

Our Voice Has to Match Our Touch

Reported by
Linda Falotico

Lynne Seagle, who has worked in human services for over twenty years, is a leading consultant in organizational development and is the director of Hope House Foundation in Virginia. She is dynamic and funny. Any written article cannot convey the lively and irreverent keynote presentation Ms Seagle gave at the **Points of Transformation Awards** on March 26th (see page 3). She captivated her audience right from her opening remarks about the backwoods funding of her home state, Virginia. During much laughter and some pointedly silent audience moments, however, Ms Seagle delivered several key points:

- ❑ Listen – to both people with disabilities and Direct Care Professionals
- ❑ Respect and help develop self-worth in staff because you expect them to respect and help people with disabilities to develop
- ❑ Level the *paying* field and expect responsibility and participation
- ❑ Pay attention to the small stuff and do it well – walk the talk! – make your voice match your touch.

Those circumstances in Virginia, which still exist today, did not stop Ms Segal from creating an innovative and self-directed lifestyle for the people with disabilities and staff of Hope House Foundation. She explained how this was accomplished. “First and foremost, in 1984, what we decided was that group homes were the original TV reality shows, and that we were no longer going to support a congregate way of providing services. People with disabilities live in homes, and why did we take them out of those homes and put them in pretend homes? They don’t work, because of the one-size-fits-all agenda, nothing that has to do with the individual.” To make her point, Ms Seagle asked everyone who wore eyeglasses to raise their hands. “Okay,” she said, “now all of you go live together!”

“A lot is learned through Direct Care Professionals and people with disabilities,” Ms Segal said. She related the story of Anna, who lived in a group home “with nine other people she hated.” Most staff time was spent in “. . . keeping Anna from killing the nine other people she hated.” When



Lynne Seagle makes sure her points are heard during a lively and informative presentation.

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Philadelphia Mental Retardation Services is pleased to announce the selection of the four organizations that will be responsible for all supports coordination in the City of Philadelphia effective July 1, 2004

Partnership for Community Supports
Carol Frangicetto, Executive Director

Philadelphia Health Management Corporation - Person Link
Richard Cohen, Ph.D., President and CEO

Quality Progressions
Joel Goldberg, Executive Director

The Consortium
John White, President and CEO



Consumers and families will soon receive information about these organizations, when and where meetings will be held, and how to make your choice. Look for more information in the next Family Forum, too.

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The Family Forum
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Let's hear from you!

Please submit articles to: Editor, Family Forum, Mental Retardation Services, 2nd fl, 1441 Sansom St., Philadelphia, PA 19102



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Points of Transformation Awards Honor Direct Support Professionals

Mental Retardation Services' Public Awareness Co-chairs Bill Krebs and Thad Campbell welcomed the audience, amid much fanfare and with dignitaries in every row of the large ballroom in the Wyndham Philadelphia on March 26th. They then introduced the

Points of Transformation Awards' Emcee, Loraine Ballard Morrill, Director of Public Affairs at Clear Channel.

Ms Morrill has emceed many of the Public Awareness Committee's special events. One of her opening remarks went right to the point: of the awards. "We know," she said, "that there is not a lot of bling-bling associated with this (audience laughter!), but there is a spiritual bling-bling that happens here – it's the bling-bling of the heart that you receive of the work that you do and the tremendous reward that your clients receive in the way you teach them and they teach you."

Following Lynne Segal's keynote address, "2004: The Year to Empower Direct Support Professionals," there was a panel discussion. Judy Dotzman and Wayne Hobson from SPIN, and Carrol Reckard and Robin Brown from Ken-Crest, talked about what Philadelphia area agencies are doing to support and empower direct support professionals and the people they serve. They answered questions, along with Ms Segal, at the conclusion of the discussion.



Co-chairs Thad Campbell (left) and Bill Krebs trade remarks in opening the ceremonies.

Then the awaited-for award ceremony began with Pennsylvania's Secretary of Welfare Estelle Richman making the presentations.



Marguerite Barnes, the Executive Director of Housekeeping at the Sheraton Society Hill, supervises 60 staff. Since September of 2001 she has coordinated the volunteer experience for students from William Penn High School's Life Skills class.

According to their teacher, Mrs. Barnes is a first class mentor who helps the students soar and make real choices in the workplace. Mrs. Barnes will not let them

say they can't, and they come to realize that they can. The students are shown love and respect and when regular employees receive rewards, so do the William Penn students. She shares her personal experiences with them to give real examples of what to look for on the road to success. The students have shared their dreams with her, and she is helping them to realize that those dreams can become a reality.

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Thanks to Barbara Lewis and Willa Selkirk for Interpreting.

The Mission of the Direct Support Professional is to follow the individual path suggested by the unique gifts, preferences, and needs of each person supported, and to walk in partnership with the person, and those who love him or her toward a life of opportunity, well-being, freedom and contribution.



Richard Davis, Job Coach, Northwestern Human Services (NHS) has worked in the Philadelphia mental retardation system since he arrived from Pittsburgh eighteen years ago. A psychology major, Richard worked at Western Center

summers when he was a student. He has worked for several agencies, including overnight staff for SPIN for eighteen years and as a job coach with Northwestern Human Services since 1997. Richard supports Pedro, a former Woodhaven resident, who has a job delivering medication for Shelley's pharmacy. Richard's supervisor writes that he and Pedro have one of the best relationships she has ever seen. Richard has found ways to give Pedro as much independence as possible and, as a result, Pedro is becoming more tolerant of crowds and being involved with others. Richard lives in West Oak Lane with his wife, who is a school teacher, and a son in Drexel University.

Sharon DiDonato, a Program Supervisor for PATH, has worked in the field for twenty years. She leads a team of three staff and ten individuals in the day program. With her experience, she is a good model for other staff who help folks interact with people in the community. Workers at local businesses have learned to see the whole person and respond positively. The consumers who are non-verbal respond to the camaraderie. They have become comfortable in their community and have a sense of belonging fostered by Sharon and her staff. Her dream is to retire and join the Peace Corps or the Park Service.



George Gajewski, a Resident Counselor for CareLink Community Support



Services, grew up in Norristown, works in Schwenksville, and lives in Royersford. What he likes best for the past three-plus years' working with the three men in the program is making them laugh and being creative with the outings he has introduced to them, such as a plane tour and carriage rides in Center City Philly. A cold-weather shore trip is in the works for something else different. George helped an "unemployable" man to get and hold a job and reunited another with his family. George and the men are active in their local church; the first Saturday of each month they help set up and participate in the Men's breakfast and go to the church's basketball games. George hopes to rise in the agency to become a supervisor of residential homes.

Patricia Hill-Major, a Life Sharing Family Living Provider, has worked at SPIN since 1990. The transformation of Dee, after she moved into Life Sharing with Pat in June, 2003, can only be described as "incredible." Dee was experiencing serious issues in her life, and when Pat, who had had a tragedy in her own life, discovered that Dee had lost someone close to her, she decided that maybe they could help each other. So, Pat and her husband opened their home to Dee through the Life Sharing program. People who have known Dee for a long time are amazed at the calm, happy, chatty person who has emerged. Dee helps Pat with her small grandson, and around the house with chores, and they enjoy day and overnight trips. The best change for Dee is that, with Pat's help, she has almost quit smoking!



Adele Levy, a Community Job Trainer at PATH, has helped bring positive changes to many people's lives over the last seven years. A good listener and observer, Adele helps people uncover their strengths and talents,

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SPOTLIGHT on CAMPS!



Here are some day and residential camps serving children, teens, adults, and senior citizens with and without developmental disabilities. Also listed are camps that serve specific special needs. This is not an exhaustive list. To save printing space, we have used some Key Codes. If there are no Key Codes in a camp's description, it means we did not have the information and, for instance, there may be transportation, or lunch may be provided in a day program. We highly recommend you contact a camp you are interested in to get first-hand details. We will appreciate your forwarding to us any additional information you receive that will be helpful to readers.


