professionals in their community.

A Mother's Perspective of ABOARD:

"An invaluable, personal resource for the parents and professionals working with children with Autism Spectrum Disorders."

My son, Eddie, was diagnosed with Autism in November of 2009 at the Developmental Unit of Children's Hospital in Pittsburgh. Although my husband and I were expecting the diagnosis, hearing our suspicions validated by the psychologist was difficult. I was provided a packet of information and resources, and we left for our cabin in Somerset to focus on family and digesting the news.

My years as a Special Education Teacher and administrator were of little comfort as I was overwhelmed by the weight of responsibility of insuring this precious, wonderful little boy would meet his greatest of potentials. Upon returning home, I delved into the massive packet and came upon the flyer for ABOARD. I sent an email to inquire on the resources in my community.

Again I was overwhelmed, but this time in a very positive way. With my permission, ABOARD had emailed all of the parents of children with ASD and members of ABOARD in my community. I received several emails from these generous women. They were offering support, guidance and reassurance. This was support I really needed during that time, as you feel very alone and vulnerable upon learning your child has unique needs.

Since that time, I have emailed ABOARD on numerous topics ranging from preschools appropriate for my son's need to summer camps appropriate for older children. My husband and I have attended several workshops and conferences referenced by ABOARD to gain knowledge on the best practices to implement with Eddie. I also have guided other families in the student meetings I facilitate to this wonderful resource when they have questions or need to know the resources they have available to them.

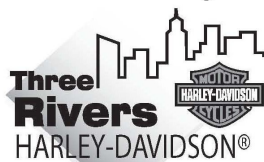
I feel ABOARD is such a personal, valuable resource for me and my family. I know now that I am not alone nor vulnerable. We parents of children with ASD are organized, caring adults with the best interests for our children and our community's children foremost in our minds every day.

By Julie Jaszczer

RIDE^{TO} THE RIVER

FOR AUTISM POKER RUN

To Benefit ABOARD
(The Advisory Board on Autism and Related Disorders)



Ride starts and ends at
Three Rivers Harley-Davidson
1463 Glenn Avenue, Glenshaw, PA 15116

AUGUST 8, 2010 • 11AM

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to win a 2011 Harley-Davidson FATBOY Motorcycle!



ABOARD

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We want
to see
you!!**ABOARD and
Venture Outdoors are
joining forces to offer
FREE FAMILY EVENTS!****Family Geocaching /South Side Park**

Sunday, August 15, 2010 from 2:00 PM - 4:30 PM

Family Fishing Derby and Walkabout/**North Shore Riverfront Park**

Sunday, September 12, 2010 from 12:00 PM - 3:00 PM

Family Outdoor Festivals

On Saturday, July 31st we'll be at McKinley Park in Mount Oliver.

On Saturday, August 28 we'll be at Allegheny Commons.

*Families are welcomed to bring TSS and Caregivers to all events!**Although these events are free we do require you RSVP
so that we can make sure to have enough volunteers on hand to help!***Please RSVP at www.aboard.org or
call 412-449-0165****If interested in becoming a volunteer during these events to
assist the families please contact****Rebecca Williams-Thomas at ABOARD 412-499-0165.**

Do You Have a Child with Autism Between 3 and 8 Years Old?

You may be interested in learning more about ... *A NEW Clinical Trial ...*

A 12 week research study to assess the safety and effectiveness of an investigational medication designed to treat the symptoms of autism in children.

Investigational medication will be compared to a placebo (fake medicine).

- No pills to swallow - medication is sprinkled on food and has no taste
- No blood tests
- All assessments done at clinical site
- Families will receive reimbursement for travel expenses

For more information please contact: **Sarah McAuliffe-Bellin, M.Ed., Senior Program Coordinator**
WPIC Merck Child Outpatient Clinic
1011 Bingham St., Franklin Building (South Side) • Pittsburgh, PA 15203
412-235-5447 mcauliffebellinsj@upmc.edu

The Value of Respite

re · spite: Pronunciation: \res-pət
also ri-spīt: an interval of rest or relief

Respite goes by a lot of different names; i.e., in-home care, attendant care, personal care, habilitation, companion, family aide, etc. Regardless of the name - and for the purposes of this article we will call it home care - this type of care remains one of the highest requested support for families caring for a loved one with a disability. Without a break from the daily care requirements, caregivers are extremely susceptible to physical, emotional, and financial problems that impede our ability to give care now and in the future¹. As a parent of a young man with a disability², I can attest that home care helps alleviate these stress related ills. I suspect that I, as well as approximately 52 million other Americans who provide care to someone with a disability, are grateful for this support.

