

THE FAMILY FORUM

Volume 14, Issue 1
January/February 2003



Celebrating CHOICE, My City My Place In It 2002 brought together hundreds of people to enjoy resource rooms, informative panel sessions, entertainment, an art display, Story Station, an Awards Luncheon, and the opportunity to learn, to make friends, and to greet old ones. See more photos at www.MyCityMyPlace.com.

Before we know it, March 2003 – **Mental Retardation Awareness Month** – will be here, so it’s time to make preparations. For the last ten years, families, consumers and providers did a fantastic job in planning many activities. These activities raised community awareness about the participation, gifts and challenges of individuals with mental retardation. See page 10 for some ideas.

You probably have many exciting ideas for March. Let’s help our neighbors realize that we all benefit by expanding opportunities for Philadelphians with mental retardation to become contributing members of our communities. To make sure your events are included in the citywide calendar, send a brief description of your planned activities **no later than February 7, 2003**. See enclosed form.

Be sure to send Family Forum a photo and a caption of your event!

For the third year, we will recognize the dedicated, life-altering work performed by direct support professionals with **Points of Transformation Awards** in a March ceremony in City Hall. We need your help to identify those unsung heroes and heroines who make a difference in the lives of persons with mental retardation in Philadelphia. The Points of Transformation Awards will reward outstanding performance and dedication and also help educate the general public about the potential of people with mental retardation and the importance of jobs on the front line. A nomination form is enclosed with this Family Forum issue. If you don’t receive one, call 215-686-0253, or familyforum@phila.gov, to request a form.

**Kathy Sykes, Director, Mental Retardation Services
Lynette Savoy, Lynn Youngman, Donna Szamatowicz
Co-Chairs, Public Awareness Committee**

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Linnett Roberts (left) and Consortium FDSS Coordinator Darlene Gonzalez take MyCityMyPlace.Com computer training at the Walnut Street West Library. Call Brenda Tingstrom at 215-686-0232 for computer training information.



SPOTLIGHT on Viewpoints

Institution vs. Community Costs

In this issue of The Family Forum we reprint a letter from Michael T. Durso, President of Parents of Woodhaven, Inc., and an edited article from The Arc of the United States' Executive Director, Steve Eidelman, which responds to the comments made by Mr. Durso and others associated with Voice of the Retarded (VOR).

The following letter, dated October 3, 2002, was written to the Editor of The Family Forum by Mr. Durso. It is reprinted in its entirety.

"I received a copy of the Family Forum as my son Lawrence is from this catchment area. He has been a resident of Woodhaven Center for twenty years.

Usually in the forum there are some statements that have no basis in fact. This was the case in volume 13 issue-5 September-October-2002.

On page 6 there is a cost comparison between community and Institutional. These numbers are untrue.

I have enclosed a Nation wide review including the United Kingdom. Would you see that Kathy Sykes gets copy. Kathy Sykes view is the same as Deputy Secretary Thaler which has proven to be wrong.

Review By-Developmental Disabilities Health Alliance Inc."

***Family Forum welcomes your viewpoints,
ideas and discussions.***

When Digs Fly... And Numbers Lie

By Steve Eidelman, Executive Director, The Arc of the United States, from The Arc Insight, Issue #3-2002, edited (for space) with permission.

Mark Twain once uttered this brilliant quote on statistical analysis: **"There are three kinds of lies: lies, damn lies, and statistics."***

Some of you may have seen or heard about the executive summary of an article *Institutional and Community-Based Systems for People with Mental Retardation: A Review of the Cost Comparison Literature* by Walsh, Green and Kastner. This study, *supported by Voice of the Retarded (VOR)*, attempts to analyze existing studies of costs arguing that community services and supports are more expensive than institutionalization. In terms of validity, it calls to mind tobacco company research on the effects of smoking on health. The report is an analysis of existing research and is not original research. And it totally misses the point.

VOR is distributing the summary of this study with a greeting: "Thank you for your efforts to disseminate the Cost Comparison Study Executive Summary! Efforts in recent years have displaced thousands of people with severe or profound

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The Arc . . . Responds

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mental retardation who are also medically fragile and/or who experience severe behavior challenges. The experiment has often met with disaster and suffering, including higher mortality rates. Sadly, the decision in some states to eliminate large centers was motivated by the unjustified belief the states would achieve cost savings.”

Displaced? Who are they kidding? I defy VOR supporters to find anyone who was “displaced” or ignored after being freed from an institution. The mortality study they cite has also been refuted. On the contrary, people who have moved from those large settings are, in the view of the overwhelming majority of analysis, better off and even if they were not, do we really want to segregate people that way? The Arc thinks not.

Our field has, in the past three decades, learned to separate “level of care” from real estate. They are two separate issues. *Where* the needed supports for a person take place, and the frequency and intensity and duration of those supports, are two separate issues.

The question of the comparative costs of institutional vs. community services is not relevant in this case – even if the costs are the same...and VOR does not even contend that the community is more expensive. The real question is: Under what circumstances should (or, more importantly, will)

the taxpaying public pay for 24-hour wrap-around services on behalf of our constituents, regardless of the setting in which those services are provided? In institutions, the taxpaying public is paying for services that are shown to produce poor outcomes for the people served. Clearly, this is poor public policy.