Day Camps


 **Adath Jeshurun's Camp Kitov** (Elkins Park): HA, T/NO – programs for ages 18 mos - 5 yrs and 4 yrs and up; 6/23 - 8/18; 9am-3:30 pm, call for fees. A Jewish cultural day camp. Included is a class for children with physical and mental disabilities. Non-Jewish children welcome. Sherry Bohm, 215-635-3490

 **Bartram Beacon Summer Camp Program** (Bartram HS, SW Phila): HA, T/NO - Ages 6-13, 6/28-8/20, 9am-4pm, FREE. Offers swimming and field trips each week and organized play. Anthony Singleton, 215-492-6366

 **Camp Happy Times** (Archway Programs, Atco, NJ): HA, T/NO, RN - Ages 3-21, Call for dates. 9am-2: 30pm. Inclusive program. Pools with lifts, arts/crafts, games, nature, fishing, paddle boating, music. Barbara Hill, 856-767-5757, www.archwayprograms.org

 **Children's Place Preschool Camp** (NE Phila): Ages 3-mos – 6yrs, 6/7–8/27. Call for prices & times. Offers day trips, wading pools, arts and crafts. 215-722-1378

 **Explore Philadelphia** (Mt. Airy Presbyterian Church, Mt. Airy): Ages K to 10 yrs. Daily field trips. Child must have completed kindergarten, be able to follow directions, and be able to ambulate. Two 5-week sessions. Call for dates and fees. Edie Appel, 215-248-3080

 **FUNDamentals Art Camp** (Pennsylvania Academy of Fine Arts, Center City): T/NO, \$\$, HA - Ages 6-15. Call for dates. Prices vary from \$160 - \$195/wk, partial scholarships available. Designed to appeal to all levels and interests of young artists. Extended camp hours available. Judy Ringold, 215-972-2061

Log onto www.MyCityMyPlace.com for a full listing of camps, including email addresses and websites, as well as other fun things to do.

The **Philadelphia Recreation Department** will be completing their camp listing soon. Call them to get on their mailing list at 215-685-0700, or visit www.phila.gov/recreation.

American Camping Association, Jenkintown, PA, 215-886-5385. Provides a free list of regional summer camps. www.aca-camps.org

National Camping Association - overnight camps, 800-966-CAMP info@summercamp.org, www.summercamp.org.

Key Code

- ★ HA – handicapped and/or wheelchair accessible
- ★ T/NO – specifically mentioned no transportation
- ★ T/YES – some kind of transportation; it may be limited; have some cost, etc.
- ★ RN – registered nurse at the camp
- ★ \$\$ – some kind of scholarship, or reduced fee, or limited resources
- ★ Inclusive – serve children with and without disabilities

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Jewish Community Center Camps (Klein Branch, NE Phila): \$\$, HA - Pre school – 9th grade, 6/21-8/14, extended hours available. Prices vary from \$350 to \$750/session. Bring a dairy bag lunch. A Kosher and inclusive program offering support, socialization and recreational opportunities for children with limited special needs. Offers swimming, sports, theater, dance, art studios, field trips. Randy Boyette, 215-698-7300 X175

Mural Arts Program (Phila Dept. of Recreation: T/NO – Ages 10 & up, FREE. Meets 3-5 days per week, 30+ locations throughout the city. Under guidance of skilled artist-teachers, learn about the history and process of mural making, while building artistic & critical thinking skills, working as teams & actively participating in communities. Amy Fiske 215-685-0751

Philadelphia Zoo Day Camps (W Phila): T/NO, HA, \$\$ - Ages 4-15, 6/21–8/20, \$125 for 1/2 day to \$535 for full day. Live animal encounters, arts & crafts, fun games and activities—campers learn about the animal kingdom, conservation, and what makes a zoo work. Lunch provided. Marcy Engleman, 215-243-5311; <www.philadelphiazoo.org> engleman.marcy@phillyzoo.org

Riverbend Exploration Camp (Gladwyne, PA): HA, T/NO, \$\$ - Ages 4-14, 6/7–9/3, \$175-\$400/wk. Campers explore natural wildlife habitat. Stacy Carr, 610-527-5234 scarr@riverbendeec.org, www.riverbendeec.org



Samuel S. Fleisher Art Memorial (So Phila): \$\$ - Ages 5-17, 7/5-7/30, 9:30am–12pm, \$90/wk, plus materials and \$10 membership fee. Sculpture, painting, figure drawing, printmaking. Nancy Wright, 215-922-3456 x312; 719 Catherine St, 19147, <www.fleisher.org>

Spring Garden Academy (Phila): Ages 30 mo-12 yr, 6/22-8/22, Mon-Fri, 8:30 am-4:30 pm. Extended care from 7 am-6 pm. Christian camp with field trips, academics, singing, drama, arts & crafts, outdoor activities. Breakfast, lunch & snack included. Fee \$130 (3-12 yr), \$145 (30-36 mo), \$35 registration. Pat Wegner 215-563-9192.

Shelly Ridge Day Camp (Roxborough/Miupon): HA moderate, T/YES, \$\$, RN - Ages 5-17, 6/23 – 8/15. Prices vary from \$120 - \$230. Transportation, add \$25 - \$35. Cathy Ritchie, Girl Scouts of Southeastern, PA, 215-564-4657 X233, www.gssp.org

Taller Puertorriqueno Inc. Summer Camp (No Phila): Ages 7 - 15, 7/5–8/13, 8:30am – 3pm. Call for prices. Extended hours available. Artist residents will focus on the visual and performing arts. Field trips. Snr. Rivera, 215-423-6320

Temple University/National Youth Sports Program (Pearson Hall, Temple Univ) - Ages 10-16, 8am 2pm. FREE. Call for dates. For low income kids living in zip codes 19111, 14, 15, 16, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 32, 33, 34, 35, 36, 37, 40, 41, 44, 49, 50 52, 54. Eight different sports plus all campers must take

swimming, track & field. Lunch provided. Tribbet Green, NYSP Director, 215-204-4783

YMCA Camp (Abington): HA, T/NO, RN, \$\$ - Ages 3-17, 6/21–8/28. Call for fee info. Bring bag lunch. Aikido, dance, performing arts, adventure, volleyball, and gymnastic camps offered. Children with disabilities are welcome. One-on-one care not available, but wrap-around workers may accompany a camper. Extended day care available. Janice Murray, 215-884-9622 X217

YMCA Camp (Roxborough): \$\$, HA - Ages 3-16, 6/21–8/20, 9am-4pm. Call for fee info. Inclusive camp. Offers arts & crafts, drama, music, games, swimming and field trips. Lunch provided. Must be ambulatory and be able to listen to directions. James Lozano, 215-482-3900

Specialty Day Camps

Bournelyf Special Camp (West Chester): HA, RN, T/NO - Ages 8-21, 6/28–8/6. Call for fee info. For mild to moderate developmental challenges. Must be interviewed by Camp Director. Offers an outdoor challenge program; hiking, rock climbing, horse back riding, in conjunction with Thorncroft Stables, and swimming. 610-692-9027

Camp Can Do (Kulpsville/Easter Seal Society): HA, T/YES, RN, \$\$ - Ages 5–21, 7/6–8/6, 9am–3pm. For physical, mental, and learning disabilities. Lunch included. Call for fee info. All new applicants must have a copy of an IEP, psychological and an interview with the camp director. 215-368-7000

Camp Carefree (Coatesville/Easter Seal Society): HA, T/YES, RN, \$\$ - Ages 5–21, 7/6–8/6, 9am–3pm. For physical, mental, and learning disabilities. Lunch included. Call for fee info. All new applicants must have a copy of an IEP, psychological and an interview with the camp director. 610-873-3990

Camp Dunmore (Media/Easter Seal Society): HA, T/YES, RN, \$\$ - Ages 5–21, 7/6–8/6, 9am–3pm. For physical, mental, and learning disabilities. Lunch included. Call for fee info. All new applicants must have a copy of an IEP, psychological and an interview with the camp director. 610-565-2353

Camp Magic (Roxborough YMCA, Roxborough): HA, \$\$ - Ages 5-21, 6/21-8/20, 9am-4pm, \$122/wk. Partial day camp also provided on Mon and Fri from 9am-4pm. Must be ambulatory and able to function in a 1:4 ratio group. Arts and crafts, games, life skills, swimming and field trips. Cyndi Manley, 215-482-3900

Camp Make-A-Friend (W Phila): HA, T/YES, RN, \$\$ - Ages 5 – 21, 7/6–8/6, 9am–3pm, \$325/wk plus \$260/wk for transportation. For developmental disabilities and seizure disorders. Child can have a G-tube. Lunch included. All new applicants must have a copy of an IEP,

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psychological and an interview with the camp director. Betty Ingram, Easter Seal Society 215-879-1000

Camp PEP (Programs Employing People, Phila): T/YES, \$\$ - Ages 5-21, 7/5-7/30, \$275/wk or \$1,000 for all 4 wk. Recreational camp for children with developmental & some physical disabilities. Special educational instructors provide reinforcement of school-year learning. Lunch, snacks, materials included. 215-389-4006.

