

The FAMILY FORUM

May/June 2002

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Family Forum wants to learn how many people who read the Family Forum have computers in their homes. Please log onto www.MyCityMyPlace.com and click the box with the big question mark at the bottom of the boxes, "Talk to Us Information." Send us an email saying you are a Family Forum reader and give us your zip code so we know the area of the city you are from. We'd like to hear your comments about MyCityMyPlace.com, too.

Learning to Find Resources the Easy Way [\(click her to enlarge photo\)](#)

Mice are no longer only bitsy gray things that scare elephants. And the computer screen is not just used for watching Pacman gobbling baddies.



The world – and it is truly the world – of the internet is available to all who want to spend some time with mice and computer screens.

Using the internet may seem intimidating so Mental Retardation Services has engaged Mark Friedman, formerly of Speaking For Ourselves fame, to help people learn how to "surf the web" as they say, and to make a resources for people with disabilities website that is a great spot to start.

Can you picture yourself using the computer to find disability resources for your family member? MyCityMyPlace.com is the URL (or address, like your street address) that can open up the world for you. MyCityMyPlace.com is a web-based Resource Directory available on the internet.

But you're a computer illiterate? Doesn't matter. You can learn. MRS is holding computer training classes around the city and is providing one-on-one trainers to help you learn.

"We've had four trainings so far at the Southwark Free Library," Mark Friedman said. "They were very successful. First time users got to use the library computers. People had to learn how to use mice, but in no time people got caught up in MyCityMyPlace.com in what they were interested in. The scary internet had disappeared – just the resources were there."

Mark related that Mary, who happens to be 80 years old, was interested in support groups for her friend. She was able to use the search engine to look up Down Syndrome. (A search engine is a term for typing in something you're looking for and having it find it for you. Sure would be nice if a search engine would find my car keys!) In a few moments, the search engine had found the

Down Syndrome support group information she was looking for. Mary wrote down the phone number for her friend to contact the group.

Another woman, Connie, has health problems. She clicked on the "health care box" on the MyCityMyPlace.com resource page. That brought up lots of resources, and Connie followed one link to the health problem she has.

"The librarians told me," Mark continued, "that between the two sessions one of the people came back to the library and used the computer. Another person used the FDSS computer that is available at their local base service unit. We hoped that would happen. The computers are right there and the librarians are there to help. The librarians thanked us for helping bring people into the library, even though we were grateful to them for making the training time available for us."

"One of the most amazing things to me is the issue of the digital divide and how it can be overcome. One woman didn't want to have an email address at the library. She thought it was too complicated. When she browsed through the boxes of resources on MyCityMyPlace.com and found what she wanted, she clicked on the email link. I was wondering what she was going to do if she didn't have an email address. She typed in her home address and asked the information be mailed to her. I was flabbergasted! That just shows how you can make use of the computer without having a computer at home. If you give people these tools, there are a lot of things people can figure out."

Families are finding MyCityMyPlace.com very useful to look up community events, learn about local parent support groups and agency activities. The Events calendar is very popular. Families and direct support professionals are using this to find things to do for the weekends and free time. The calendar is updated monthly from the *Family Forum* calendar and is available 24 hours a day. A second calendar from the Philadelphia Representative's Office of Arts and Culture has an extensive list of all the special exhibits, demonstrations and events being held by the city's museums, dance and music groups. It is excellent for finding things to do for the weekend on a moment's notice.

The top ten places people are visiting on MyCityMyPlace.com are: Education, Recreation, Worship/Religion, Getting A Job, Events Calendar, Housing, Friends, Advocacy, Assistive Technology, and Healthcare. Come see how people with disabilities are attending classes at the Philadelphia Community College or taking computer courses at Liberty Resources. Families are going on-line to find support groups and helpful resources for

their friends. Future items will cover the new Self-Determination and the State's Transformation Project. Soon, we will have more Bulletin Boards for parents to talk to other parents about key issues and share useful resources with each other.

The latest item to be added will be this year's Camps Listing. The listing available on the Website will be searchable and updated frequently. A new offering is a Camp Transportation Bulletin Board where family members can post rides they are offering and/or rides needed to individual camps along with contact information. The parties will be responsible for contacting each other and making their own arrangements.

Mark explained the design of the site, "MyCityMyPlace.com is designed to promote choice, self-determination, and inclusion. I'm working on my Ph.D. in technology to see how tools can help people and non-profits be more effective in achieving their mission. How can we help families get information about disability resources quicker, more reliably? The web page is designed for first-time users. We want to draw people in, have them focus, like a laser. The design of the resource boxes gives quick easy choices to interest someone – almost like the cover on a book. In the trainings so far, it looks like that quick-choice is working. People were quickly drawn in, focused. They were looking up resources in no time at all."