If it is agreed that people should not have to essentially leave society in order to receive the basic support they need to live their lives, then it does not make sense to offer needed supportive services outside of the community setting. The issue is not really one of costs (although this certainly makes a difference), but rather one of civil rights. Other than in the criminal justice system, I can't think of another situation where such restrictions take place, nor one that tolerates the effective control of one group by another.

[The original article then printed portions of “the executive summary” and refuted the statements. Visit www.thearc.org website for the entire article. The article ended with —]

Lies, damn lies, and statistics. I am proud to say I know where The Arc stands, what we stand for, and that we hold Integrity and Honesty as two of our core values. I challenge VOR to adopt similar principles, and to live by them.

** While historians argue about the original source of the quote, they now seem to agree that the source was Baron Leonard Henry Courtney. Courtney lived from 1847 to 1929 in England.*

The **Career Advancement Network (CAN)**, at Temple University “ . . . will give you the support you need; offering a variety of services and training programs that will equip you for the climb including: computer training/literacy and enhancement; personal counseling, stress reduction and emergency assistance; GED classes; money management; fun activities for families; career planning, job coaching and advanced job placement; a variety of job training programs; convenient hours including evenings and weekends” You qualify if you're working; you live in Philadelphia; you're not enrolled in any employment training program funded by PA DPW and have a child under 18 years of age. Call 215-787-1000, Patricia Levy, pmlevy@temple.edu.

Understanding Your Child's Legal Rights to Special Education



by Len Rieser, reprinted with permission from the *Public School Notebook*, Fall 2002

What are my child's rights to special education services, and what can I do if I have a problem? We'll try to provide some quick answers here.

First, here's a special announcement for parents whose children are in schools run by EMO's (or "education management organizations") – private companies or organizations such as Edison, Victory Schools, or Foundations. The fact that an EMO is managing your child's school does not change your or your child's legal rights.

Your child still has a right to be evaluated-and periodically re-evaluated-for special education, and, assuming he or she is eligible, to an appropriate Individualized Education Program (IEP) and placement. All of the procedures and timelines that apply in traditional public schools also apply in your school. This is also true of charter schools.

So what should you do if you have a problem with your child's program or placement?

Start at the school, by talking to the teacher, counselor, and principal. If you're uncertain about why your child is having problems, or what he or she really needs, you may want the school to do a re-evaluation. You could also have your child evaluated by someone outside the school system; this may have to be at your expense, but sometimes you can get the school to pay for it.

Either way, once you know what sorts of changes you want you can ask for an IEP conference to

Hotline for Parents Addresses School Issues

Philadelphia public school families looking for answers about their schools and the recent changes in the School District have a new information source they can call.

The **Philly Public Education Connection**, a hotline for parents and community members, has been launched through a partnership of 10 local organizations. The hotline provides answers to questions on school-related issues and connects callers to parent and community organizations working on these issues. It is staffed by both English and Spanish speakers.

Sponsoring organizations include the Notebook as well as Philadelphia Citizens for Children and Youth, the Education Law Center, and the Philadelphia Education Fund.

The hotline can be reached at 215-563-9057. Questions can also be asked through a website – www.phillyedconnection.org – which includes fact sheets on commonly asked questions as well as access to school-by-school data for Philadelphia.



discuss them. IEP conferences are usually held once a year, but you can have one anytime.

If this approach doesn't work, here are some next steps.

- ❑ If your child attends a regular public school managed by the School District, contact the Special Education Lead in the Regional Office. Your school can tell you how to reach this person.
- ❑ If your school is run by an EMO, ask for the name and number of the EMO special education coordinator and contact that person. Charter schools usually also have a special education coordinator.

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Free Legal Help for Seniors

The SeniorLaw Center (formerly known as Judicare), provides free legal representation, community education, advice, information and referrals and advocacy to Philadelphia residents ages 60 year or older who meet eligibility guidelines. In addition to its new name, it has a new address and phone number – 100 S. Broad Street, 18th Floor, Philadelphia, PA 19110, 215-988-1244. The website is www.seniorlawcenter.org



SeniorLAW Center’s staff and its panel of attorneys assist with legal problems regarding: housing (including: landlord/tenant issues; home repair contractor problems; real estate taxes; code enforcement violations; property damage); consumer protection (including financial exploitation; utilities; contracts and warranties; consumer fraud; debt collection); family matters (including protection from abuse; custody, support and advocacy; personal planning (including wills, power of attorney; advance health care directives; probate of small estates).

Mediation Guide in Multiple Languages

CADRE and the Alliance publish “Special Education Mediation: A Guide for Parents” in multiple languages, including Spanish and Hmong. This booklet provides an overview of the mediation process and how it works. The following are some topics addressed in the booklet: What is Mediation?, Individuals with Disabilities Education Act, How To Request Mediation, The Benefits of Mediation, Frequently Asked Questions About Mediation, How to Prepare for Mediation, Important Sources of Information.