Camp Surefoot (Levittown/Easter Seal Society): HA, T/YES, RN, \$\$ - Ages 5-21, 7/6-8/6, 9am-3pm. For physical, mental, and learning disabilities. Lunch included. Call for fee info. All new applicants must have a copy of an IEP, psychological and an interview with the camp director. 215-945-7200

Carousel Farm's Educational Center (Ivlyland, PA): HA, RN, T/YES - Ages 3-21, 6/21-8/13, 9:30am - 3:15pm. Call for fees. For children with mental retardation, mild to severe disabilities and autistic spectrum disorders. Horseback riding, swimming, arts and crafts, music, dance, life skills, sports. Licensed by the PA Dept of Ed. Linda Lagrotte, 215-355-6498

Carousel House Day Camp (W Phila): HA, T/YES, RN - Ages 5-21, 7/6-8/13, \$125/wk. Must be able to provide own daily care. Must be able to participate in active and quiet group activities. Must not require one-to-one supervision. Includes lunch. Offers field trips, guest entertainment, swimming, arts & crafts, music, dance, sports, and hiking. Scott Bowman or Stuart Greenberg, Dept of Recreation, 215-685-0160

Carousel House Sports Camp (W Phila): HA, T/YES, RN - Ages 16 and up, 8/16-8/27, \$50 for 2 wks. Offers basketball, football, softball, and trips. Lunch and transportation included. Tom Schoening, Dept. of Recreation, 215-685-0160

Center for Families & Relationships (NE Phila): Ages 6-12, 7/26-8/20, Mon-Fri 9am-12pm, \$80/wk; special family rates. Early drop off at 8 am, \$5; late pickup at 1 pm, \$5. Learn how to express your feelings in healthy ways through art, writing and communication. 215-537-5367

Community Council CMH/MR (W Phila): T/YES - Ages 8-13, 6/28-8/20, 10am-4pm. Learning therapy support program with structured activities. Must be a resident of West Phila. Door to door transportation provided. Lunch provided. Fees paid by Medical Assistance or HMO. Patricia Whitlock, 215-473-7033

Elwyn Development Center (Elwyn, PA): HA, T/NO - Completed K thru 2nd. Ages 5-7, 9am-4pm. 6/21-8/20, \$130 /wk. Week of 6/30-7/3 is \$140. Before and after care is \$3.50/hr. Camp themes differ each week. Lynn Constable, 610-565-6770

Elwyn Summer Camp (Elwyn, PA): HA, RN - Ages 13-21. Must be approved through your school district. Call for dates and fees. Beverly Cook, 610-891-2197

LaSalle University Summer Inclusion Program (Simmons Elementary School, Horsham, PA): T/NO - Pre-K to 12th grades, 7/5-7/23, 9:15am - 1:15pm, \$100/wk. Welcomes children with disabilities as well as their siblings without special learning needs. Possible extended school year program. 10-12 students per class. Program for older students include discovering learning styles, career exploration. Families can carpool. Nancy Simon or Bob Gordish, Hatboro Horsham Special Education, 215-358-1005

LEKOTEC (Jefferson Hospital, W. Phila): HA, RN, T/NO, \$\$ - Ages 4-13. \$25/day. Mental or physical disabilities. Educational toys, software and play promote development. Celia Brandt 215-578-3616, Cecilia.Brandt@mail.tju.edu

Open Hearts, Open Doors (JCC, Cherry Hill, NJ): HA, T/YES, RN, \$\$ - Ages 3-13. Call for dates and prices. Inclusive. Provides peer modeling of age-appropriate social skills and friendships with non-disabled kids. Eileen Alias, 856-751-1666 X114; 2395 W. Marlton Pike, Cherry Hill,, ealias@jfednsj.org

Penna. School for the Deaf (PSD), Early Childhood Communications Summer Programs (Germantown): T/YES, HA - Ages 3-7, 7/5-8/12, Mon-Thurs, 9am-2pm. Fee is \$90 for entire program, plus \$10 registration fee. Traditional camp activities provide communication experiences for Deaf and Hard of Hearing children. Breakfast & lunch provided. Marsha Miceli, 215-951-4722


PDDC Sports and Arts & Crafts Camps (N Phila): HA, T/YES - Ages 10 and up, 7/5-8/20, 9am-2:30pm, Call for fees. Inclusive program. Provides lunch. Held at a huge, new air-conditioned site, 4424 N. Front St. Ask for free video. Pat Bell-Wright, 215-229-4550 x125, www.arcpddc.org, camp@arcpddc.org.

Phillies Baseball Academy Summer Camp (Various PA, NJ and DE locations): Ages 7-14, 8:30am-3:30pm, \$290/wk. Extended hours available. Offers baseball instruction, Phillies uniform and baseball cap, 2 tickets to a Phillies Home Game, and membership into the Phillies Baseball Academy. Lunch not included. Call for dates, locations, and car pooling info. Mike Trachtenberg, 610-520-3400 X231

Programs Employing People Camp (Greenfield, School, Center City, Phila): HA, T/YES Ages 15-22, 7/5-7/30, 8:30am-3pm, \$275/wk. Swimming, arts and crafts, field trips, music, dance, sports, and playground events. Special education instructors also provide reinforcement of school-year learning. Ratio 1-3. Includes lunch. 215-389-4006; Info@pepservices.org, www.pepservices.org/camp.html


Special People in Northeast (SPIN) (Norcom Community Center, NE Phila): HA, T/YES, RN, \$\$ - 6/28-8/20, 9am-3pm. \$150/wk for youth ages 5-12, \$180/wk for teens & adults. Program is for children with or without disabilities. Arts


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 & crafts, swimming, sports, computer, cooking, theatre, and horticulture. Combo Program: Ages 12-15, \$180/wk, combines recreational activities with field trips, swimming & special events. Explorer Program: Ages 15-21, \$195/wk, daily field trips. Transportation provided ages 12 & up. Gene Spoerl, 215-613-1074; www.spininc.org


 **Variety Club of Philadelphia** (Bok Technical HS, So Phila): HA - Ages 9-16, 7/5-8/20, 8:00am-6pm, FREE. Offers recreational and educational activities. 215-952-6200


Overnight Camps


 **Camp Jaycee** (Poconos): HA, RN - Ages 7 yrs and up, 6/13-8/7, \$1050/2wks. Child must be able to be self-feed, regular diet, no restrictive medical problems. All activities are geared toward the individual camper's ability. Nature, horseback riding, swimming, boating, music, arts & crafts, sports, dance and movement. 609-443-1200, www.campjaycee.org


 **Camp William Penn** (Poconos): T/YES, RN - Ages 8-12, 7/8-8/12, \$45 to \$60/wk. Child must be a Phila resident. Offers swimming and boating activities, campfires, arts & crafts, hiking and fishing. Pam Johnson, Dept of Recreation, 215-685-0701


 **Camp Victory** (Millville, PA): HA, T/YES, RN, \$\$. Ages vary per camp. Call for specific information. Setting hosts various specialty camps on different dates: bereavement, epilepsy, dwarfism, diabetes, ventilators, autism family, kidney disease, cancer and remission 5 yrs, arthritis, spina bifida adult/children, special needs, family, deaf and hard of hearing, heart disease, asthma, severe/chronic skin disorders, burns, diversified treatment alternatives, 570-458-6530, www.campvictory.org

 **Girl Scouts of Freedom Valley PA:** HA moderate, T/NO, RN - Ages 5-17, 6/27-8/7. Prices vary from \$225. Provides camping experiences at Camp Tohikanee (Quakertown) and Camp Tweedale (Oxford). Cathy Cronk, 610-933-7555 X238, www.gsfdc.org


 **Girl Scouts of Southeastern PA:** HA moderate, T/YES, RN - Ages 5-17, 6/27-8/6. Prices vary from \$215 - \$450. Transportation is an additional \$25 - \$35. Provides camping experiences at Shelly Ridge (Roxborough/Miquon), Camp Laughing Waters (Gilbertsville), & Camp Hidden Falls (Poconos). Cathy Ritchie, 215-564-4657 x233, www.gssp.org

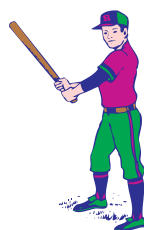
 **Girl Scouts of Penn Laurel PA:** HA, T/NO, RN, \$\$ - Girls ages 5-17, 6/21-8/7. Prices vary from \$170 to \$400. Provides camping experiences at Camp Echo Trail and El-Wa-Ho (York County) and Furnace Hills (Lancaster County). Vicky Miley, 800-673-2561, www.pennlaurel.org


 **Living Waters Camp** (United Church of Christ, Schellsburg, PA): \$\$ RN - Ages 6-20. Prices vary from \$135. Provides inclusionary opportunities for children with mild disabilities. Must be ambulatory and be able to follow directions. Fishing, arts & crafts, swimming, bible study, campfire, canoeing, sports, and archery. Joni Walker 814-733-4212, www.westol.com/~pennwest


 **Paradise Farm Camps** (Downingtown, PA): T/NO, RN, \$\$ - Ages 7-15, 2-wk sessions. Call for dates. Fees based on ability to pay. Offers drama, arts crafts, hiking, canoeing, rock-climbing, fishing, nature activities, and carnivals. Inclusive program. Must be able to follow directions and be able to ambulate. Also offers a Mother's Retreat with children ages 3-12 during the week of August 2-6. Greg Thornton, 610-269-9111, greg@paradisefarmcamps.org, www.paradisefarmcamps.org


