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Please join Berks ASA in recognizing the individuals who made our billboard project come together: Jack Llewellyn and Lamar Advertising for generously donating billboard space; Amber Mintz, former Berks ASA President, for donating the design; Berks ASA Board Member Bob Pratt for organizing this project; and all those who made the Berks ASA Walk for Autism such a success, as production fees were paid from proceeds from the Walk.

Editor: Sheri Taylor-Mearhoff  
Design: Amber Mintz  
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PO Box 6683  
Wyomissing PA 19610  
PH 610-736-3739

## **Berks County Chapter of the Autism Society of America 6th Annual Conference**

### **Teaching the Hidden Curriculum to Children & Adolescents with Autistic Spectrum Disorders & Other Social Cognitive Challenges**

Friday, May 6, 2005  
9:00 AM - 4:00 PM

The Inn at Reading,  
Reading, PA

(5) Act 48 Credits  
Available

This conference will address the hidden curriculum – the set of unwritten rules that no one has been directly taught, but everyone knows. Violations of these rules can be troublesome to devastating. That is, lack of hidden curriculum knowledge could make an individual a social outcast, keep him from getting a job, or otherwise reduce his quality of life. This presentation overviews the hidden curriculum and provides sample items, a model for assessment, and strategies to teach this complex area. Attendees will have an opportunity to apply their newly acquired knowledge in two break-out sessions.

Participants will receive the book "The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social



Situations" by Brenda Smith Myles, Melissa L. Trautman, and Ronda L. Schelvan; Foreword by: Michelle Garcia Winner

**About the Presenter:**

Brenda Smith Myles, Ph.D. is an associate professor in the Department of Special Education at the University of Kansas where she co-directs a graduate program in Asperger Syndrome and autism. The recipient of the 2004 Autism Society of America's Outstanding Professional Award, she has written numerous articles and books on Asperger Syndrome and autism including *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns* (with Southwick) and *Asperger Syndrome and Adolescence: Practical Solutions for School Success* (with Adreon), the winner of the Autism Society of America's Outstanding Literary Work.



Myles is on the executive boards of several organizations, including the Organization for Autism Research, and Maap

Services Inc. She is also the editor of *Intervention in School and Clinic*, the third largest journal in special education.

Register Online at [www.autismsocietyofberks.org](http://www.autismsocietyofberks.org) or mail registrations by 4/30/05 to:

Autism Society of Berks County,  
PO Box 6683, Reading, PA 19610

## LOCAL RESOURCES

### Berks ASA

This is the first call to make if you have questions about whom to call first, what to ask for, or need to talk to other families who have 'been there' or even just for new ideas.  
PH 610-736-3739

[www.autismsocietyofberks.org](http://www.autismsocietyofberks.org)

### Social Security (SSI)

People with a medical diagnosis of autism may qualify for Federal Social Security Income (SSI), but there are low income/asset limits.  
PH 610-320-5235 or 800-772-1213

### MA (Medical Assistance)

Children age 0-21 with a medical diagnosis of autism qualify for PA Medical Assistance, if they are declined for Social Security (most are). MA helps cover some wrap-around services, medical visits, and prescriptions. Ask for 'intake'. Note your child has a diagnosis of autism (write 'MA Application for Disabled Child\*', See Handbook Section 355.4\*) on your application (Form 600C), and mention it again during your interview.  
PH 610-736-4022.

\* Download a 'loophole' guide at [www.php.org](http://www.php.org) (20pp.)

### SAM (Service Access Management)

Call SAM for children under age 3 for a developmental delay screening, evaluation and eligibility for services. Ask for the 'intake process', note your caseworker, and be persistent.  
PH 610-236-0530

### BCIU (Berks County Intermediate Unit)

Call the IU for developmental delay evaluation/early intervention services for children ages 3-5. You do not need a diagnosis to be eligible for services. Ask for 'early intervention'.  
PH 610-987-8400

For details, visit and click the resources link at [www.autismsocietyofberks.org](http://www.autismsocietyofberks.org).

## Project Lifesaver

By Stacie Dreibelbis

For many parents like me, with a child with an autism spectrum disorder, the fear of our child wandering away from home is something that we live with daily. I worry about the gate being locked on the back fence or the garage door being left opened or my son escaping in public. Most of the time he is good about staying with us, but there have been times when we have caught him on his own heading for the creek not far from our home. It is something that my family and my son's school constantly work with Casey to correct.

This past November I watched the ABC-TV series "Extreme Makeover: Home Edition" and learned about a unique program to aid families with special need dependents at risk for flight. In this episode, the Vardon Family's home was being made over and special care was going into the home's security because they have a son with autism who has escaped in the past. The show teamed up with the Project Lifesaver Organization to provide the family with a home perimeter system. Additionally,

Project Lifesaver donated a professional tracking unit to the local police department and gave them training so that now, not only the Vardon's son, but also anyone in the community can be protected.