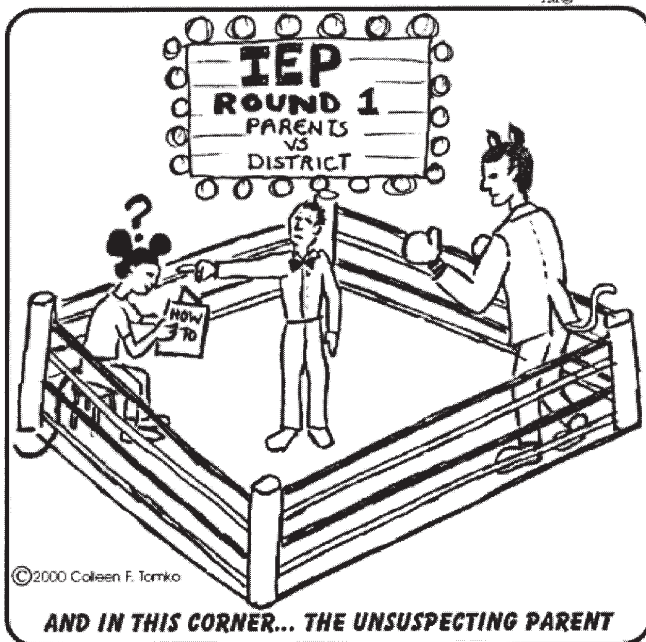


- ❑ On the web, for the English parent guide: go to <http://www.directionservice.org/cadre/ParentBooklet.cfm>.
- ❑ Spanish parent guide: <http://www.directionservice.org/cadre/espanol.cfm>
- ❑ Hmong parent guide: <http://www.directionservice.org/cadre/semhmong.cfm>

This product was jointly developed by CADRE and the Technical Assistance Alliance for Parent Centers (the Alliance). CADRE is the Consortium for Appropriate Dispute Resolution in Special Education, a federally-funded project that encourages the use of mediation and other collaborative strategies to resolve disagreements about special education and early intervention programs.

The website of Kids Together, Inc., is designed “to provide helpful information and resources to enhance the quality of life for children and adults with disabilities . . .” In addition to helpful info, the cartoons are funny and to-the-point! Visit www.kidstogether.org or email staff@kidstogether.org.

THE PARENT SIDE™



Mom's Travel Trauma

By Amy Keitzman, an active parent with the FDSS Consortium Family Advisory Committee



Kate Keitzman

I have never found it easy to let go where Kate is concerned. But encouraging her to go on public transportation and then agonizing 'til she gets where she is going (and home again) is like no other kind of torture. Although we have had no bad things happen yet, that doesn't stop me from beating myself up in advance. What kind of mother would let her disabled daughter take such risks? Yet, for some compelling reason, I go on encouraging her.

The local train station is practically on the campus of the school Kate attends, so I am letting (that is, teaching and encouraging) Kate to take the train home by herself after her play rehearsals. She does have a cell phone with her, but walks alone to the train station. The first time she did it without me or her Dad, the play practice went almost an hour longer than it was scheduled to, so it was dark well before she got home. Also we hadn't worked out the cell phone protocol very well, and when I tried to call her, she must have been in one of those in-between places where the reception was poor. She did answer the phone, but then kept fading in an out and then stopped altogether.

I, of course, tried to call her several more times, but could not get her. The train ride itself is only a half an hour long, so after an hour I was frantic. Kate finally called me as she was stepping off the trolley just two blocks from our house. She had gotten off the train, found the trolley stop and got on the right one and gotten home! She had never done all that in the dark before! I didn't know whether to laugh or cry.

Sometimes I think I am crazy, and I know that other parents of disabled teens think I am, too. But my mentor in this area started training her son to take public transportation when he was ten years old. Almost everything bad that could have happened to him did. He forgot to get off and ended up lost, way the heck up in the Northeast. He was even hit by a car once although he was not seriously hurt. He not only survived, but is quite an accomplished traveler now. I remember when I first

met the two of them, I thought she was crazy. I also thought, "He is a boy, and my child is a girl, and the risks are different." But I soon realized that if Kate is going to have as big a life as she can, she will have to take risks. This, of course, means I will have to suffer that peculiar torture; a combination of abject fear and terrible guilt (in advance of anything bad happening), that only crazy mothers like my mentor and I experience.

So far my worst experience was sending her off to visit her Grandmother in Florida this year. Although I got her to the airport nearly two hours before take-off because of the increased security measures, I failed to think that they might not automatically let me accompany her to the gate. I was stunned when we got to the security clearance area, and they informed me that only ticketed passengers could go beyond that point. I was informed that I could go back to the ticket counter and get a pass. However, I had my middle daughter with me, and I just wasn't sure what to do.

The three of us put our heads together and decided that Kate could do it on her own. It was a straight shot to the gate from the security area, and Kate really wanted to try it by herself. She was a little nervous, but not as nervous as I was. It took Kate forever to get finished with security since they were making folks take off their shoes, and she had

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Mom's Travel Trauma

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sneakers with laces. Finally, we watched her stroll down the concourse and out of sight. I kept looking at Megan, my fourteen-year old and asking, "Do you think she'll be alright?" Megan reassured me over and over until we finally left.

Once we were in the car, I had a horrifying thought. This end was easy, but what about when she gets to Tampa? That airport is much more complicated. I tried calling my mother to warn her, but she did not answer. I never was able to get her. She lives about an hour from the airport, but must have left very early and done some shopping or visiting on the way. Knowing my mother, I felt reassured on a thinking level. She would have no trouble getting a pass, but my worry-mind went into over drive.