Specialty Overnight Camps

 **Asthma Camp Experience** (Schwenksville, PA): T/YES, \$\$, RN - Ages 8-13, Call for dates and prices. First year campers with moderate to severe asthma receive first consideration. Teaches asthma management skills. Offers swimming, arts and crafts, boating, nature, basketball, rock climbing wall. Linda Stezelberger, American Lung Assn, 610-941-9595 or 800-LUNG-USA



 **Atlantic Coast Special Education Services** (Delaware Beach, DE): HA, T/YES, RN - Ages 18 & up, 6/1-10/4. \$3,045/3-week session; \$1,015/1-week session. Mild to moderate mental, physical, auditory, and emotional disabilities; focus is on social skills and independent living. Lloyd Elling, 302-537-7263, lelling111@aol.com, www.AtlanticCoast.org

 **Black Rock Retreat** (Quarryville, PA): \$\$, HA, RN - Ages 16-60, call for dates, \$180. Mental retardation, but not severe or profound disabilities. Crafts, nature, archery, recreational group games, Bible time, singing, and swimming. Jamie Sensenig, 800-858-9299; www.brr.org

 **Camp Chatterbox** (Worcester, PA): HA, RN, T/NO - Ages 5-16, 8/16-8/22, \$700 Augmentative Communication Camp for children who rely on communication devices. Parent must accompany child. Typical camp activities. Dr. Joan Bruno, Children's Specialized Hospital, 908-301-5451, CampChatterbox@earthlink.net; www.campchatterbox.org

 **Camp Helping Hands, Inc.** (Kutztown, PA & Avalon, NJ): HA, RN, \$\$ - Ages 5-adults. Call for dates, \$500/wk. Three 1-week programs in Kutztown; four 1-week shore program in Avalon. Scholarships available. 610-754-6491

 **Camp Huntington** (Woodstock, NY): HA, RN - Ages 7 and up, 6/27-8/15. Prices vary. For learning

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and developmentally disabled. Arts & crafts, home economics, music, film making, drama, swimming, work-training, and gardening. 854-679-4903, www.camphuntington.com

Camp Joy (Schwenksville, PA): T/NO, HA, RN - Ages 4 & up, 6/6-8/21. Prices vary. Mental retardation, autism spectrum disorders, brain injury, and other neurological disabilities. Swimming, arts & crafts, horse back riding, music & performing arts, campfires. Sleepover camp runs Sun – Sat. Day Camp runs Mon – Fri. Also provides year round respite. Angus Murray, 610-754-6878, <www.campjoy.com>

Camp Kweebec (Schwenksville, PA): T/NO, RN, \$\$ - Ages 8-17 with epilepsy and seizure disorders. call for dates & prices. Swimming, boating, sports, campfires, pizza parties and crafts. Denise McFadden, Epilepsy Foundation, 215-629-5003, 800-887-7165

Camp Lee Mar (Lackawaxen, PA): T/NO, RN - Ages 5-21, 6/30-8/17, \$6,400 /7wks. Mild to moderate developmental challenges. Academic education is provided to continue the IEP. Speech/language therapy, music/art therapy, daily living skills, sensory/motor perceptual training, computers, heated pool, AC buildings, therapeutic horseback riding and overnight trips. Ariel Segal, 215-658-1708, www.leemar.com, g400@aol.com

Camp Merry Heart (Hackettstown, NJ—Easter Seals): T/NO, RN, \$\$ - Ages 5-adult. Four adult sessions: 6/13-6/18 & 6/20-6/25, \$720; 6/27-7/8, \$1,140; 50 yr and up session 7/25-7/30, \$720; youth camp, 5/20 yr, 8/1-8/12 & 8/15-8/20, \$1,140. Asperger syndrome, autism, mental retardation (mild-moderate), neurological disabilities, pervasive development disorder, ADHD, physical/orthopaedic disability, seizure disorder. 908-852-3896

Children's Specialized Hospital Overnight Camp (Pocono Mtns.): \$\$, T/YES, RN – Ages 8-12, two sessions, 6/27 & 7/4. Call for prices; some assistance available. Transportation provided from Mountainside, NJ for small fee. For children with Asperger Syndrome, ADD/ADHS, learning disability, neurological disability, pervasive developmental disorder, physical/orthopaedic disability, speech/language disability, traumatic brain injury, and children with no disabilities. 908-233-3720

Eagle Springs Programs (Pine Grove, PA): HA, RN, T/YES - Ages 18-80, sessions are 8 days long from mid June to August. Call for prices. Mountain program in Pine Grove-Blue Mountains. Shore Program held in Ocean City is offered to adults who have social skills and are independent. Various pick up points for transportation. 570-345-8705, 570-345-4401, tchamil@aol.com

Handi*Camp (Spring City, PA, Newfield, NJ, or Ephrata, PA): HA, T/YES, \$\$, RN - Ages 9-21, 6/21-6/25 (Vineland); Ages 21-40, 5/31-6/11 (Pottstown). \$300 5/days; \$350 6/days. Physical and mental disabilities. Swimming, field trips, sports, arts & crafts,

cooking classes, music. Brian Robinson, 717-859-6404, handi-camp@juno.com

Keystone Camp (Poconos): HA, T/NO, RN - Ages 6 & up, 6/13–8/14, \$185/night or \$370 for one-on-one/night. Campers can attend from 1-9 weeks. Physical & mental disabilities. Campfires, music, drama, arts & crafts, paddle boats, field trips and swimming. Gloria Lance, 570-842-4521, glance@keycommresp.com, www.campkey.com

Lions Camp Kirby for the Deaf & Hearing Impaired (Upper Black Eddy, PA): T/NO, RN, HA moderate - Ages 7-16, call for prices and dates. \$25 registration fee. Cooking classes, hiking, swimming, planting trees, arts & crafts. Kathy Geroni, 215-249-3710

Muscular Dystrophy Association (Worcester, PA): HA, T/YES, RN - 1st session, ages 6-12, 6/6-6/12; 2nd session, ages 13-21, 6/13–6/19. FREE for children registered with MDA. Marge Lucas, 610-729-0050

Mustard Seed Farm Camp: RN, \$\$ - Ages 7-21, 8/1-8/1, \$290. A Christian camp for special needs children. Mental retardation, ADHD, other disabilities. Must be able to self-feed, toilet, and bathe. Offers arts & crafts, nature program, Bible stories, music, and games. Barbara Hamarich, 610- 323-8866

PA Lions Beacon Lodge Camp (Mt. Union, PA): HA, RN, \$\$ - 6-day for special care and transitional, \$375. Age 6-senior, 6/12-6/17, 6/19-24, 6/26-7/1; transitional camp for adults only 6/5-6/10 transitional for adult and children. 11-day for visually impaired, \$500. Age 6-senior 7/3-7/14 and 7/17-7/28; adults only 7/31-8/11. Moderate to severe MR, including autistic spectrum, visually impaired. Will provide transportation from bus or train station in Lewistown (30 mile drive). 814-542-2511, beacon1@hcworkshop.com, www.beaconcamp.homestead.com

Special Vacations (Mt. Union, PA & Ocean City, NJ): HA, RN, T/YES - Ages 21 & up. Dates from June thru September: Dude Camp; Shore Camp; Lancaster; Mountain Lodge Retreat. Prices range from \$575 - \$650. For adults with unlimited abilities Pat McFarlane, 215-844-1295

Summit Camp (Honesdale, PA): Ages 8-17, Full season 7/1-8/22, \$9,500; half season 7/1-7/26 & 7/27-8/22, \$5,300. Minicamp 8/23-9/1, \$1,845. Travel camp, ages 16-19, 7/26-8/19, \$5,495. Diagnosed with AD/HD, Verbal & Non-Verbal Learning Challenges, Asperger's Syndrome. Regina Skyer, 800-323-9908

Variety Club (Worcester, PA): HA, RN, \$\$ - 1st session is for ages 7-12; 6/27-7/11, \$500; 2nd session is for Ages 13-17, 7/18-8/6, \$500. Physical disabilities, such as cerebral palsy, spina bifida, muscular dystrophy, orthopedic damage, visual/hearing impairments, etc., with functional average intellectual capacity and must be able to self-catheterize. Also provides year round weekend respite. Stephanie Curran, 610-584-4366

DID YOU



▶ **Dental Care** – The PA Dental Association maintains a directory of free and reduced-fee dental clinics, sorted by county, at <www.padental.org>. For children's oral health care, call Penn Dental (215-898-5965), Temple Dental (215-707-2900), St. Christopher's Kids Smiles (215-492-9291). Penn and Temple include routine or emergency care for adults, too. For free teeth cleaning, call Philadelphia Community College, 215-781-8625.