Project Lifesaver International is a Charitable, Non-profit 501 (c)(3) Organization. Project Lifesaver is an innovative rapid response program aiding victims and families with Alzheimer's disease and other disorders such as Down syndrome and Autism. By forming partnerships with local law enforcement and public safety organizations, Project Lifesaver deploys specially trained teams with the most reliable technology available to quickly locate and return wandering adults and children to their families and caregivers.

The individual at risk for flight wears a tiny water-resistant transmitter with a tamper-resistant band on the wrist or ankle (they have also attached it to shoe laces in the past). The transmitter puts out a silent radio signal. (Radio signals have been found to be more reliable than GPS systems because they can transmit through buildings, wooded areas, etc.) Project Lifesaver equips the local law



1 in 166 have autism<sup>SM</sup>  
You know someone with autism.  
[www.autismsocietyofberks.org](http://www.autismsocietyofberks.org)  
April is Autism Awareness Month - 610-736-3739

\* Source: Centers for Disease Control

The Autism Society of Berks is promoting autism awareness month in April through a billboard campaign. We would like to acknowledge the generous in-kind contributions from Lamar-Reading for the billboard locations and from Blue Sky Inc. for the billboard design. Many thanks to both for their continued support of our organization. Watch for the billboards across Berks County!

enforcement agency with a receiver that can tune into each person's unique radio signal and specially trains them in locating the individual if they were to get lost. The agency's personnel is also trained in the methods necessary to communicate with the individual with special needs to gain their trust and put them at ease for the trip home. For this reason, only public safety or government organizations may be active members of Project Lifesaver.

Currently, Project Lifesaver has completed 1,073 rescues across the nation at a 100% success rate! The average time of rescue is less than 30 minutes! To address the concerns many of us have about our dependents with an autism spectrum disorder wandering from home, the Autism Society of Berks County is making plans to bring Project Lifesaver to Berks County. Watch for further updates on this exciting project on our website and in this publication.

For more information on Project Lifesaver, please visit: [www.projectlifesaver.org](http://www.projectlifesaver.org). ◀

### Boyertown ASD Support Group

For Parents & Caregivers of children on the Autism Spectrum. Meetings are every second Friday of the month, 7 PM, at St. Columbkil's church in Boyertown, 2nd Floor Classroom. Babysitting Available For more information contact Toni Pederson at [dajaped@comcast.net](mailto:dajaped@comcast.net)



## Changes in Federal Special Education Law

In January 2005 Education Law Center conducted a teleconference on the changes to the Individuals with Disabilities Education Act (which is now called the Individuals with Disabilities Education Improvement Act - IDEIA). The Berks Autism Society hosted one of the training sites. Below is information that was shared at the training.

### "At-a-Glance Changes to IDEA in 2004"

#### Early Intervening Services

- Up to 15% of special education funding can be used for early intervening services for regular education students in K - 12 who need additional academic and behavioral support to succeed in a general education environment
- Services can include professional development and educational and behavioral evaluations, services and supports, including scientifically based literacy instruction

#### Evaluations

- Specific learning disability no longer requires significant discrepancy between performance and expected achievement (new test = response to intervention; "RTI")
- If a student moves to a new school district during an evaluation, new district

## RESEARCH

**Pittsburgh's CeFar**  
The Center for Autism Research (CeFar) under Dr. Nancy J. Minshew, is currently funded by NIH to search for the cognitive and neurological basis for autism. The Center is recruiting families of people with autism. Healthy controls that meet the same criteria are also necessary and being recruited. Participants may receive up to \$385 for their time. Some studies may be completed by mail. Studies continue over several years. Interested families should call 412-624-9462 or email: [autismrecruiter@msx.uprn.edu](mailto:autismrecruiter@msx.uprn.edu) for details.

### Autism Research Project

This project is a joint effort to help research the causes of autism, and to find a cure. By donating your brain (much like any other organ donation), you will help give researchers access to the first step - basic research. Contact: Jane Pickett, PhD, Director, 877-333-0999 or at [atp@brainbank.org](mailto:atp@brainbank.org)

### Sibling Study

The Center for Autism and Related Disorders at the Kennedy Krieger Institute in MD is studying the social and communication predictors in siblings of individuals with an autism spectrum disorder. Sponsored by NIH and directed by Rebecca Landa, PhD, CCC-SLP, this study looks at patterns of development in siblings. This study requires travel and involves both the child with autism and the sibling, starting as early as birth. Contact: Dr. Rebecca Landa at 877-850-3372. [www.kennedykrieger.org/kki\\_staff.ifp?pid=1048](http://www.kennedykrieger.org/kki_staff.ifp?pid=1048)

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## VOCATIONAL TRANSITIONS

Vocational Information for parents is available as technical assistance and support through **PATTAN**, otherwise known as Pennsylvania Training & Technical Assistance Network.