The plane was due to land shortly after 6 p.m., so starting at approximately 7:30, I called my mother every ten minutes. When there was still no response at 8:30, I got more and more panicky . . . sure that something had gone terribly awry. I knew that they had probably stopped for dinner on the way home, and I also knew that my mother would have called if any problem had occurred, but, of course, that did not stop the rising panic. I had to stop myself from calling the police in Florida more than once. They did not call me until nine thirty! Everything had gone fine, but that was the worst afternoon and evening ever! I think it shortened my life by a decade.

I am sure there will be more mishaps and more adventures in Kate's travels. Perhaps my life will be shortened back to zero by the time this is over. But I also get to experience the joy and satisfaction of seeing my oldest daughter gain competence and confidence in the world in which she must function if she is to have the life she deserves. Besides, as one great comedienne said, "If you can't be a good example, you'll just have to be a horrible warning!"

If You've Got Air Travel Trauma --

The Department of Transportation has an aviation consumer disability toll-free hotline – 866-266-1368 and TTY 866-754-4368. The hotline has been tested by the disability community and their comments were incorporated to improve the hotline system. Should you experience disability-related air service problems, be sure to use the hotline number.

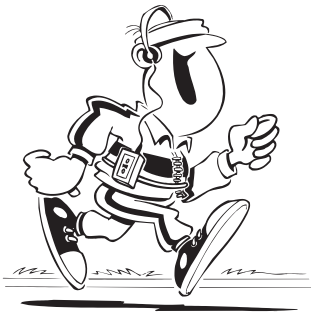


Make an Internet e-Buddie

My name is Lauren Taintor, and I am the program manager for e-Buddies, the newest of friendship programs from Best Buddies International. e-Buddies is an email friendship program between an individual with an intellectual disability and a non-disabled individual. They are matched based on age, gender, and similar interests, and agree to email each other once a week for a year. Criminal checks and child abuse checks are conducted on both sides. Each individual is required to provide 3 references and is matched with someone out of state. e-Buddies agree to a code of conduct, which among other things prohibits in-person meetings and the exchange of any attachments, and actual email addresses aren't used. You must be at least 10 years old and have access to the Internet at least once a week to join. The program is free, safe, and fun! To sign up, simply go to www.ebuddies.org and click "sign-up."

We currently have a waiting list of volunteers who would like to be matched, but we do not have enough individuals with intellectual disabilities to pair them with. Contact me via email LaurenTaintor@bestbuddies.org or (412) 521-4228. I look forward to hearing from you soon!

DID YOU



KNOW?

▶ **Arts Therapy** – The Kardon Institute for Arts Therapy assists individuals with special needs to achieve personal growth through the arts. Sessions are individualized to the goals and interests of each client. Financial aid available. Multiple locations. Call 215-637-2077 X105.

▶ **System Revamp** – PA State Rep. Dennis M. O'Brien (R-Phila.) has launched a study of state special needs services with an eye toward streamlining and improving them under a new Office of Developmental Disabilities. "I've identified at least eight departments where people have to go to solve a special needs problem," he says. "It's absolutely impossible for parents to navigate the system." O'Brien says he will spend 12-18 months studying the system in PA and other states, gathering opinions and crafting a new structure. To reach Rep. O'Brien, call 215-632-5150. Source: Special Kids magazine.

▶ **Book of Phila Disability Culture** – Through articles, sermons, drawings, poetry, photos and other media, "No Restraints" (New City Press, \$20) takes us inside the minds of Philadelphians with disabilities. Described as "an anthology of Disability Culture in Philadelphia," Gil Ott, of Liberty Resources, has selected contents ranging from essays to creative presentations through words and art. To order, call 215-634-2000, www.libertyresources.org.

▶ **Teachers' Website Aid** – Teachers of students with learning disabilities can access a website created by the Council for Exceptional Children's Division for Learning Disabilities – www.TeachingLD.org – where they can find research-based strategies, tips, e-mail, newsletters and national conference information.

▶ **Van Modifications** – Whether you're looking for a completely new vehicle or just want to make a few repairs or modifications, Van Conversions, Inc., can help with complete custom conversions of mini and full size vans to meet your specific requirements: sales, installation and

service of adaptive driving accessories, power seats, and lifts. They also have rentals and pre-owned vehicles. Call 610-666-9100, www.vanconinc.com.

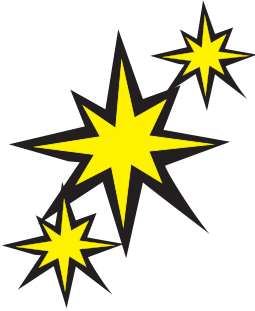
▶ **Special Needs Radio Program** – WNWR AM 1540 is now airing "Special Needs," a live talk show, Wednesdays, 12:30-1:30 p.m. The show provides information for Philadelphia parents and care givers of children with special needs. To reach Samuel Burwell, call 215-877-6373 or write sburl28665@aol.com You can hear archived broadcasts at www.wnwr.com.

▶ **Web Safety for Kids** – Get this free brochure, "Child Safety on the Information Highway," from the National Center for Missing and Exploited Children. Call 800-843-5678, or visit www.safekids.com. Another helpful site about parental-control software is "Resources for Internet Parents" at www.netparents.org. The PA Education Department Internet site contains a special section with numerous links to safe educational websites. From www.pde.psu.edu/kidsplac.html, children can go to numerous safe sites containing all sorts of educational information.