▶ **Cuidado Dental** – La Asociación Dental De PA mantiene un directorio de clínicas dentales gratis o a bajo costo. Este directorio esta clasificado por Condado en <www.padental.org> Para el cuidado de salud oral de los niños, llame a Penn Dental (215-898-5965), Temple Dental (215-707-2900) St. Christopher's Kids Smiles (215-492-9291). Penn y Temple también incluyen cuidado rutinario o de emergencia para adultos. Para una limpieza dental gratis puede llamar al Philadelphia Community College, 215-781-8625.

▶ **Social Activities** – Gam Yahad brings adults with developmental disabilities and their families together with rabbis, professional staff, and volunteers at area synagogues for educational and social activities. There are about six two-hour programs a year. For information, call Ann Rappoport, Jewish Family and Children's Services at 215-673-0100.

▶ **Actividades Sociales** – Gam Yahad reúne a personas adultas con incapacidades en el desarrollo y a sus familiares, con Rabinos, personal profesional y voluntarios en las sinagogas del área, para actividades educacionales y sociales. Hay alrededor de seis programas al año de dos horas cada uno. Para información Favor de llamar a Ann

KNOW?

Rappoport, Jewish Family and Children's Services al 215-673-0100.

▶ **Telephone Chat** – Jewish Family and Children's Services conducts a monthly program that links socially isolated individuals in an hour-long telephone discussion. Each monthly call features a guest speaker, followed by a question-and-answer period and a chance for participants to socialize over the phone. Call JFCS central intake, 215-698-4500, or <www.jfcsphil.org>.

▶ **Charla Telefónica** – Jewish Family and Children's Services conduce un programa mensual que conecta a individuos socialmente aislados en charlas telefónicas de una hora de duración. Mensualmente el programa cuenta con un conferenciante, una sección de preguntas y respuestas y la oportunidad de los participantes de socializar a través del teléfono. Favor de llamar JFCS 215-698-4500, <www.jfcsphil.org>

▶ **Accessible Polling Places** – The Department of Justice released new guidelines to assist local election officials in ensuring that polling places are accessible to voters with disabilities. "ADA Checklist for Polling Places" covers a wide range of accessibility issues, including parking, passenger drop-off areas, walkways, building entrances and hallways, as well as use of the voting area. It helps

election officials recognize and identify accessibility problems at the schools, churches, and public buildings that serve as polling places. The checklist is available online at <www.ada.gov/> and <www.ada.gov/votingck.htm>, or by telephone through the ADA Information Line at 800-514-0301 (voice) and 800-514-0383 (TTY).

Visit www.MyCityMyPlace.com
for resources

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Any websites noted in The Family Forum are provided for your information and are not rated or reviewed. We welcome your input about useful sites you have visited. Email familyforum@phila.gov.

Did You Know?

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▶ **Lugares de Votación Accesibles** – El Departamento de Justicia hizo público las nuevas guías para ayudar a los oficiales electorales locales a asegurarse que los lugares de votación sean accesibles para los votantes con impedimentos. La lista de cotejo que provee ADA cubre una amplia variedad en cuestiones de accesibilidad, incluyendo estacionamiento, zona para dejar pasajeros, pasillos, entradas de edificios y vestíbulos, como también el uso del área de votar. Ayuda a los oficiales electorales a reconocer e identificar problemas de accesibilidad en las escuelas, iglesias y edificios públicos que sirven como lugares de votación. La lista esta disponible en la Internet en la siguiente dirección <<http://www.ada.gov>> y <<http://www.ada/votingck.htm>> o llamando a la línea de información de ADA 1-800 514-0301 (voz) 1-800-514-0383 (TTY).

▶ **Inclusion of Students With Disabilities: Strategies for Teachers and Parents** by Mary Beth Klotz, PhD, National Association of School Psychologists, at <<http://www.naspcenter.org/inclusion.html>>, is a brief article that addresses the definition and rationale for inclusion; effective classroom strategies; what teachers can do; and parents as partners. It includes a list of resources and websites.

▶ **La Inclusión de Estudiantes con Impedimentos: Estrategias para Maestros y Padres**, por Mary Beth Klotz, PhD, Asociación Nacional de Psicólogos Escolares. <<http://www.naspcenter.org/inclusion.html>>. Esto un artículo corto que habla sobre la definición y razones para la inclusión, estrategias efectivas en el salón de clases y que pueden hacer los maestros y los padres trabajando juntos. Este incluye una lista de recursos y sitios en la Internet.

▶ **My Child's Special Needs**, A Guide to the Individualized Education Program, by the Office of Special Education and Rehabilitative Services, U.S. Department of Education, can be found at <<http://www.ed.gov/parents/needs/spced/iepguide/index.html>>. The purpose of this guide is to assist educators, parents, and state and local educational agencies in implementing the requirements of Part B of the Individuals with Disabilities Education Act (IDEA) regarding Individualized Education Programs (IEPs) for children with

disabilities, including preschool-aged children, but not infants/toddlers.

▶ **Las Necesidades Especiales de mi Hijo**, una guía para el Programa de Educación Individualizado conocido como IEP de la oficina de Educación Especial y Servicios de Rehabilitación del Departamento de Educación de EU. Puede encontrar la guía en <<http://www.ed.gov/parents/needs/spced/iepguide/index.html>> El propósito de la guía es asistir a educadores, padres y agencias de educación estatales y locales a implementar los requerimientos de la parte B de la ley IDEA en cuanto al Programa de Educación Individualizado (IEP) para niños con impedimentos, incluyendo niños en edad preescolar, pero no infantes o niños pequeños.

▶ **Autism Living and Working (ALAW)** – ALAW works to secure supports necessary to sustain the participation of adults with autism in the community and to enable them to form households apart from their parents. Visit <www.autismlivingworking.org> or 610-935-9499. Source: PPCRN newsletter.

▶ **Autismo, Viviendo Y Trabajando (ALAW)**. ALAW trabaja para asegurar el apoyo necesario para sostener la participación de adultos con Autismo en la comunidad y permitirles formar un hogar aparte del de sus padres. Visite <www.autismlivingworking.org> o puede llamar al 610-935-9499: Fuentes: PPCRN newsletter.

▶ **Epilepsy Training** – The Epilepsy Foundation of Eastern Pennsylvania is offering press presentations and educational trainings statewide on seizure first aid and general information on epilepsy to various audiences. For more information contact Andrea Koretz-Smith at 570-472.0299 or 800.887.7165, ext. 108 (PA only) Their website is <www.efsepa.org>.

▶ **Entrenamiento En Epilepsia** – La Fundación de Epilepsia del Este de Pennsylvania ofrece continuas presentaciones y entrenamientos educacionales a través del Estado en primeros auxilios para convulsiones e información general de la epilepsia para diversas audiencias. Para más información favor de llamar a Andrea Koretz-Smith al 570-472.0299 ó 1-800-887-7165, extensión 108 (solo en Pennsylvania) su página en la Internet es <www.efsepa.org>.

Thanks to Emileo Pacheco for Spanish translation.

Dave Miller, executive director of Greenwich Services, died from cancer at age 79 this March. He served as Greenwich's exec since 1971 and had many interests -- raising cattle and selling Christmas trees from his farm in Chester County. Every summer he grew vegetables on the family farm and shared bushels of produce with residents at Greenwich, friends, and colleagues. Memorial donations and condolences may be made to Greenwich Services, 910 Church Lane, Philadelphia 19138.

The Department of Public Welfare is establishing a Children's Behavioral Task Force. The Task Force will be charged with advising Secretary Richman on what behavioral health services should be provided to children and adolescents and how best to provide them.



The Task Force will be divided into committees that will meet via phone, email or listserv. Chances are you can participate fully without ever having to leave home!

It is extremely important that families and people with disabilities make up a large part of the Task Force. The real life experiences of families who have youngsters with behavioral challenges needs to be told and the opinions of those families considered and respected. You can easily join the Task Force by going to DPW's website <www.dpw.state.pa.us>. Click on "Enter DPW," and on your left side you will see "Children's Behavioral Task Force" in the list. Click on it, and you will get a page giving an overview of the effort and a simple form you can fill out and submit through the internet. Secretary Richman's office number is 717-787-2600.

Mural Arts Program Offers Free Arts Classes

Philadelphia's Mural Arts Program would like to invite Philadelphia youth to take part in free mural arts classes.



Classes are held at 18 sites throughout the city. If interested in applying, contact the Mural Arts Program Big Picture Program at 215-685-0751.

Big Picture is a year long, mural-training and art education program within the Mural Arts Program. Throughout the year, students follow a curriculum that exposes them to the process of mural making. Lessons are designed to help youth participants become creative thinkers and to better prepare them for the workforce through skills in problem solving, critical thinking and teamwork.