Mark went to an FDSS outreach at Warren E. Smith in early April. He set up the computer and projected MyCityMyPlace.com on the wall. People saw right away how easy it was to find a resource. "Thirty people signed up that night for the training," Mark said. "We guarantee you will learn. We're set up to help people who have never used a computer before. Volunteers like Lynn Youngman, Jackie Carlucci, PMHCC. and Janet Williams, Mental Retardation Services – all one-time first-time users – are helping in the one-on-one training. Connie and Mary by the end of the day were able to look up stuff and find really useful resources. We guarantee you can learn," Mark emphasized again.

Contact MRS at 215-686-0253, to sign up for MyCityMyPlace.com Internet training when it comes to your area.

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Charles Haley, Computer Guru

By Mark Friedman

Charles is the person helping to update and maintain the monthly Events Calendar for

www.MyCityMyPlace.com He does the data entry to put the activities and events on the calendar. Charles has a computer at home that he can use for entering the dates on the Calendar, but he prefers to do the calendar

work at the Speaking For Ourselves Office. That way, he doesn't tie up his phone line, and he can get help if he needs it in entering all the activities. The best part for Charles in doing the calendar is the challenge. The worst part is that he finds the data entry boring.



Charles graduated from high school in 1985 and has been working with computers since he was in the fifth grade. For the past three years he has served as the volunteer "computer guru" at Speaking For Ourselves, working with their computer teaching program. Charles configures and repairs computers, and does data entry in the office. He occasionally makes house calls to members in their homes with computer problems.

Charles used to work at a Drivers License Center downtown, taking photos for licenses. He is a graduate of PDDC's Employment Partners clerical training, and he was first hired as the first Communication Aide doing copying work. Charles is also active with North Light Community Center where he does Karate and Computer Access, and he is a member of The Arc Ambassadors. Charles is most proud of his acting roles with the North Light Players. He has been in the Wizard of Oz, Sleeping Beauty and Fiddler on the Roof, to name a few. With all this going on in his life, it is not surprising to learn that Charles has received a Brighter Futures Award. You can contact Charles at CharlesLHaley2nd@aol.com

The Events Calendar is one of the most visited pages at www.MyCityMyPlace.com People like to be able to visit 24 hours a day to find things to do on the weekend or places to go in free moments. You can have your events added to the Calendar by

filling out the form on www.MyCityMyPlace.com
MyCityMyPlace.com is sponsored by the Public Awareness
Committee of Philadelphia Mental Retardation Services.

Contact Freda Egnal at MRS, 215-686-0253, to sign up for
MyCityMyPlace.com Internet training when it comes to your area.

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mark at the bottom of the boxes, "Talk to Us Information." Send us
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code so we know the area of the city you are from. We'd like to
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Wheelchair Clinics

Tired of hassles with wheelchairs? Have you considered a wheelchair clinic? Wheelchair clinics were created to provide one location where wheelchair repairs, adaptations, or new wheelchairs could be ordered.

The clinics provide an occupational therapist (OT), or a physical therapist (PT), for an evaluation and recommendation. They often provide a choice between several wheelchair vendors, otherwise known as durable medical equipment (DME) providers. They also help to obtain insurance authorization through Medicare, Medical Assistance, and/or private insurance.

Listed below are SOME of the wheelchair clinics in the Philadelphia area. Call them for an appointment, and they will tell you what prescriptions are needed and what insurance they accept.

Bryn Mawr Rehab Hospital (610) 640- 3943, (outpatient intake) (610) 640- 7895

Chestnut Hill Hospital (215) 233- 6240

Hospital of the University of PA (215) 349- 5585

Magee Hospital (215) 587- 3032

Moss Rehab Hospital (215) 456- 9475

Pennsylvania Hospital (215) 829- 7923

When you visit the clinic for an evaluation, be prepared to provide complete medical information, insurance information, and past wheelchair information. Remember to:

- 1) Get documentation of the clinic visit.
- 2) Make sure any loaner wheelchairs are equivalent to the individuals present wheelchair.
- 3) Remember to ask how long the process of repairs, adaptations, or the new wheelchair order will take to complete.
- 4) Be prepared to be a persistent advocate. (Source: Health Care Alert, Issue #13, PCHC Newsletter)

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Are You Up-to-Date on Extended School Year Programs?

By Janet Stotland, Education Law Center - PA

Last year, under pressure from the Education Law Center and the federal Office of Special Education Programs, the State's Extended School Year (ESY) regulations were substantially amended. Some of the most important changes/clarifications were that: ESY is not limited to children with "severe" disabilities (although these children are most likely to qualify).

A child can qualify because of a "regression/recoupment" problem, or because of "other factors" that make it unlikely that the student "will attain or maintain skills and behavior relevant to established IEP goals and objectives." "Retrospective data" (that is, documented past history) on regression and recoupment are not required for a child to qualify. Other evidence that can be relied upon in making ESY determinations includes reports by parents of negative changes, or observations and opinions by educators, parents and others.