▶ **Diapers through Medical Assistance** – Children with special needs three years of age and older are eligible to receive diapers through Medical Assistance. Your child must have an active MA card and a Pediatrician's prescription for the diapers. It must include your child's name, weight, birth date, diaper size and if he/she is incontinent, and specify 180 diapers with six refills. Then call Interphase, 215-743-1100, and give them the MA # and prescription information. Diapers will be delivered directly to your home. Upon delivery you must provide the driver with the pediatrician's prescription.

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

Ideas For Mental Retardation Awareness Month Activities, March, 2003



Activities are limited only by our imagination.

Planning events to celebrate MR Awareness month in March is a wonderful opportunity to educate, reach out to, and build partnerships in the community with schools, churches, businesses, recreation centers, civic groups, etc. We want to let people know that folks with mental retardation have the same needs and desires as everyone else, are in the community, and want to be a part of the fabric of our city.

Families: Start a sibling or dads support group. Educate your elected officials about the needs of persons on the waiting list and more funding for staff salaries. Invite guest speakers to help families connect to community resources, and learn about new programs, funding, and their rights. Organize a health fair or an adult literacy program. A concert for children and their peers could be a fun event.

Community: Staff can host an open house or progressive dinner at different programs and homes. Join your community association, a community garden, or town watch. *What opportunities can you find?*

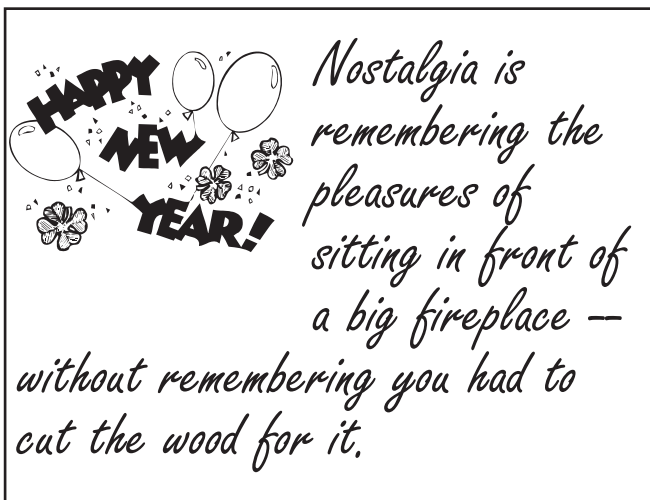
Social and Recreational activities: Visit your neighborhood recreation center, athletic teams, senior or cultural center to discuss participation for persons with mental retardation. Organize an inclusive activity or an arts and crafts show.

Employment: Survey your community's businesses, city services (libraries, fire stations) and non-profits (hospitals and churches). Recognize an employer who supports individuals with disAbilities on the job and publicize in the local media. Invite potential employers to a luncheon and a tour to discuss hiring people with disAbilities and training volunteers.

Self-Determination/Self-Advocates: Ask an individual with mental retardation what they like to do and support their desire for a friendship, hobby, job, worshipping, participating in the community, etc. Share life stories at community organizations, places of worship and through radio and television shows.

Spirituality: Encourage houses of worship to welcome people with disAbilities; ask religious leaders to preach about the gifts and contributions of all people. Develop work and volunteer opportunities at your church; invite consumers to be part of a choir; recognize and use everyone's gifts.

Media: Prepare a feature article telling a heartwarming story about direct care staff, someone who is on the waiting list, or is a contributing member of the community after living in an institution. Give an award to a neighbor, volunteer or staff person who has improved the quality of life for an individual with a disAbility, and publicize the presentation in your local press. Make a video about agency services and/or how people with disAbilities are included in communities activities.



The Family Forum extends its sympathy to the family of Steven Graubard, a 2002 Brighter Futures winner. Dr. Graubard passed away from cancer before the November 2002 event.

We are also saddened by the untimely passing of Susie Trout, a long-time parent activist with NHS-Knights Road, Parents Exchange, the Temple DD Center, and others.



Profiles Sought for Book for Kids with Disabilities

New Mobility is starting a project, described as “a book FOR kids with disabilities . . . to create a unique resource filled with peer support – kids sharing their experiences with other kids.” Jean Dobbs requests contacts with active pre-teen or young teens, youth organizations that introduce their members to adaptive sports, recreation, the arts, etc. If you can help Jean make contacts for the book, email her at jean.dobbs@earthlink.net. Source: C2P2 listserv

The Sojourner, produced by The Philadelphia Tribune, is a quarterly visitor's guide that “takes a comprehensive look at African-American culture in Philadelphia on the first Friday of January, April, July and October.” To list your events, call 215-893-4080, ext. 139.

The world always looks brighter from behind a smile.



Access Sports distributes donated sports tickets for lots of different events (no Eagles or Flyers tickets) to agencies serving individuals with special needs and low-income children and youth groups. Contact Ms Harris at 215-951-0330 ext. 131. She is also looking for individuals who would be interested in being Active Advisory Board Members, as well as potential funding sources. Source: DHS Resources



Pennsylvania's Property Tax/Rent Rebate Program is open to seniors 65 or older, widows and widowers 50 or older, and disabled Pennsylvanians 18 or older with an annual household income of \$15,000 or less. Applicants can exclude 50 percent of Social Security or federal railroad retirement benefits in determining income eligibility. The rebate of up to \$500 is based on the property tax or rent paid in 2001. Inquiries about a claim may be made by calling the Department of Revenue's toll-free number, 1-888-PA-TAXES. More than \$2 billion has been paid to qualified applicants since the lottery-funded Property Tax/Rent Rebate Program began in 1971.