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HIV testing saves lives. Rapid HIV testing results are available in twenty minutes. The Centers for Disease Control and Prevention has estimated that one-fourth of the approximately 900,000 HIV- infected people in the United States are not aware that they are infected. About 40,000 people in the U.S. get infected each year. Half of those people are under 25. St. Christopher's Hospital for Children Family Program offers free and confidential rapid HIV testing for youth ages 14 - 24. Walk-ins are welcome on Monday, Wednesday and Friday's from 9 a.m. to 4 p.m. and Tuesday until 5 p.m. at Erie Avenue at Front Street, 3rd floor. If you have questions, contact Ebony at 215.427.5341 or 215.427.5284; or via e-mail askeb1@yahoo.com.



Adele Levy

and then matches them to a job opportunity they find interesting. Every day Adele assists people to become valued employees. She explains different choices and options and helps people take responsibility. Adele, and the people she supports, show that labels should be broken, and that all people want the same things in life. So many people from business,

co-workers, family members, and consumers have wonderful things to say about her work. She worries that it is getting tougher to find jobs. For many years Adele worked as a bookkeeper and accountant and then decided she needed to work with people, a job she is very good at.



Anna Christine

McCabe, is a Residential Counselor, at COMHAR – for the past fifteen years at the Bennington Street CLA. She is tireless and unwavering in her support of the gentlemen to help ensure that each person’s choices

and dreams are respected. Dreams realized include an Elvis fan’s visit to Graceland (the thrill of his life) and a ten day trip to Maine, complete with a lobster catch. Christine has supported her consumers through medical crises, finding jobs, and is a friend, advocate, guide and teacher for the residents of Bennington Street. Family members says that Christine’s consistency and dedication in the life of their loved ones has a made a real difference in their quality of their life. Peers also look to Christina McCabe for guidance and experience. Christine grew up in Philly and is a single parent of three successful daughters and two grandchildren. And the future? She’s not looking to retire – she’s staying with her “guys.”

Neal Sheppard, a Supports Coordinator at PATH for two years, likes getting resources to empower individuals to act for themselves. Through skill and patience, Neal eventually helped a man who never left his home to move to a boarding home, get involved in a day program, and start art classes. By working with another

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Direct Support Professionals’ Code of Ethics

From the National Alliance for Direct Support Professionals. Visit <http://rtc.umn.edu>

- ❑ **Person-Centered Supports:** As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.
- ❑ **Promoting Physical and Emotional Well-Being:** As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.
- ❑ **Integrity and Responsibility:** As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.
- ❑ **Confidentiality:** As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.
- ❑ **Justice, Fairness, and Equity:** As a DSP, I will promote and practice justice, fairness and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.
- ❑ **Respect:** As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.
- ❑ **Relationships:** As a DSP, I will assist the people I support to develop and maintain relationships.
- ❑ **Self-Determination:** As a DSP, I will assist the people I support to direct the course of their own lives.
- ❑ **Advocacy:** As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

man to find rent, budget and employment training, he and his teenage daughter are now in stable housing. Although new to Philadelphia, he quickly learned community resources. Neal helped a brother and sister with their mother's funeral, utility assistance, connections with a bank and landlord, a place to



live, a church and a doctor, and helped the woman's dream of continuing to live independently become a reality. Neal is working toward his Masters in Social Work at Bryn Mawr College, but plans to continue in his current position because he loves what he does.

Neal Sheppard, with Secretary Estelle Richman and Loraine Ballard Morrill, also received the Hal Prushan Award, presented by Ruth and Earl Prushan, in memory of their son.

The Recreation Department of Norcom Community Center at SPIN is a unique group of nine personalities and with eclectic backgrounds. From top left, **Elinore Spinotta, Sharon Strickland, Ora Johnson, Marilyn Meisenzahl,** (from bottom left) **Rachael Hassan, Alianda Laniya, Molly Morgan and Sarah McBride** collectively represent more than 60 years' experience in supporting people to make informed choices about how to spend their time. In 2003, this group averaged over 2,000 hours of class time per week. Classes offered are in response to the interests of participants and range from morning music to computer skills, literacy, furniture refinishing, drama, sign language, and other social-confidence-building programs that help provide a stimulating sensory experience. The Recreation Department works together to offer special events several times a month including talent shows, dances, dinners and movie nights. Elinore developed a picture registration form for people who cannot read to foster independence. Rachel and Sarah ran an inclusive drama program. Ora and Sharon, teach new skills with numbers and letters and are also working toward their own degrees in social services. Lorraine has been coordinating a Philly Cares program to distribute food to people who can't get out, while studying for her Bachelor's degree in nursing. Molly does creative work with sensory stimulation activities. Marilyn makes daily visits to nursing home residents to get them out into the community. Alianda has a great impact



with her creative art ideas, revisiting an enthusiasm for ceramics, and is completing her certificate for Therapeutic Recreation Specialist. Instead of sitting home, many people choose to be at NCC because of this top-notch Recreation Department staff.

Our Voice Has to Match Our Touch

Con't. from front page

Anna said she wanted to live independently.... “We were, like, no problem, chick.”

The situation quickly got complicated and, through Ms Segal’s hilarious story telling, the audience was led up to a meeting in which Anna said she wanted to live with her friend, Nathaniel. When the caseworker explained to Anna that in the State of Virginia a man and a woman couldn’t live together unless they were married, Ms Segal told how quickly the meeting was ended when Anna pointed to Ms Segal and said, “Well, she does.”

Three months’ later, Anna and Nat moved in together, and an amazing thing happened. They had been each receiving about eighty hours of support a week, and together they needed less support. Why? Because they were taking care of each other a lot better than when they had been supported apart.

“What were we witnessing?” asked Ms Segal. “Oh, we were documenting like crazy, but not once, not once, did we ever mention the power of love. We never said, these two people love each other. And yet, we know how powerful love is. We know about this power, yet when it comes to people with cognitive disabilities, we lose touch about that power. I ask you to think about – birth to death – never meeting one person that just blows your circuits. I ask you, what if the only people you could date are those you work with or who are on the same van? **We got to do a lot more for people with disabilities finding love and romance in their lives!**”

Kirk’s story highlighted (as did all the other stories) the direct care worker’s input into the person’s life. All the king’s men couldn’t find a job for Kirk, but his direct care worker (who had no experience in supporting people with disabilities) simply asked, why? Why does Kirk take off every night and what does he do? Turned out Kirk was a night owl and a job stocking shelves in a store at night was the perfect answer. It just took someone who was interested in Kirk, who cared what he thought and wanted.

“We try, in this industry, to fool ourselves that we need all these advanced degrees, and all this specialized training,

to work with people with disabilities. **What I would suggest to you,**” Ms Seagle said, “**is that all you need is an interest in serving and the ability to be kind.**” In other words, pay attention to the small stuff.

After these personal stories, Ms Seagle approached an agency budget. “You know, if you want to know what an organization believes in, throw away their mission statement . . . and read the budget. Let’s face it, that is our dirty secret,” she said. “The further you get away from the person with a disability, the more money you make. And the closer you get, the less money you make. And we stand around and talk about values. Look in the mirror. It starts with us.” At this point, there was dead silence in the audience.

The solution used at Hope House Foundation was to equalize salaries. They froze the higher salaries and raised the lower ones, until no position’s salary was more than \$1,000 different, including the director’s, across the board. Now there was huge applause. “We talk and talk and talk about values, but it is now time for us to walk about it also,” Ms Seagle stated.

Another issue was promoting from within. “If we can’t develop our own staff,” Ms Seagle challenged, “what are we doing in the business of helping people with disabilities? Every top manager in our organization came from within. Our voice has to match our touch.”

“We tell direct care staff, don’t punish people with disabilities. But you pick up most organizations’ personnel manual, look under employee discipline . . . seems like punishment works just fine. *We’ll-write-you-up!* We tell direct care staff people to work with people with disabilities’ talents, work around their weaknesses . . . then we hand out standardized job descriptions, written exactly the same way for everyone, as if everyone had the same education, background, culture, dreams, weaknesses and strengths. Our voice does not match our touch. We need to start managing direct care staff in the very same way we want them to support people with disabilities.”

Participatory management is the number one strategy used at Hope House Foundation. “Any decision that directly affects you, we’ll first ask you what you think,” Ms Segal explained. “That’s it. But

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Our Voice Has to Match Our Touch

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it's a complex system to stay true to. You have to have an organizational climate that allows adult dialogue between equals." This requires that staff has not only an opportunity, but a responsibility, to participate.

Ms Seagle emphasized that participatory management also requires staff development. Using examples of staff undervaluing themselves, Ms Seagle asked, "If direct care staff do not value their own time, how do we teach people with disabilities to value theirs? We have got to understand there is a link. Development – not training – is what we do. Development is development of self. Closing that gap between who you are and who you want to be because if you don't understand that journey yourself, how will you help a person with a disability walk that same journey? When you learn how to look critically at yourself, and learn how to talk to your peers, and family members, and people with disabilities about *how you are doing*, that is a skill that is worth its weight in gold."