A resource directory/database is available, noting successful transition programs and services throughout PA. Check PATTAN's website at [www.pattan.k12.pa.us](http://www.pattan.k12.pa.us). Using the left hand index bar, click the "Transitioning" link.

A printed guide for choosing supports and services for students in transition is available through the **PA Office of Mental Retardation (OMR)**. The guide contains listings of helpful service definitions. Call your county MH/MR office for details or to request one. Call toll free, 888-565-9435.

A transition guide, called *Parent Brief, Transition Planning for Success in Adult Life* is available through the **National Transition Network**, Institute on Community Integration, University of Minnesota, MN. This guide outlines transition goals, a checklist for planning, things to consider 2-3 years out, and seeking private services, eligibility criteria, waiting lists and other issues that may arise. In addition the Institute has an online newsletter and website at <http://ici.umn.edu/welcome/default.html>.

Source: Pattan Newsletter

### SSA's Ticket to Work:

The Social Security Administration (SSA)'s 1999 Ticket to Work program works like this: qualified disability recipients are issued tickets, which they can use to obtain vocational services from approved providers to achieve certain (work-related) outcomes. Contact your local Social Security office for details or visit [www.ssa.gov](http://www.ssa.gov).

must complete evaluation within 60 days of initial consent to evaluate unless parent agrees to a different timeline

- Districts can use hearing system to compel an initial evaluation, but not initial consent to services

### IEP's

- Parents and LEA can agree to amend IEP without IEP meeting; can develop a written document to amend or modify current IEP; can "meet" via video and conference calls
- Parent must request a copy of the of the IEP with amendments incorporated
- Parents and LEA can agree in writing to excuse a member of IEP Team if not needed, or if member submits input in writing prior to meeting
- Benchmarks and short-term objectives eliminated from IEPs, except for students who take alternate assessments aligned with alternative achievement standards (PASA)

- 15 states can apply for pilot program for 3 year IEPs

### Transition/Exiting Special Education

- Transition planning requirement moved to age 16, and no requirement to invite other agencies or to establish linkages
- Appropriate, measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and independent living skills
- When children who have been receiving special education graduate, the team has to write a summary including recommendations for success in adult life

### Highly Qualified Teachers

- Teachers must meet requirements to be considered 'highly qualified' - criteria is different for teachers teaching content, supporting regular education teachers

and if students will be taking alternate assessments

### Discipline

- Case-by-case determination before ordering a disciplinary change in placement
- Immediate removal to alternative setting up to 45 school days for special circumstances: weapons, drugs, serious bodily injury
- LEA, parent, and relevant members of IEP Team make manifestation determination
- Only a manifestation if: caused by, or had a direct and substantial relationship to disability, or if direct result of LEA's failure to implement IEP
- Special discipline protections for "thought-to-be" students only if: parent expressed in writing need for special education; parent requested evaluation; or LEA personnel expressed specific concerns about a pattern of behavior directly to supervisory personnel
- No special discipline protections for "thought-to-be" students if: parent has not allowed an evaluation; parent has refused special education; or child evaluated by LEA and determined not to have a disability

### Resolving Disputes

- Procedural Safeguards Notice generally given only 1 time a year; also given: upon initial referral or parental request for evaluation; upon first occurrence of filing due process complaint; upon request by parent
- Procedural Safeguards Notice can be placed on Internet website
- Disputes resolved through mediation embodied in legally binding agreement enforceable in state and federal court
- Parent must file due process complaint within 2 years of date parent or LEA

knew or should have known about the problem

- No two year timeline if LEA made specific misrepresentations or withheld information from parent
- Due process complaint notice must be legally sufficient; receiving party can object to sufficiency within 15 days of receipt
- LEA and/or parent must respond to charges due process complaint notice within 10 days of receipt
- Amend due process complaint notice only if other party consents or HO grants permission
- Resolution session will be held within 15 days of receiving notice of parent's complaint
- Disputes resolved at resolution session embodied in written settlement agreement enforceable in state and federal court; agreement can be voided within 3 business days of execution
- Complaints not resolved within 30 days of receipt may go to due process hearing
- HO cannot have a conflict of interest; must be qualified
- Only issues in due process complaint notice may be raised at hearing
- HO will decide case on substantive grounds; procedural violations only relevant if denial of FAPE; HO can order compliance with procedural requirements
- Appeal to court within 90 days of HO decision (or in accordance with State law)
- Attorneys' fees against a parent or parent attorney for frivolous, unreasonable complaints; actions brought for improper purpose: harassment, delay, increase cost of litigation. ◀



## Aaron's Acres 2005!

Aaron's Acres is pleased to announce that for the summer of 2005, there will be two 2-week sessions of camp held at the Jewish Community Center of Reading. Camp begins on Monday, June 20 and ends on Friday, July 1 for the first session. The second session begins on Tuesday, July 5 and ends on Friday, July 15.