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Understanding Your Child's Legal Rights . . .

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If your problem still isn't solved, here are some more options:

- ❑ If your school isn't providing the services on your child's IEP or isn't responding to your requests for an evaluation or IEP conference, you can file a complaint with the state Department of Education. Call the Department's CONSULT line at (800) 879-2301 to start this process.
- ❑ If you believe that your child needs more or different services, try the Special Education Mediation Service. This state-run program will send a trained mediator to meet with you and school staff. The mediator won't take sides or make a decision, but will try to broker an agreement. The program is quick, painless, and has a good track record, call (800) 222-3353.
- ❑ You can request a "pre-hearing conference." This is basically a formal meeting, designed to try to avoid the need for a special education "hearing."
- ❑ Finally, you have a right to a special education "due process hearing." This is a legal procedure in which a state appointed hearing officer takes testimony about your concerns, hears from the school, and then makes a legally binding decision. It's a formal procedure, and it requires preparation. Often, this includes finding an expert (such as a psychologist) who can testify about why the services your child is receiving aren't appropriate. You may also want to hire a lawyer. Free legal services are sometimes available for income eligible clients. Because the hearing process is more complex and time consuming, it's best to think of it as a last resort.

For more detailed information, including fact sheets on many common questions, see Education Law Center website, www.elc-pa.org. To order fact sheets, call (215) 238-6970. For further help, call the Education Law Center at (215) 238-6970 between 9 am and 1 pm. Because of the volume of calls, please check publications for help first.

A Different Journey: Personal Stories for Parents by Adults with Disabilities

Stan Klein and John Kemp are co-editing a book for which they invite personal stories. For this book, adults who have grown up with disabilities and/or health care needs are invited to write short essays for parents of children with disabilities and/or health care needs. In their essays, authors are asked to write an essay that they wish their own parents had read or been told while they were growing up. Authors of essays accepted for inclusion in the book will receive \$125 for the right to include their essay. Here are specific guidelines for essays:

1. Please write an essay of about 1,500 words, or less. Add a biography of about 150 words, or less, that would follow the essay in the book. At the end of the essay, please write your mailing address, telephone number, fax number, and email.
2. Please submit your essay as an attachment in Microsoft Word to an email or paste your essay into the body of your email. Send email to: stan@disabilitiesbooks.com
3. If you submit your essay by regular mail, please double space the text. If at all possible, please also submit the essay on a disk. Please label each page of your printed essay and the disk with your name and address. Please send the printed copy and disc to: Stanley D. Klein, Ph.D., DisAbilitiesBooks, Inc., P.O. Box 470715, Brookline, MA 02447-0715.
4. Deadline: all essays are to be received by February 15, 2003.

Source: Brian Cox, Executive Director, Maryland Developmental Disabilities Council, www.md-council.org, www.family-networks.org, sent to Family Forum by Donna Szamatowicz.

Supporting Someone with a Seizure Disorder

Did you know that over two million Americans have been diagnosed with a seizure disorder? And that the incidence of seizure disorders is greater in individuals with disabilities? Seizure disorder is a condition that can be potentially life threatening, so it is extremely important that anyone who supports any individual with this diagnosis has complete information and is comfortable intervening when needed. It is also important to know that many seizures that occur are not medical emergencies. A seizure may end after a minute or two without harm. Knowing what to look for and what to do is key to the management of seizure disorder.

To insure the safety of the individuals we support, all care givers should receive Seizure Management Training to include:

- ❑ an overview of seizures (definition, types, causes, triggers, treatment options, how to ensure privacy)
- ❑ instruction on what to do during a seizure
- ❑ instruction on when to initiate emergency services
- ❑ first aid for seizures
- ❑ seizure information specific to the individual (remember that seizure activity varies widely from person to person).

Here are some tips to remember when supporting someone during a seizure:

- ❑ try to prevent or break the person's fall and lower gently to the floor
- ❑ turn the person on his/her side (this helps the person breathe freely)
- ❑ loosen any tight clothing around the neck (this helps the person breathe freely)
- ❑ move any objects in the immediate area that could cause injury (for example, furniture with sharp edges)
- ❑ do not put anything in the person's mouth (it is not possible for the person to swallow his/her tongue)

- ❑ do not hold the person down or restrain the person in any way (this can cause injury)
- ❑ let the person lie on his/her side until the seizure is over.

Following a seizure, seek medical attention if there is an injury. Always document seizures according to your agency's policy.

Call 911 if the following occurs:

- ❑ the seizure lasts more than 5 minutes
- ❑ seizures are occurring one right after the other without time to recover between seizures
- ❑ the person is taking a long time to recover from the seizure
- ❑ the person is having difficulty breathing or the person's skin color is "not right" (for example, gray or bluish)
- ❑ the person has never had a seizure before
- ❑ the person shows signs of injury

For resource information on seizure disorder, visit the Epilepsy Foundation website at www.EFA.org.



This information is to increase your awareness of these medical conditions. It is not intended to replace medical advice. If you believe you or someone you support has this condition, please seek the advice of a physician.