Last summer, we received a number of complaints – late ESY eligibility determinations, districts that failed to develop individualized ESY, IEPs, and others. For the past several months, we have been working with the PA Department of Education to develop a Basic Education Circular (BEC) that would prevent some of these problems, and eliminate some widely held misconceptions about ESY programs. That BEC has just been issued, and ELC will send copies on request. ELC also has a new "Fact Sheet" on ESY programming.

Some of the "highlights" of the BEC are: All children with disabilities must be considered for ESY eligibility at their annual IEP meetings, not just children with severe disabilities; IEP team reviews for ESY eligibility for children with severe emotional disturbances, autism, moderate and severe levels of retardation or multiple disabilities must be completed by February 28 of each school year, and the Notice of Recommended Assignment (NORA) issued to parents (with program specifics if eligible) no later than March 31. Since this BEC is just being issued in early February, some districts may legitimately have difficulty convening these IEP meeting by the end of the month. This BEC should, at least, give families substantial leverage in getting the meetings scheduled ASAP.

Whenever a family asks that a child be considered for ESY eligibility, an IEP team meeting must be convened, and the decision conveyed to the parents via a NORA. Negative decisions can be challenged through the procedural safeguard system. ESY programs are not limited to self- help and basic skills. Academic and vocational goals can also be part of an ESY program. Although most ESY programs are designed to make up for the long summer break, ESY programs can include weekends or even continuous programming. A child's ESY program cannot be changed over the parents' objection and request for a hearing until all due process procedures have been completed. If fully understood and implemented, these new regulations, and the new BEC, will be a big help to families trying to get ESY services for their children.

For more information, or for the fact sheet, contact the Education Law Center-PA at 215-238-6970 or email elc@elc-pa.org

Did You Know?

Dental Care – Special Smiles, LTD, is a state of the art dental facility specializing in the treatment of patients with emotional, behavioral, cognitive, and developmental disabilities. Located in Episcopal Hospital at Front Street and Lehigh Avenue, their goal is to provide dental care solutions for persons with special needs. Special needs patients are those individuals with disabilities whose routine dental care services may not be provided by a general dentist due to resistance to treatment in a traditional dental office setting. Patients must be at least 14 years old and currently enrolled in one of the following HealthChoices programs: AmeriChoice, HealthPartners, or Keystone Mercy Health Plan. Contact the Member Services Department to obtain a referral for dental treatment, or call Special Smiles directly at 215-427-7495.

Social Security – People who get benefits can earn more in 2002. There's good news in 2002 if you're younger than 65 and you work while getting Social Security survivors or retirement benefits. You'll be able to earn more money this year and keep all of your benefits. You can earn up to \$11,280 (up from \$10,680 in 2001). After you earn \$11,280, \$1 is withheld from your benefits for every \$2 you earn. If you will reach age 65 during 2002, \$1 will be withheld for every \$3 of earnings above \$30,000 until your birthday month. After your 65th birthday, you can receive your full benefit amount no matter how much you earn. There are a variety of ways to contact Social Security. Call 800-772-1213. You can use the automated phone services 24/7, or call between 7 a.m. and

7 p.m. on business days to speak with a representative. If you're deaf or hard of hearing, call the TTY number, 800-325-0778, 7 a.m. to 7 p.m. Or you can use the FAX Catalog. Call toll-free, 888-475-7000, for an index and to order specific items. You can write or visit your local Social Security office. And, of course, there's the website – <http://www.ssa.gov/reach.htm>.

Legal Help for Seniors – The Judicare Project provides free legal services and advocacy to low-income seniors, aged 60 or older, who are homebound or disabled. They encourage contact from Asian, Latino, and other seniors with limited English. Call 215-238-6390 or www.scjudicare.org.

Vehicle Modification Contacts – Here are some telephone numbers for vehicle modification – Chrysler, 800-255-9877; General Motors, 800-323-9935; Ford, 800-952-2248; Saturn, 800-553-6000 (press 3). Compensation for new vehicles' modifications are sometimes available from individual manufacturers based on certain restrictions. It's worth a call if you're buying a new van.

Right to Education Guide – The 2002 edition of "The Right to Special Education in Pennsylvania – A Guide for Parents" is available from the Education Law Center. Single copies for parents and advocates are free. Others may purchase copies at \$7.50 each or arrange for bulk order discounts. Call 215-238-6970 or email elc@elc-pa.org

PACENET Eligibility Expanded

Pennsylvanias seniors PACENET drug prescription eligibility has been expanded by \$1,000. If you lost your PACENET eligibility due to the cost-of-living Social Security increase, contact your County Assistance Office. You will be enrolled retroactively, and no one will be removed this year due to a COLA. If your income was just a bit too high previously, you also should contact the Assistance Office. Due to the income increase, you could be eligible.