Aaron's Acres is unique in that it provides a camp-like experience for the child with special needs and his/her family. While the camper is at Aaron's Acres, the siblings have the opportunity to meet others in similar situations and then attend a camp program for typical children (at the JCC). In addition, the parents have the opportunity to take care of themselves by attending sessions offered by Aaron's Acres. Relevant topics will be offered and the discussions will be led by professionals in the community (topics might include the following: behavior management, advocating for your child within the school system). Other sessions might include massages, manicures or makeovers.

The camp is supervised by the program manager of Aaron's Acres, Risa Paskoff,

## YOUTH GROUPS

### Social

Jacob's Kids: Lincoln Park Church has started an ecumenical ministry for children with disabilities in 2nd-6th grade. For details, call Becky Chadwick at 610-927-2207.

### Easter Seals:

Offers social-communication groups, one for children ages 7-18 and another for children ages 3-5 with autism spectrum disorders. First come, first serve, limited space. Call Michele Miller at 610-775-1431.

Center for Pediatric Therapy: offers social-communication groups for children with ASD in grades K-6. Groups are limited to 4 children. For details, call 610-670-6800.

### Sports/Rec

TOPSoccer is part of the Wilson Soccer League. Contact Joe Marsden by phone 610-796-8714. The season runs from Aug to mid-Oct. Ages 6-18 all disabilities/abilities.

### Challenger Baseball

Exeter: Contact Gina Cooke, GCooke5967@aol.com, 610-582-5967.

South Heidelberg: is open to individuals with a disability ages 5-21. Starts April 22nd - June 10th. Fee is \$20, unless financial hardship. For more info, contact Holly Baim at 610-693-6614 or HGB73@aol.com

### Camps

Easter Seals offers Camp Lilly for kids age 6-17, call 610-775-1431.

Aaron's Acres offers a two-week camp in Berks, call 717-368-1372.

A Boyertown Autism Support Group has a camp through the local YMCA. Email Toni at dajaped@comcast.net

## THE NUMBERS

### NATIONAL

1 in 166 have autism  
 1 in 5 have a developmental delay or behavior problem\*  
 # Source: CDC, AAP

Children Ages 6-21 w/autism  
 1992-93 .....15,319  
 1999-00 .....65,575

\*\* In 2003, 10 children per day are diagnosed in California, 7 days a week—with 'classic autism' alone—not Aspergers, Rett's Syndrome, Fragile X, PDD, or PDD-NOS. (California is the only state that actively measures autism rates.)

### PENNSYLVANIA

Students age 3-21

Increase, 1993-2002

Autism ..... 71.3%  
 All other disabilities: ... 29%

Increase, 2001-2002:

Autism ..... +22%  
 All other disabilities: ... +5%

2002-03 students with autism or developmental delay

age 3-5: .....10,768  
 age 6-11: .....3,395  
 age 12-17: .....1,429  
 age 18-21: .....231

Total .....15,823

### BERKS COUNTY

Students age 3-21 with autism or developmental delay

1990-1991 .....98  
 2002-2003 .....3,366

Sources: www.pde.state.pa.us,  
 http://ed.hbg.psu.edu/ssr2004.htm,  
 the Census, www.FightingAutism.org

a licensed social worker. Michele Miller, an occupational therapist, is the site supervisor. The staff will be comprised of special education teachers as well as graduate and undergraduate students studying social work, special education, psychology and occupational therapy. Middle school and high school students are encouraged to volunteer their time and become "buddies" to the campers. In this way, these students act as positive role models for the campers and participate with the campers in all activities. A nurse is present at all times in order to address any medical needs. Staff to child ratio is low in order to promote positive interactions and appropriate behavior for these children. The camp day is comprised of typical camp-like activities including: swimming, arts and crafts, music, playground time and snacks. During the session, there will be family events held in the evening in order that all family members can attend and have the opportunity to meet others in an informal social setting.

Children with all different developmental disabilities are accepted into the program (i.e. children in wheelchairs, children who are not toilet trained are welcome at Aaron's Acres). Financial assistance is provided to those in need of this support. If you are interested in this camp program, please feel free to contact Risa Paskoff at 717-368-1372 or e-mail at paskoffj@aol.com for more information or to receive a camp application. ◀

## Encore Performance of Theatre Camp

By Sheri Taylor-Mearhoff

Last summer the Berks Autism Society sponsored a one week Theatre Camp for children on the spectrum and their siblings. The feedback was so positive that we decided to have an encore performance! Here is information about Theatre Camp 2005:



The Theatre Camp is a wonderful opportunity for children on the spectrum to benefit from the positive modeling of "neuro-typical" siblings. It also provides enjoyment and skill building for siblings. The beauty of the Theatre Camp is that all the children work on enhancing social skills without even realizing it.