How do I secure home care?

There are many avenues to secure home care; from natural supports (family and friends); community partners, volunteer programs to formal paid supports, such as ACHIEVA Home Care. In most cases, families secure the assistance of family and friends or funding, mostly through Home and Community Based Waivers, for paid supports. In Pennsylvania, there are many waivers available to people with disabilities. Each waiver has their own eligibility guidelines and may differ in the supports available³. The three known waivers for individuals with intellectual and developmental disabilities are the Autism, Person Family Directed Support, and the Consolidated Waiver. All offer financial assistance to support the cost of home care.

How do I secure home care if I don't qualify for a waiver or I'm on a waiting list?

In Pennsylvania, all children under age 21 who have serious disabilities are entitled to Medical Assistance benefits regardless of their parents' income. Under Early Periodic Screening Diagnosis and Testing (EPSDT), Medical Assistance-eligible children have an entitlement to all services covered by federal law that are medically necessary, including physicians' services, dental services, in-home services (personal care attendants, home health aides and/or skilled nursing), augmentative communication devices, and hearing aids.

Personal care services, or home care, is a Medical Assistance benefit that children under age 21 can receive if medically necessary; i.e., prescribed by a physician that are designed to provide assistance to individuals with their activities of daily living; such as getting up, dressing, bathing, grooming, toileting, eating, and meal preparation. Personal care services are NOT wrap-around services; they are meant solely to assist the child with activities of daily living and are not therapeutic in nature.

The federal government explicitly states that personal care services are available to individuals whose inability to meet their daily care needs are due to intellectual and/or behavioral disabilities. As a result, families of youngsters with intellectual disability, autism,

or serious emotional disorders who need assistance to perform their daily living activities are entitled to receive personal care services.

How to apply for Personal Care Services

The application process for personal care services is substantially the same regardless of whether the child is enrolled in a Medical Assistance Managed Care Organization (MCO) through "HealthChoices" or receives Medical Assistance through the "fee-for-service" system⁴. Please note the request for personal care services for those in the HealthChoices program should be submitted to the child's physical health Managed Care Organization (in Allegheny County, this could be Gateway, Unison and UPMC for You), not to the child's behavioral health MCO.

The family should request that the child's primary care pediatrician write a letter of medical necessity. The letter should include ALL the following information:

- * an explanation of the child's disability; a detailed description of the activities of daily living that the child cannot undertake on his own or without assistance (e.g., getting up, dressing, bathing, grooming, eating, meal preparation, toileting).
- * an explanation as to why the parents are "unable" or "unavailable" to take care of the

The Value of Respite

child's activities of daily living (e.g., parent works; parent must attend to the needs of other children; parent needs time to perform necessary household activities, such as shopping or laundry; parent has a disability).

- * an exact request for the number of hours per week of personal care services needed; and if appropriate, the days of the week on which services are needed which should relate to the purpose of the personal care.⁵

The family should submit the letter of medical necessity to their respective MCO who will then forward their letter to the medical director for review. Once approved, the MCO will refer the family to contracted home health agencies who are able to provide these services. ACHIEVA Home Care has provided these supports for over 6 years to families enrolled in both Gateway and Unison managed care organizations. However, if families are inter-

ested in using an agency that specializes in care for people with intellectual and/or physical needs, such as our organization, ACHIEVA Home Care, they need to request the service be provided by ACHIEVA.

Once the individual is approved for supports, families are usually authorized for a certain amount of hours per certain days. In essence, your physician has prescribed the supports. Any changes in hours and days would first need to be approved by the MCO in conjunction with your child's physician.

In many cases, families are encouraged to apply for these supports due to the ever growing waiting list for waiver funds. In fact, families are required to apply for these supports prior to waiver coverage, as waiver is the payor of last resort. For those families waiting for funding for home care, this may be a viable choice. We encourage families to apply and will guide them through the process.

By Rose Warman, ACHIEVA Home Care Director

For further assistance in this process please call ACHIEVA Home Care at 412 995-5000 x505.