"We don't trust a direct-care person to spend ten dollars without documenting it ten times, but we leave them on their own doing some of the most intimate acts with people with disabilities. Our trust seems so skewed in terms of what we're asking people to do. Stop talking so much and really start doing more in partnership with the direct care personnel that we employ. Participatory management, investment in their own development, re-looking at this pay plan, and then all of this noise we have about person-centered planning, and all of these things, we won't need. Because you know – and I know – that what makes a difference in every person with a disability's life is the person walking beside them. And that's that direct care staff person. And that's what makes the difference ... good or bad. We know that."

By using the people doing the small stuff in the civil rights movement as an example, Ms Segal wrapped up her presentation. "Don't get fooled," she said. "It's not about big stuff. It's about small stuff, done every day . . . done extraordinarily well."

To contact Lynne Segal at Hope House Foundation, call 757-625-6161, or visit www.hope-house.org.

Art Work Entries Sought from Young Artists With Disabilities

Deadline: August 6, 2004

VSA Arts and Volkswagen of America called for entries to identify promising young artists, ages 16 to 25, with physical, cognitive, or mental disabilities. This year's theme, "Driving Force," challenges artists to consider what motivates and inspires creativity. Artwork may illustrate actual aspects of the artist's inspiration, such as the environment, myth, or personal discoveries. Abstract work that relates to the artist's feelings or emotions is also encouraged. Work may also reflect the experience of living with a disability and its role in shaping or transforming motivations.

Fifteen finalists will be awarded various cash awards and selected artwork will be included as part of an exhibit in Washington, D.C., during October 2004, that will then tour throughout the United States for the following two years. Art must be an original work that has been completed in the last three years. Eligible media include paintings and drawings, fine art prints, photography, and two-dimensional mixed media. Complete program and application information is available on the VSA arts web site, <www.vsarts.org>, or 800-933-8721 x3877.

Mayor's Aging Commission Offers Opportunities for Older Workers



Through the Mayor's Commission on Services to the Aging's Senior Community Service Employment Program, low-income older adults (55-plus) are placed in community services organizations to learn work skills while earning minimum wage for 20 hours per week.

The Commission also assists any 55-plus resident, regardless of income, to find employment. Call 215-686-8450 for information.

REPEATABLES

These are regularly scheduled meetings. However, check before you go for time, location, or date changes, especially holidays and the summer.

MONDAYS

- ☆ 1st Mon 6:30-9pm Speaking for Ourselves, St. Joes College, 5600 City Line, 610-825-4592
- ☆ 1st Mon 10-12pm PATH FDSS Adv. Com, Mary McAvooy, 215-728-4660
- ☆ 2nd Mon 7 pm COMHAR FDSS Adv. Com, Lydia Barashango, 215-537-4822
- ☆ 2nd Mon 10-12pm Northeast FDSS Adv. Com, Patty Caterina, 215-831-2883
- ☆ 2nd Mon 1:30pm Mayor's Commission on People with Disabilities, 16th fl MSB, 1401 JFK, 215-686-2798

TUESDAYS

- ☆ 1st Tues 10am CATCH FDSS Adv. Com, Diane Jordan-Adams, 215-755-9804
- ☆ 2nd Tues 10am Hall Mercer FDSS Adv. Com, Madeleine McMahon, 215-829-5276
- ☆ 2nd Tues 5:30pm NHS/Mt Airy FDSS Adv. Com, Diane Howard, 215-248-6834
- ☆ 2nd Tues 10am-noon, Vision for Equality, 718 Arch St, 6th fl. 215-923-3349 x137

WEDNESDAYS

- ☆ 3rd Wed 7pm Consortium FDSS Adv. Com, Darlene Gonzalez, 267-284-0050
- ☆ 4th Wed 6-8pm JFK FDSS Adv. Com, Betty Harrigan, 215-568-0860
x3214 Note: Nov 03 meeting on Nov 19

THURSDAYS

- ☆ 2nd Thurs 1:30pm SEPTA Advisory Com. on Accessible Transportation, 1234 Market, 11th fl, 215-580-7145
- ☆ 2nd Thurs call for time WES FDSS Adv. Com, Shenette Blount, 215-227-8946 or 45
- ☆ 3rd Thurs 10am-12pm FDSS Steering Com., 1441 Sansom St, Deborah Groom, 215-686-0224
- ☆ 3rd Thurs 12-2pm Managed Care Coalition, Liberty Resources, 1341 N. Delaware, 215-634-2000 x240

FRIDAYS

- ☆ 1st & 3rd Fri 7-9pm Easter Seals Phila teen social club, 3975 Conshohocken Ave, Kendra Brooks, 610-565-2353 x231
- ☆ 3rd Fri 1-3pm Consumer Connection, Liberty Resources, 1341 N. Delaware, 215-634-2000 x320
- ☆ 4th Fri 1-3pm Support Group for people with disabilities, Liberty Resources, see above

SATURDAYS

- ☆ 2nd Sat 1-4pm Disabled in Action, American Friends Ctr, 1501 Cherry, 215-627-7255

Help in Maintaining a Family Medical Record

By Julio Nieves, PCHC

Maintaining a complete medical record can be time-consuming and particularly challenging for families and caregivers who support an individual with special needs. The Family-HIRS (Family Health Information Recording System) was developed at Philadelphia Coordinated Health Care, the Southeast Regional Health Care Quality Unit. It provides parents and caregivers with a user-friendly tool for maintaining health information.

Some of the advantages of using the Family-HIRS are:

- ☑ Health information is readily available in an emergency
- ☑ Helps prevent diagnostic errors
- ☑ Helps prevent medical errors
- ☑ Helps to insure that all preventive tests are performed
- ☑ Helps prevent duplication of tests
- ☑ Tracks immunization
- ☑ Keeps complete and accurate health information for everyone providing support for the person with disabilities.



For a copy of the Family - HIRS, contact Philadelphia Coordinated Health Care at 215-546-0300, ext. 3206, Kim Wunner. If you would like a training on the Family - HIRS, visit our website at <www.PCHC.org> or call Bonnie DiRidolfo, ext. 3681.

**www.MyCityMyPlace.com
for more dates and
resources**

MORE INFO

- ☆ Networks for Training 123 S. Broad St, 23rd fl, annual course guide available, 215-546-4111 x3454, www.networksfortraining.org .

Sun Mon Tue Wed Thu Fri Sat


May 2004



1 Families First training session. Woodland & 66th Streets Headstart Program FREE. 10a-3p 215-204-1772



2 Suicide Awareness Week
- Rennie Harris Pure Movement presents the History of Hip Hop at Free Library 1901 Vine 1:30 p



3 *SFO, *PATH
-YAI/NIPD Annual Conference on MR/DD in New York City for info 212-273-6100

4 *Catch
-PA Waiting List sponsors Understanding the MR system training at Catch. 215-755-9804

5 Cinco de Mayo
- Jazz Standards concert at Trinity Memorial Church with Warren Davis and Joe Richardson 2pm call 215-732-2515

6 Kilimanjaro: To the Roof of Africa in Tuttleman IMAX theater at the Franklin Institute for showtimes call 215-448-1111



7 *Easter Seals
-MRS and PCA Developmental Disabilities Conference. Registration at 8:30a. 3535 Market Street 215-686-0228

8 *Disabled in Action



9 Mother's Day
- Komen Race for the Cure. Registration at Eakin's Oval 8:30a 215-238-8900



10 *COMHAR, *Northeast
-Derrick Bell speaks on racial reform at Friends Select School 17th and the Pkwy. FREE 215-563-4184

11 *Hall-Mercer, *NHS/Mt Airy *That All May Worship



12 -UPENN graduate Naomi Chung presents Art Exhibit at Gross McCleaf Art Gallery 127 S. 16th St. 215-665-8138


13 *SEPTA, *WES Special Ed. Law Conference at Lehigh University 8:30a-3:30p 610-758-6563

14 5/14-5/17 Art Philadelphia 2004 Consumer Art Show at the Convention Center -5/15 Alliance for Inclusive Education at Liberty Resources 11a-1p info 215-634-2000 x 295

15 Deaf actress TERRYLENE presents one woman show "In the Now" 6-10p. Tickets \$50-100 215-569-8104 - Alvin Ailey Dance Company at Kimmel Center 215-893-1999

16 Dept. of Pastoral Care for people w/ disabilities celebrate Welcome and Access. For info 215-587-3530 - Philabundance community clean-up 215-339-0900

17- March for Inclusion 11am at the Clothespin/ City Hall info 215-634-2000x 295
-American Theater for Youth presents Cinderella 10a & 12p at the Kimmel Center



18 Morning Bird Walks join an experienced bird watcher from 7a-9a at Churchville Nature Center 215-357-4005

19 *Consortium MH/MR Annual Plan FY05-06 hearing 10am-2pm at 1101 Market Street, 7th floor. 215-686-9498

20 *FDSS Breakaway Bicycle Tours various fun and training rides at Breakaway Bikes 18th and Sansom 215-568-6002




21 *Easter Seals *Consumer Connection



22 Art all around us Exhibit at the Please Touch Museum. Learn about local artists and explore self-expression. 215-963-0667


23 -The Seraphin String Quartet presents Mozart, Beethoven, and Schumann at Trinity Memorial Church 3p 215-732-2515 \$5 admission

24 Come visit the Philadelphia Athletics Museum for a history lesson in your favorite sport! 215-323-9901




25 -BUGS! At the Tuttleman IMAX Theater at the Franklin Institute. For showtimes call 215-448-1111

26 *JFK
--Come Visit the Rodin Museum 22nd and Ben Franklin Pkwy. \$3. 10a-5p Closed Mondays and holidays.