Through fun filled theatre activities, the children will practice skills like reading facial expressions and body language,

### Theatre Camp Registration Form:

Camper's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_ Age \_\_\_\_ Grade \_\_\_\_\_  
 Parent's Name \_\_\_\_\_ Phone \_\_\_\_\_ Email \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Emergency Contact Name \_\_\_\_\_ Phone \_\_\_\_\_  
 Will an assistant/TSS be attending the program with the child? YES NO  
 If yes, please indicate name and agency \_\_\_\_\_  
 Any significant medical concerns (allergies, seizures, etc.)? YES NO  
 If yes, please specify \_\_\_\_\_  
 Indicate reading ability: \_\_\_ non-reader, \_\_\_ beginning reader, or \_\_\_ on grade level reader  
 Other: \_\_\_\_\_

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interpreting the meaning of voice intonation, communicating emotions, and identifying the emotions of others. The children will prepare a culminating performance for their parents that will be held on the last day of camp. Pre and post skills assessment will be conducted by the program facilitator to evaluate the effectiveness of the program.

Who: Children on the Autistic spectrum and siblings (ages 6 through 13)

When? August 8 - 12, 2005. Two sessions of the program will be held - the morning group (10 AM - 12 PM) will be for younger children and the afternoon group (1:00 - 3:30 PM) will be for older children.

Where will it be held? The Jewish Community Center in Reading, PA

Who runs the program? Cindy Schneider is the program facilitator. She is an Autism Consultant with over 20 years experience as a special education teacher and as a director of children's theatre.

There is no cost for the program but spaces are limited. Children will be registered on a first come, first serve basis. ◀

*How do I register? Mail or email the following information to the Berks Autism Society. Email= [theatreamp@autismsocietyofberks.org](mailto:theatreamp@autismsocietyofberks.org) ; Mailing address = Autism Society of Berks County - PO Box 6683, Wyomissing, PA 19610.*

## A Different Kind of Hero

*From Janine Langella: My daughter wrote this essay about her brother for the annual PTA sponsored Reflections contest. She was selected as a finalist from her school, and her piece was submitted to the district level. I thought you may want to share it with the people on your list, and they can pass it on to whomever they wish as well. She is 12 years old, and I think she has a better understanding of what is going on in this*

*world than most adults do.*

Everyday he gets up. He has to be helped in the bathroom. He needs to be cleaned and eating his breakfast is really hard. He hates to eat; sometimes just smelling food makes him gag. He smells everything. He gets dressed with help, and then they come to our house or he gets on a bus and he goes to them. They teach him how to walk, how to use a fork and spoon, how to speak and how to look at you when you call his name. He has no friends, but he is always busy. He hardly talks, but most of the time when the phone rings it is for him. I am talking about my baby brother.

He is 3 years old, I am 12. Even though I am older, I look up to him now, and I probably always will. He is my different kind of hero. He has Autism.

Everyday is a struggle for him to learn how to do the things we do. Like going to the bathroom. Putting on your clothes, eating a bowl of cereal, or just saying good morning. Instead of getting to play with a bunch of little kids like other 3 year olds, he is busy inside classrooms learning how to be a person. Some people think that a kid with autism has no feelings, not true. I say they have too many feelings.

With my brother in my life I can now see kids who have the same disability. I see how it is for them. I think about when my brother gets older, and I know he will always be different. I know that he will get laughed at, and I know he will not have many friends. All I can say is I feel sorry for the people who will never give him a chance to shine. They will be missing out on the greatest thing in the whole world and that is simply...him, my brother with Autism.

He is my different kind of hero plain and simple. He has made me see that not everyone is perfect. He has taught me without even having to speak a word that life is what you make of it. Either you

## THE COSTS OF AUTISM

### Early Intervention:

\$50-\$60,000 per year  
for a 40 hr/week intensive Lovaas replication site program, usually a 3-4 year program

### Public Education:

\$8-\$30,000 per year (per CDC)

### PA Approved Private School

\$80-\$100,000 per year  
(assuming a placement is available)

### Institutionalization:

\$100,000 per year for average patient

### Outcomes: 1999-2000

#### Graduation Rate

Autism ..... 47.3%  
All disabilities ..... 56.2%

### Federal Special Education Funds Unspent by PA, 2000-2002

\$48,706,968

Source: Budget Svc, BECS, 1/26/04

### Lifetime Costs:

Diagnosis: ..... \$32 Million  
Education: ..... \$1.6 billion  
Respite ..... \$608 million  
Medication .... \$825 million  
Day Services ... \$5.8 million  
Housing ..... \$17 billion  
Total: ..... \$25.8 billion

Source: *The Advocate*, 2000 v33(6)

### Risk of Early Death

A 2001 study 'Causes of Death in Autism' (Pickett, Shavelle, Strauss) examined mortality data for California and found "in the no or mild mental retardation" group, deaths by seizures, nervous system dysfunction, drowning and suffocation were all more than three times higher than what would be expected from the general population," and "children between the ages of 5 and 10 had the highest SMR [mortality risk]".