ACHIEVA is proud to offer a lifelong support system for individuals with disabilities and their families that includes early intervention services, camping and recreation, residential supports, home care, vocational supports, family trust services and lifelong advocacy and family supports. ACHIEVA is the only organization in western Pennsylvania to offer this lifelong partnership to individuals with disabilities and their families.

Article Footnotes:

¹ ARCH Respite, <http://chtop.org/ARCH.html>

² Family Caregiver Alliance, <http://www.caregiver.org/>

³ PA Department of Public Welfare, <http://www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance/SuppServWaivers/>

⁴ <http://www.dpw.state.pa.us/Resources/Documents/Pdf/Publications/HealthChoices/HealthChoicesComparison-Eng.pdf>

⁵ Personal Care Information provided by Pennsylvania Health Law Project. Application guidelines - <http://www.phlp.org/Website/Questionnaire/Eligibility.asp>

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Asperger Syndrome and Relationships

We, Caitlin and Phil, have been partners now for more than four years, and we both have Asperger Syndrome (AS). As is typical among people with autism, we have both struggled with relationships and have had to overcome sensory, emotional, and social barriers to become a couple. What we have been able to create with each other is an intimate bond built on our cognitive compatibility and our respect for our neurological differences.

The first question many people ask us is, "Where did you meet?" The answer is that we met at a library potluck in Amherst, Massachusetts. The potluck also happened to be a singles event, although neither of us was there to meet someone.

We think the more important question is, "Why are we still together?"

Like any couple, our compatibility is a complex mixture of genetics, upbringing, and past experience. Added to this mix is our AS. On a purely statistical basis, it is amazing that we ever met each other. Common to other couples, the basis of our compatibility is communication.

Since the diagnosis of AS is recent, there was little formal social skills training when we were young, and so we had to develop our communication skills using what was available.

Caitlin spent her youth training in the theater, learning social skills by rehearsing scenes with other actors. Her directors told her that she lacked emotional expression on stage, and so she studied facial expression charts and learned to reproduce the expressions she saw using mirrors and video cameras. Later she learned conversation skills by practicing theatre improvisation with her fellow actors.

Phil spent more than twenty years in therapy. Therapy is often not well suited for training people on the autism spectrum. The assumption of many therapies is that the answers lie within the patient. In Phil's case, he needed specific training to even know what the questions were. Phil was fortunate to find therapists who used directive approaches to help him learn the skills he needed.

The social training that we received was piecemeal, but it turned out to be effective over time. Caitlin participated in theatrical productions, and in the process, learned how to have conversations and communicate her emotions to other people. Phil attended group therapy, and in the process, learned how to manage stress and engage in clean transactions. Phil learned that a clean transaction is a literal form of communication with no sarcasm, emotional spin, or implied message. This form of communication is particularly well suited to those of us on the autism spectrum.

More than any other factor, the social, emotional, and psychological training we received during our early years has contributed to our continued relationship. We both take care of our disagreements, decisions, and emotions as we go along, never letting them build. We understand the psychology and the limitations of our AS, and we never argue. We know that the cost of building up emotions and releasing them explosively would be so much stimulation that it would take us days to recover.

Another aspect of our AS that helps our relationship is that we both take what the other says at face value. When we ask what time it is, we are simply asking for information, even if we are late for an important meeting. When we praise each other, or are affectionate, it is simply a

statement of how we are feeling at that moment, with no other motivation. A question is always just a question. A statement is always just a statement.

As is common for people on the autism spectrum, we both have difficulty processing sound, touch, and visual information. When we are together, we are careful to interact in a way that does not create unexpected sensations for each other. We are both sensitive to each other's needs, and will immediately stop any activity that is uncomfortable for the other person.

On a day-to-day basis, we don't feel that we are so special in our relationship, but we are both very happy that we found each other. What seems remarkable to other people is something that we both know: with training, people on the autism spectrum can have successful, long-term intimate relationships.

We share our experiences because they may help other people on the autism spectrum have relationships. We also share our way of being together as a model that many neurotypical couples may find useful. A therapist that we know once asked us, "Don't you ever put each other down?" From her question, we gathered that she thought that giving insults was a normal part of a relationship. She seemed surprised when we told her that we don't use sarcasm or unkind remarks to communicate with each other. Maybe this is a part of autism spectrum culture that the rest of the world could benefit from.

by Caitlin Freeman and Phil Garrow

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