Sources: Epilepsy Foundation of America; Mosby's Clinical Nursing Handbook; Health and Wellness Reference Guide, developed for the Commission on Compliance, State of Tennessee, 7/98.

Graduation time is approaching. Let's hear about this exciting step in your life. Send Family Forum



REPEATABLES

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

SUNDAYS

- ☆ Library – free, on Stage at 2 p.m. at the Central Library, 1901 Vine St, Montgomery Auditorium. Come at 1:30; no reservations. 215-686-5372.

MONDAYS

- ☆ 1st Mon – 6:30-9pm – Speaking for Ourselves, St. Joe's, McShane Hall, 5600 City Line, 610-825-4592
- ☆ 2nd Mon – 7 p.m. – COMHAR's FDSS Adv. Bd, 100 W. Lehigh, Lydia Barashango, 215-537-4822
- ☆ 2nd Mon – call for time – WES FDSS Adv. Bd, 1315 Windrim Ave, Michelle Carey, 215-227-8985 x29
- ☆ 2nd Mon – 10am-noon – Northeast FDSS Adv. Bd, Roosevelt Blvd & Adams, Patty Caterina, 215-831-2883

TUESDAYS

- ☆ 1st Tues – 6:30pm – Community Council FDSS Adv. Bd, 4900 Wyalusing, Sallie Lambert, 215-473-7033 x273
- ☆ 1st Tues – 10am – CATCH FDSS Adv. Bd, 2632 S. Broad, Diane Jordan-Adams, 215-755-9804
- ☆ 1st Tues – call for time – NHS/Knights Rd FDSS Adv. Bd, 11082 Knights Rd, Loren Wilson, 215-632-9040 x204
- ☆ 2nd Tues – 5:30pm – NHS/Mt Airy FDSS Adv. Bd, 27 E. Mt Airy Ave, Diane Howard, 215-248-6834

WEDNESDAYS

- ☆ 3rd Wed – 7pm – Consortium FDSS Adv. Bd, 26 S. 40th St, Darlene Gonzalez, 267-284-0050
- ☆ 3rd Wed – 6-8pm – JFK FDSS Adv. Bd, 112 N. Broad, 2nd fl, Betty Harrigan, 215-568-0860 x3214

THURSDAYS

- ☆ 2nd Thurs – 1:30pm – SEPTA Advisory Com. on Accessible

Transportation, 1234 Market, 11th fl, 215-580-7145

- ☆ 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

- ☆ 3rd Thurs – 5-8:30pm – Go West, stroll grounds of U of P, food, drink & music, 888-go-west7

FRIDAYS

- ☆ 1st Fri – 1-3pm – Support Group for people with disabilities, Liberty Resources, 1341 N. Delaware, 215-634-2000 x276 or x248
- ☆ 1st Fri – evening – Visit Old City free "open house," in all the art, ceramic, craft exhibits; Old City Arts Assn, 215-625-9200
- ☆ 1st & 3rd Fri – 7-9pm – Easter Seals Phila teen social club, 3975 Conshohocken Ave, Kendra Brooks, 610-565-2353 x231 for registr. form
- ☆ 3rd Fri – 1-3pm – Consumer Connection, Liberty Resources, 1341 N. Delaware, 215-634-2000 x320

SATURDAYS

- ☆ 1st Sat – Frankford Friendly, free concerts, arts, food & things for sale, 4200-5000 Frankford Ave
- ☆ 2nd Sat – 1-4pm – Disabled in Action, American Friends Ctr, 1501 Cherry, 215-627-7255

ONGOING

Contact for dates

- ☆ C2P2 (Competence and Confidence: Partners in Policymaking) – leadership training program for people with disabilities, parents of children with disabilities, and college students, 215-204-1356 (voice/TTY), millerk@temple.edu
- ☆ Networks for Training – 123 S. Broad St, 23rd fl, annual course guide available, 215-546-4111 x3454, www.networksfortraining.org

JANUARY 2003



- ☆ See Repeatables for Details on Dates with asterisks

JAN 1 8:30am

- ☆ 102nd Mummers Parade, going east from 15th & Market Sts to 5th St

JAN - to the 10th

- ☆ Brown Sugar & Spice Holiday Doll Collection, African American Museum, 701 Arch St, 215-574-0380

JAN - to 2-1 from 9:30am

- ☆ Just for Kids, interactive experiences to uncover our perception of risk, \$9-\$12, Franklin Institute, 222 N. 20th St, 215-448-1200

**JAN 3 -- Support Group, Teen Socials, Old City 1st Fri

JAN 4, 11, 18, 25 9-10am

- ☆ Sled Skating for people with lower limb disabilities, Blue Cross River Rink, Festival Pier at Penns Landing, \$5 includes sled & instruction, reservations req'd, 215-925-rink

JAN 6 & 13 6-8pm

- ☆ MyCityMyPlace.Com computer training, Katherine Drexel Library, Knights Road, Loren Wilson, NHS, 215-632-9040 x204

**JAN 6 -- Speaking for Ourselves 1st Mon

**JAN 7 Comm. Council 1st Tues

**JAN 8 9:30am-noon

- ☆ Aging, see Networks

**JAN 8 1:30-4pm

- ☆ Alzheimer's Disease, see Networks

**JAN 9 SEPTA Adv Com 2nd Thurs

**JAN 11 -Disabled in Action 2nd Sat

JAN 11-19

- ☆ Phila Int'l Auto Show, adults \$10, PA Convention Ctr, sponsored by Auto Dealers Assn, 610-279-5229