### Risk of Ending up in Juvenile Court: High

A 2003 government report found an disproportional number of teens with learning or behavioral problems end up in juvenile court.

Source: *National Council on Disability, Bazelon Center for Mental Health Law*

## SPEAK UP BY FAX OR EMAIL

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\* Faxing your letter is the best way to communicate your concerns, and provides your legislators with tangible, in-hand evidence quickly.

get up every day and do your best, or you get up and give up. Like I said, he is only 3 years old, but he is so smart. He will probably never realize just how much he has taught me. Just how much he means to me, and just how much I will continue to learn from him and use in my life. I am a better person for knowing him, and having him.

He inspires me, and he is such a great teacher, He will always have me, and I will always have him. I hope that through him I can help other people out there understand what it is like for a kid like my brother. I am a better person because of him, and to me there is no greater hero than one who can teach you how to be human, and humble. ◀

Source: SCHAFFER AUTISM REPORT, January 27, 2005

## Home Companions

### The little known dogs of Canine Partners for Life (CPL)

By Jennifer Kriesel

Home Companion dogs serve a very special group of individuals, whether it be young children or the elderly. The

Home Companion recipient may benefit from the emotional ties from the dog to help motivate progress in physical therapy or occupational therapy. When a child is disabled, the family may not have the time or energy to raise and train a dog for companionship for this special child. By placing a well trained, well mannered dog with these children, the dog bonds to the child instead of the care giver and becomes "their own", providing 24 hour a day therapy and love. CPL also places dogs with the elderly who would like the companionship of a dog but do not have the health or stamina to train a dog of their own.

Though CPL places full service dogs with children over the age of 12, younger children may benefit from a home companion until they reach the age where they can interact successfully with their own Full Service dog. Many of our Home Companion applicants need a dog that also has seizure alert capabilities. These amazing dogs alert to on coming seizures to enable the child to get somewhere safe before the seizures strike. Unfortunately, only one in

## The Dogs of CPL

**Full Service Dogs** - These are dogs which provide physical assistance to their partner 24 hours a day in all home and public environments. Full service dogs are placed with recipients aged 12 and older. Seizure alert dogs are a subset of CPL's full service dogs which detect and alert to upcoming seizure activity in addition to providing physical assistance.

**Home Companion Dogs** - For those individuals needing less assistance than a full-service dog, CPL provides Home Companion dogs. Home Companion dogs are well trained companions in the home environment and are suitable for all ages. Home companion dogs do not provide physical assistance so any form of disability will be considered.

**Residential companion dogs** - These dogs are placed within residential communities such as group homes and retirement communities to provide constant pet therapy. The community must be local to CPL.



ten dogs will possess this wonderful gift.

Home Companion dogs are generally placed when they are between one and two years of age. CPL does not specifically raise and train home companion dogs. These dogs are usually dogs in our program that do not have the hip integrity to fulfill the needs of a full service dog, or may not have the confidence to perform in a busy public environment. These dogs have basic obedience, social skills and manners and may possess more complex skills, but not always. These dogs do not have the public access rights that a full service dog is entitled to, but they serve an important purpose in the lives of their human partners.

CPL has placed over 80 Home Companions in a 250 mile radius of our Cochranville, PA facility. We have just started to place home companion dogs farther away to meet the needs of a

growing list of applicants. Currently our waiting list is 6-12 months long. The disabilities that we serve include: seizure disorders, cerebral palsy, spina bifida, all forms of autism, fragile x syndrome, downs syndrome, global developmental delay, hydrocephalus, neurological impairments, Badet Bledel syndrome, Wolf-Hirshhorn syndrome, hypertonia, Tourettes syndrome, sensory integration dysfunction, dyxprasia, and more. We feel we are just starting to become known for our home companion dogs, so more disabilities will be able to be served in the near future. If you know of a disability group that would like a speaker to talk about these wonderful dogs, please contact our Director of Development at (610) 869-4902 x 16 or e-mail her at [jkriesel@k94life.org](mailto:jkriesel@k94life.org).

*If you would like an application or would like more information, please contact our Home Companion coordinator Mary Fertig at (610) 869-4902 x 12 or e-mail her at [mfertig@k94life.org](mailto:mfertig@k94life.org). We have applications also available on our website at [www.k94life.org/doghomecomp.htm](http://www.k94life.org/doghomecomp.htm).*

## ABOUT ASA

The Autism Society of America was founded in 1965 by a small group of parent volunteers out of their homes. Today ASA has over 20,000 members and over 200 chapters.