Technology help

If you are a person with a disability who currently uses technology to be more independent (electronic organizers, palm pilots, personal digital assistants), Temples Institute on Disabilities wants to hear from you for their research project. For more information, call 215-204-2247, TTY-215-204-1356, or email friedman@voicenet.com Visit www.temple.edu/inst_disabilities

The Nurturing Parenting Program

Helping to handle stress and anger – for parents and adolescents, 12-19 years of age

The Nurturing Parenting Program -- for parents and adolescents 12 to 19 years old – is a free ten-week program for families to take together. Parents meet separately from children with two trained facilitators while youth participate in self-esteem building activities with their own facilitator. The program is for any family that wants to get along better, communicate more, and feel closer to each other.

A new class begins on March 30th and will run through to June 1, 2002, at Parkside Recovery, 5000 Parkside Avenue, Philadelphia, PA 19131. Sessions are held on Saturday from 11:30 a.m. to 2 p.m. A free catered lunch is provided. Van transportation is provided to families who live in West Philadelphia and around Center City. Tokens are distributed to those who live elsewhere. For registration or information call Dr. Nancy Lydick, 215-879-6116, ext. 227

The program works for all kinds of families: two-parent, single-parent, foster, adoptive and blended families. In addition to the program for parents of adolescents, there are programs designed for parents and their infants/toddlers and parents and their school-aged children. These groups will meet at a later date.

This program is designed to help adults and children learn how to handle their feelings, communicate their needs and feelings of others, and take charge of their own behavior; replace hitting and yelling as disciplinary techniques with other, more effective techniques such as redirection, time-out, choices and consequences, praise, family rule, problem solving, etc.

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Points of Transformation Awards



*David Williams,
Habilitation Spec.,
CommunityTrans.
Program, PDDC*

*Kristine M. Young,
In-Home Supports
Coord. Catholic
Social
Services*

*Hattie Jean
Washington, Resident
Advisor II, Greenwich
Services*

*Alisa Bowman,
Community Integrated
Coordinator, JEVS*



*Vincenia Ferguson,
Residential Skills
Counselor, PATH*

Points of Transformation Awards were presented on March 15, 2002, to fourteen Direct Support Professionals on the front lines who are helping transform the lives of people with mental retardation, enabling them to follow their dreams and contribute to the community. Dedicated Direct Support Professionals are crucial to the success of people with developmental disabilities becoming part of the community, gainfully employed, enjoying family and friends, practicing their faith and contributing their gifts. These are the unsung heroes who often receive little recognition and inadequate compensation. They are crucial to the success of the States plan to end the waiting list and transform the mental retardation system.



*Jessica Heart, Res
Skills Trainer, PAI*

The second annual Points of Transformation Awards was held to continue to keep the crisis of recruitment and retention of quality front-line staff on the front burner. What is the problem? The crisis in staffing caused by low salaries leads to severe shortages of staff for community MR programs. High vacancy and turnover rates (50 to 125%) create inefficiencies and drain resources through use of overtime and temporary workers. Quality of care is directly



Award for Christine Rue, Employment Consultant, PATH, accepted by Alan Erlich (shown)

affected. The MH/MR Coalition, representing providers, advocacy groups, and counties in Pennsylvania, calculated last year that \$100 million over two years will address the historic under-funding of MR salaries. (In Philadelphia, Direct Support Professionals earn only 48% of what other workers earn.)

Last year, there was some success in addressing this issue. The Governor included an additional \$17.5 million in his FY 2001-2002 budget to address direct support worker recruitment and retention. Philadelphia received approximately \$5 million to be divided among more than 5,000 direct support workers and front line supervisors in both MH and MR residential and day/vocational programs. The largest amount of funds will be directed to staff making less than \$8.50 per hour. Where are we now? The proposed budget for FY 2002-2003 carries forward the \$17.5 million awarded statewide in last years budget, but has no new money for recruitment and retention. An additional \$65 million is needed to assure Qualified Staff The Link to Quality.



Mary MacAvoy, M Manager, FDSS Coordinator, PAT



Lorraine Ballard Morrill, Pwer 99 Radio News and Public Affairs Director was the event's Emcee



lead productive lives.

MRS Director Kathy Sykes (left) and MRS Director of Operations, Larry Pace made the award presentations - here to.

Meanwhile dedicated Direct Support Professionals, continue to support people with mental retardation to develop their abilities and



Sonia Fonseca, Habilitation Specia PDDC



*Bedelia D. Williams,
Day Support
Counselor, TAIG*

*Kimberly Williamson,
Community Support
Counselor, Horizon
House*

*Carolyn Allen,
Residential Counselor,
JEVS*

*Darlene Gonzalez,
FDSS Coordinator,
Consortium*

*Liz Nau
Associa
Speciali*

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