27 Train the Trainers Workshop: Assistive Technology 101. 8:30a-12p at Temple University Ritter Hall Annex 215-204-3370



28 Pennsylvania State Fair at the Philadelphia Park Racetrack info 215-525-2031




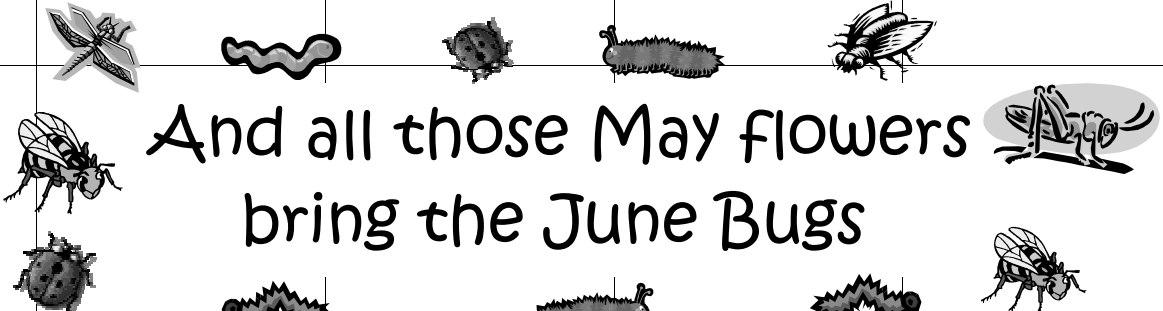
29 American Sign Language interpreted show "Courduroy" at the Walnut Street Theater for Kids 1pm, \$12



30 Time for a Teddy Bear Picnic at the Please Touch Museum. Bear shaped sandwiches, magic show, coloring and more! 215-963-0667



31 Memorial Day -World No Tobacco Day

Sun	Mon	Tue	Wed	Thu	Fri	Sat
<p>June</p> 	 <p>2004</p>	<p>1 *Catch -PA Waiting List Campaign presents Understanding the MR system at Vision for Equality 215-923-3349 - 6/1-6/4 AAMR annual meeting info 1800-424-3688</p>	<p>2 Academy of Fine Arts annual Student Exhibition 10a-5p \$5 215-972-7600</p> 	<p>3 -6/3-6/6 Achieve Retreat weekend for teens and pre-teens. Info 215-629-5003 x 102 - National Mural Art Conf. For info contact Brian 215-686-0739 -Teen Art Expo at Free Library w/ refreshments 4pm 215-686-5415</p>	<p>4 *Easter Seals - Hootie and The Blowfish at the MANN Music Center 8pm for tickets call 215-893-1999</p> 	<p>5 The Pennsylvania Ballet presents Swan Lake at the Academy of Music 2p & 8p 215-893-1999</p> 
<p>6 Cancer Survivor's Day - National Headache Awareness Week -Spring Oktoberfest Grand Park Opening games, prizes, music and meet Miss Canstatter 2004. 215-322-0424</p>	<p>7 *SFO, *PATH - Four-day outcomes training at Horizon House. To register 215-686-9437</p> 	<p>8 *Hall-Mercer *NHS/Mt. Airy *That All May Worship -West Oak Lane Farmer's Market Ogontz and Middleton Street 3p-7p</p> 	<p>9 -BUGS! At the Tuttleman IMAX Theater at the Franklin Institute. For showtimes call 215-448-1111</p> 	<p>10 *SEPTA, *WES - People's Light and Theater Company present "Born Yesterday" a Yankee Doodle comedy. \$30 610-644-3500 - 6/11 Last day of School for Archdiocese</p>	<p>11 - Visit Morris Arboretum Garden Railway Display 100 Northwestern Ave. 215-547-5777</p> 	<p>12 *Disabled in Action - StrawBEARy Fun at the Camden Children's Garden. Crafts, food and fun. 856-365-8733 -Hazardous household waste collection 215-686-5560</p>
<p>13 -A taste of Chocolate at the Academy of Natural Sciences. Enjoy rich chocolate see a real cacao plant (where chocolate comes from) and pet live rainforest animals. 215-299-1000</p> 	<p>14 *COMHAR *Northeast -Watercolor workshop at Tyler Arboretum, paint in the open air. Pre-registration required 610-566-9134</p>	<p>15 6/15-6/18 PA Mental Health Consumers Conference in Scranton PA. Info 570-343-3000 - PIRATES! RIOTS! TREASON! Take a candlelit tour of historic old city and its famous criminals 215-525-1219 \$10</p>	<p>16 *Consortium -Willie Nelson and Family in concert at the MANN Music Center 8p. For tickets call 215-893-1999</p> 	<p>17 *FDSS Last day of public school for students - Nice weather for a stroll down historic Main Street and explore the unique shops, galleries and restaurants info 215-482-9565</p>	<p>18 *Easter Seals *Consumer Connection Last day of school for teachers - Walk Philadelphia Tours explore neighborhoods of Phila with a tour guide 215-625-WALK</p>	<p>19 Summer Stroll for Epilepsy, 8a registration, 9a walk. Contact 215-629-5003 x 105 - Moss-Lined hanging basket workshop with Caroline Eells 1:30 p at Tyler Arboretum \$22. Registration 610-566-9134</p>
<p>20 Father's Day -Summer Solstice -River Rendezvous Weekend at the Academy of Natural Sciences. Discover all new things about our water and how to keep it safe! 215-299-1000</p> 	<p>21 -What floats your boat? Come take part in hands on exhibit at the Independence seaport museum. Even walk through a 22ft replica of 19th Century Shad Skiff 215-413-8621</p>	<p>22 The Rosenbach Museum celebrates Maurice Sendak and one of his most popular books "Alligators Jamboree, with every letter A to Z". \$8 215-732-1600</p> 	<p>23 *JFK - Master painter Arthur DeCosta's still life paintings exhibited at the Woodmere Art Museum in Chestnut Hill 215-247-0476</p>	<p>24 The MANN Music Center presents The Philadelphia Orchestra at 8p. For tickets 215-839-1999</p> 	<p>25 6/25-6/27 World of Possibilities Expo: features the latest in assistive & adaptive tech and other products for people w/ disabilities. Baltimore Convention Center 410-649-7000</p>	<p>26 Family First Empowerment Training: The Basics of Early Intervention at NW Regional Library 10a-3p FREE. 215-204-8280</p>
<p>27 -Chocolate Heaven Weekend, presentations by the Hershey Museum, sampling of Jubilee Chocolates, and make your own clay candy holder 11a-3p at Academy of Natural Sciences 215-299-1000</p> 	<p>28 ASL Interpreted "Hello Dolly" at Walnut Street Theater 8p. \$42 through Creative Access 1800-732-0999</p> 	<p>29 Come visit the Dream Garden at Curtis Center thousands of hand fired artwork creates a replica of an original painting by Maxfield Parrish it's simply... dreamy! 215-238-6484</p>	<p>30</p> 	<p>Now it's time to say goodbye. See you all in July!</p> 		

In Philadelphia on June 1-4, 2004 . . .

AAMR 128th Annual Meeting and Exhibit Show

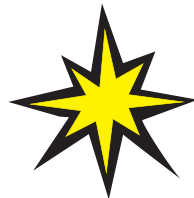
Community Health Supports: Facing the Challenge

Philadelphia Marriott Downtown



Come hear nationally renowned experts on three important issues in the field: Criminal Offenders, Psychotropic Agents, and Health Promotion.

Register on-line at www.aamr.org and print preliminary program, or call 800-424-3688.



Religion & Spirituality Division Retreat

The Good News of Access and Inclusion in Faith Communities

On June 4, presentation, reflection time, and discussion will be facilitated by the Archdiocese of Philadelphia staff. Two adults with mental retardation will share their perspective and spirituality. Full day registration for members \$30, non-members \$40, at Vision for Equality, 718 Arch Street, Philadelphia, Pa 19106.

More information is on Page 8 of the Preliminary AAMR program available at www.aamr.org, or Vision for Equality, 215-923-3349.

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