Membership to National ASA automatically entitles you to membership in our Berks Chapter. For more information:  
[www.autism-society.org](http://www.autism-society.org)  
PH: 301-657-0881

### About Berks ASA:

The Berks Chapter was founded in 2000 to meet the needs of Berks families who have come to terms with the diagnosis of autism, as well as those newly diagnosed with autism. We provide information, resources, referrals, and informal monthly meetings to help stimulate helpful parent-to-parent conversations and to generate positive actions on behalf of individuals with autism and their families.

### We Offer:

Mentor families for those new to the diagnosis and process  
Lending Library available county-wide through Berks Public Libraries, see our website for a complete list of books  
Family Events  
Comprehensive, workshops, and trainings for parents and professionals  
Fundraisers and community autism awareness projects  
And much more!

### Contact us at:

[asaberks@aol.com](mailto:asaberks@aol.com)  
PH: 610-736-3739

### Disclaimer:

The Autism Society of America, Berks County Chapter is a 501 c (3) charitable organization. We do not endorse any individual programs, therapies, schools, theories, or practices of any individual person. We are not meant to be a replacement for medical or legal advice.



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## The Right to FAPE: a Free, Appropriate Public Education

### Federal Law: IDEA

The Federal law referred to as IDEA established the rights of disabled children, age 3-21 to a free, appropriate public education (FAPE). It is changing as of July 2, 2005. Here are some websites that can help you interpret and understand the law.

### US Dept of Education (DOE)

[www.ed.gov](http://www.ed.gov)  
[www.ideapractices.org](http://www.ideapractices.org)

### Our Children Left Behind

(a parent volunteer site)  
[www.ourchildrenleftbehind.org](http://www.ourchildrenleftbehind.org)

### IDEA: law, Interpretations,

caselaw and what it means  
[www.fape.org](http://www.fape.org)

### Special Ed Attorney sites

[www.wrightslaw.com](http://www.wrightslaw.com)  
[www.reedmartin.com](http://www.reedmartin.com)  
[www.kerrlaw.com](http://www.kerrlaw.com)

### PA Special Education Law:

"Chapter 14"

### PA Dept of Education

[www.pde.state.pa.us](http://www.pde.state.pa.us)  
PH 717-783-6913

### Education Law Center of PA

A non-profit legal advocacy organization. Site and documents in Spanish as well. Ask for the 'black book', their free guide to special ed law.  
[www.elc-pa.org](http://www.elc-pa.org)

Get a free copy of IDEA and PA Chapter 14: call Senator O'Pake at 610-929-2151.

# Pennsylvania Verbal Behavior Project

By: Mary Barbera, RN, MSN, BCBA

The Pennsylvania Verbal Behavior Project (PA VB Project) is a unique collaboration between Supporting Autism and Families Everywhere (SAFE), a non-profit parent support group based in Wilkes-Barre, and the Pennsylvania Training and Technical Assistance Network (PATTAN).

It began in 2001, when George R. Shadie, President of SAFE, and parent of a 15-year-old son with autism joined a handful of others to begin brainstorming about ways to bring Applied Behavior Analysis (ABA) and more specifically Verbal Behavior (VB) programming to public school classrooms. SAFE's late Cofounder, Claire T. Shadie and others had managed to create state-of-the-art home ABA programs for their children and were anxious to continue to help public school classroom staff embrace ABA and improve programming for students with autism.

In 2002-2003, two classrooms in the Wilkes-Barre area became the first model ABA/VB classrooms in the State of PA through an \$80,000 grant from the Pennsylvania Department of Education (PDE). These two classrooms were patterned after the Verbal Behavior classrooms set up by Tom Caffrey in Brick, New Jersey. Fran Warkowski, Ph.D., BCBA, was the Director of the

Bureau of Special Education in PA at the time and shared George's vision to increase quality ABA programming within public schools. Few individuals are aware that Dr. Warkowski is a Board Certified Behavior Analyst and completed extensive training under Dr. Vincent Carbone, and International expert in the ABA/VB field. The timing was impeccable!

In 2003-2004, the Project was expanded to twelve model site classrooms again through a grant given to SAFE from the PDE. The twelve model ABA/VB classrooms were located in Wilkes-Barre, Chester County, Montgomery County, Lancaster, Harrisburg, and Greensburg. The Project was a huge success. Lynette Weaver, Coordinator of Special Education for the West Shore School District, on February 3, 2004 wrote, "To say the Verbal Behavior Project far exceeded my expectations would be an understatement. In thirty two years of working in the field of special education and in being involved in many initiatives, the Verbal Behavior Project should stand as a model for all future endeavors."

The model more than quadrupled in 2004-2005, when 57 model classrooms were accepted into the Project, including six model site classrooms in Berks County. Each model site receives: 1) training from National ABA/VB experts; 2) materials such as

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Language Builder Cards, video cameras and Direct Instruction materials; and 3) on-site weekly guided practice from SAFE consultants. An interesting side note is that 1/3 of the 30 SAFE VB consultants are professionals who are also parents of children on the Autism Spectrum.