****JAN 13 COMHAR, WES, NE 2nd Mon**

****JAN 14 --NHS/Mt Airy 2nd Tues**

****JAN 14 5:30-8pm**

☆ What is an Individualized Estimated Resource (IER) and How Do I Use It?, see Networks

****JAN 15 -- Consortium, JFK 3rd Wed**

****JAN 15 9:30am-noon**

☆ The Use of Hospice Care, see Networks

****JAN 15 1:30-4pm**

☆ Understanding OBRA, see Networks

JAN 15 10-noon

☆ Families First Brunch, special session: Exploring the Gifts of Friendship, Diamond Club at Temple U, registration req'd, Mary Mikus, 215-204-1772

****JAN 16 -- FDSS Steer. Com 3rd Thurs**

JAN 17-19

☆ Junior Wheelchair Basketball Tournament at Carousel House, Stuart Greenberg, 215-685-0160



****JAN 17 -- Consumer Conn. 3rd Fri**

JAN 17-18

☆ Science-Based Interventions to Improve Language and Other Skills for Children with Autism, by AJ Foundation for Children with Autism, \$175 both days, \$100 one day, Bucks Community College, Newtown, PA, 215-598-8237

JAN 19

☆ JCC Maccabi Games, Day of Caring & Sharing Carnival, Haverford School, 215-735-0803

JAN 19 2-4pm

☆ Gam Yahad, Share a Mitzvah Day with volunteers, Congregation Adath Jeshurun, 7763 Old York Rd, Elkins Pk, 215-673-0100 x123



JAN 20

☆

****JAN 21 1:30-4pm**

☆ Communication Supporters Group, see Networks

****JAN 22 9:30am-noon**

☆ Assistive Technology & Environmental Concerns, see Networks

JAN 24 Public schools closed

JAN 29 10am-3pm

☆ MRS Outcome-Based Performance Measures Training Sessions: An Overview of Outcomes, for individuals with disabilities, families, Direct Support Professionals, Vision for Equality, 718 Arch St., Joan Hecht, 215-686-9436



FEB 1, 8, 15, 22 9-10am

☆ Sled Skating, see Jan 4

FEB 1 10am-4:30pm

☆ Families First free training, NE Regional Library, Cottman & Bustleton, registration req'd, Mary Mikus, 215-204-1772

FEB 2 Groundhog Day



FEB 2, 9 & 16 noon-2:30pm

☆ Drawing Together, all ages, \$3 children, parents free, Phila Art Museum, West Entrance Hall, first come-first served, 215-684-7605

****FEB 3 Speaking for Ourselves 1st Mon**

FEB 3 6:30-9pm

☆ Creative Interventions, PICC General Members meeting, Lovett Library, 6945 Germantown Ave, Doneza Smith, 215-731-2464

****FEB 4 -- Community Council, CATCH, NHS/Knights Rd 1st Tues**

****FEB 4 9:30am-4pm**

☆ Understanding Person Centered Planning & Self-Determination, see Networks

FEB 7 6:30-9:30pm

☆ Valentine Dance at Carousel House, Stuart Greenberg, 215-685-0160

****FEB 7 -- Support Group, Teen Socials, Old City 1st Fri**

****FEB 8 Disabled in Action 2nd Sat**

****FEB 10 COMHAR, WES, NE 2nd Mon**

FEB 11 10am-3pm

☆ MRS Outcome-Based Performance Measures Training Sessions: An Overview of Outcomes, for individuals with disabilities, families, Direct Support Professionals, Location TBA, Joan Hecht, 215-686-9436

****FEB 11 -- NHS/Mt Airy 2nd Tues**

****FEB 11 5:30-8pm**

☆ Everything You Ever Wanted to Know about Sexual Relationships but were Afraid to Ask, see Networks

****FEB 12 11am-1pm/1pm-3pm**

☆ Communication Technology & Communication Forum, see Networks

****FEB 13 -SEPTA Adv Bd 2nd Thurs**

FEB 14 Valentine's Day



FEB 16 2-5pm

☆ Black History Month Dinner, Carousel House, Stuart Greenberg, 215-685-0160



FEB 17 Presidents Day

****FEB 19 -- Consortium, JFK 3rd Wed**

****FEB 20 -- Managed Care Coalition, Go West 3rd Thurs**

****FEB 21 Consumer Connection 3rd Fri**

****FEB 24 9:30am-4pm**

☆ Sorting through Autism, Mental Retardation, and Mental Illness, see Networks

FEB 25 & 26

☆ MRS Outcome-Based Performance Measures Training Sessions: In-Depth Introduction to Outcomes, Direct Support Professionals and Support Coordinators, Location TBA, Joan Hecht, 215-686-9436

☆ See Repeatables for Details on Dates with asterisks

For Expanded Dates
Visit
[www.
MyCityMyPlace
.Com](http://www.MyCityMyPlace.Com)

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MRS Internet Resource Directory
www.mycitymyplace.com



Make plans now for Mental Retardation Awareness Month in March and be sure to nominate for a Points of Transformation Award the Direct Support Professional who has made a difference in the life of a person with disabilities.

If undeliverable, please return to:

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Learning from
 people with
 mental retardation