The VB Project is being evaluated several different ways as the result of much work by Dr. Bill Galbraith and Mr. Mike Miklos, both Behavior Analysts employed by PATTAN. Each student in a model site classroom receives an Assessment of Basic Language and Learning Skills (ABLLS) at the beginning and end of the school year. Each student's progress on the ABLLS as well as their progress on a social skill rating scale will be evaluated. Over 300 professionals participating in the Project completed a pre-test and will be given the same test later this spring. Growth in their knowledge of ABA and VB concepts will be measured using pre and post-test scores. In addition, all 57 sites received a site review at the

beginning of the year and will receive another review at the end of the year to measure progress towards implementation of various components. Finally, satisfaction surveys will be completed by participants. Videos and results of the PA VB Project will be presented at the ABA conference this May in Chicago as well as at the National Penn State Conference in August.

For more information about the PAVB Project, contact Debi Namey, SAFE Administrator of the PA VB Project, at 1-877-510-SAFE, option 1 or check [www.pavbsafe.org](http://www.pavbsafe.org), [www.autismsafe.org](http://www.autismsafe.org) or [www.pattan.k12.pa.us](http://www.pattan.k12.pa.us).

*The Berks ASA  
Board thanks our many  
volunteers for their many  
dedicated hours!*

## AUTISM NOW

Autism falls under the "umbrella" of Pervasive Developmental Disorders along with Asperger Syndrome, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder not otherwise specified or PDD-NOS.

According to the latest statistics from the CDC, autism occurs in 1 in every 166 births.

Based on statistics from the US Dept of Education and other governmental agencies, autism is growing at the rate of 10-17% per year. At these rates, the prevalence of autism could reach 4 million Americans in the next decade.

Autism is a complex neurological disorder that typically appears during the first three years of life. It impacts normal development in areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and nonverbal communication, social interactions, and leisure or play activities.


Autism is now the most common developmental disability, surpassing childhood diabetes, childhood cancer, and Down syndrome combined. Autism affects between 1 and 1.5 million American children and adults.

Autism is as individual as fingerprints. No two people have the same degrees of abilities or difficulties. Autism often includes eating, digestion and sleeping issues, seizure disorder, sensory issues, as well as fine and gross motor skill delays.

Autism often hides a person's unique gifts, including intelligence and a simple wish for friendship. There is no known cause or cure for autism, but there is hope.

Learn more.

Sources:  
Autism Society of America,  
[www.autism-society.org](http://www.autism-society.org)




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## President's Message

This is my last message as the President of the Autism Society of Berks County. During my year as president, it has been exciting to see our chapter grow and mature. We have become a financially sound organization that continues to promote awareness of Autistic Spectrum Disorders throughout the county through our annual Walk for Autism Awareness, our billboard project, and area outreach. We also provide support and education through our Chapter meetings, our annual conference, our newsletter, our website and listserv, our Family activities, and camp sponsorships.

Most recently, our board voted to bring Project Lifesaver (please see enclosed article) to Berks County. It would not be possible to provide this wealth of services to our community without the hard work of our entire board, Chapter members, and the businesses/organizations that have supported our important work. It has been a pleasure to serve as president and be a part of the growth of our organization. I urge you to become more involved with the Autism Society of Berks County so we can grow even stronger. For information on how to get involved, please visit our website at [www.autismsocietyofberks.org](http://www.autismsocietyofberks.org).

Sincerely,

Bob Pratt

## Mark Your Calendar

All General Membership meetings are held at the Reading JCC building.

April 2nd ... 3:30 - 5:30 PM... Family Swim at Aquabilities in Birdsboro

April 11th... A Time for Sharing Our Pleasures and Concerns: A Facilitated Session of Sharing & Networking for all of us.

May 6th... Annual Berks Autism Society Conference - "The Hidden Curriculum", Keynote Speaker: Dr. Brenda Smith Myles, author of many books and articles on Asperger Syndrome & High Functioning Autism

August 8th - 12th .... Theatre Camp (You must register by contacting [theatrecamp@autismsocietyofberks.org](mailto:theatrecamp@autismsocietyofberks.org))

Sunday, September 11th.... Autism Society of Berks County's 3rd Annual Help Solve the Puzzle: Walk for Autism Awareness at Gring's Mill Recreation Area

All children must be accompanied by an adult to children's activities (except the Theatre Camp). Babysitting is available for General Membership Meetings, RSVP at [info@autismsocietyofberks.org](mailto:info@autismsocietyofberks.org) or by calling 610-736-3739.

Information about all upcoming events can be found at our website: [www.autismsocietyofberks.org](http://www.autismsocietyofberks.org)

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