

Hispanic Father Shares His Knowledge

*Interview by Julio Nieves, Health Care
Technical Assistance Specialist
Philadelphia Coordinated Health Care*

Emilio Pacheco has lived in Philadelphia since 1998, with his wife, Ana, and son, Joel, who has physical and mental disabilities. Emilio has been translating Family Forum's "Did You Know?" into Spanish.

FF- What made you and your family leave your home in Puerto Rico? Why did you choose Philadelphia?

EP- Well, my family and I were traveling back and forth from Puerto Rico to Boston. When my father, who lives in Philadelphia, learned of my situation, he invited us to stay with him. My father and I really did not have a relationship, so I thought this would be a good opportunity to know him. Unfortunately, after several years, the relationship did not work and we were on our own. In addition, mental retardation services for Joel in Puerto Rico were limited.

FF- How are the services for people with mental retardation in Puerto Rico?

EP- Puerto Rico is a beautiful island and is my home, but when it comes to mental retardation services, resources are very limited ... almost none ...



**Emilio Pacheco with his family,
Ana and Joel.**

and that's if you live in the metropolitan area. If you live in a rural area or country there are none.

FF- How was it for you and your wife, Ana, when your son Joel started going to school?

EP- We were full of anxiety; we did not know how to react. In Puerto Rico, I took him to school, and then picked him up. Now a bus was picking him up and dropping him off. The hours that Joel was in school were the longest hours of the day. When he came home we would look at him, and we

La traducción en Español
se encuentra en la pagina 8.

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New Advocacy Group Forming

SELF-ADVOCATES, FAMILIES AND COMMUNITIES UNITED is the current name of a new advocacy group, composed of caregivers, family members, self-advocates and community members who receive supports through the MR system. The mission of this group is to establish ourselves as equal partners with the MR System in planning, policy and decision making to ensure quality, choice, and satisfaction in our lives. To this end we have been holding meetings as necessary during the transition from BSU service to the new supports coordination organizations and will continue to meet periodically, addressing any related issue that occurs. We have been able to address a number of issues already to resolve potential problems during this period. This is an independent organization with affiliation only with ourselves. There is no conflict of interest in seeking to ensure quality, choice, and satisfaction in our lives.

If you are interested in joining us and supporting this endeavor, please contact Lynn Youngman at 215-928-0765, for further information. To be placed on the mailing list to ensure notification for future meetings, contact Barbara Nattile, at 215-923-3349, Ext. 114. Lynn Youngman

**Visit www.MyCityMyPlace.com
Join the e-Announcements Listserve
Call for New Registrations & Customer Service
215-685-4MRS (4677)**

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Let's hear from you!

Please submit articles to: Editor, Family Forum, Mental Retardation Services, Suite 5200, 701 Market St., Philadelphia, PA 19106-1532



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Family Forum Contact - Freda Egnal

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MRS Internet Resource Directory

www.MyCityMyPlace.com

Family Forum's are archived on the web

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Feel free to reprint articles from *The Family Forum* Just give us credit. Thanks!



SPOTLIGHT HIPAA Info from DLP



Access to Family Members' Records under HIPAA

This report from Disabilities Law Project has been edited for space. For the full report and more information on HIPAA, visit DLP at <www.dlp-pa.org>, or call (V) 215-238-8070, (TDD) 215-789-2498.

The Disabilities Law Project (DLP) has received many questions regarding how the Health Insurance Portability and Accountability Act (HIPAA) applies in situations when a parent or other family member seeks health-related information or records of their relative with a cognitive impairment. This Fact Sheet briefly explains the applicable HIPAA regulations.

The HIPAA statute and its regulations govern the use and disclosure of individuals' health information by "covered entities" (e.g., doctors or service providers), including the circumstances under which a family member of an individual with a disability (e.g., autism or mental retardation) can access the individual's health information. HIPAA provides that covered entities are required to disclose to an individual his own health information upon his request. HIPAA also provides that the individual's "personal representative" is entitled to be treated the same as the individual. The term "personal representative" is used to define the scope of a family member's access to the records of both adult and minor relatives with disabilities.

Access When Relative is a Minor – If a parent, guardian, or other person acting in loco parentis has authority to act on behalf of an unemancipated minor in making health care decisions, the covered entity generally must treat that individual as the personal representative of the minor who can authorize access to the minor's records. Thus, a parent or guardian of a minor – regardless of whether the minor has a disability – generally has the right to request the minor's health care information.

Access When Relative is an Adult with Appointed Guardian – If an adult has a guardian who is authorized to make health care decisions, then the guardian is treated as the individual and has the right to request the individual's health care information.

Access When Relative is an Adult without Appointed Guardian – An adult – regardless of disability status – is presumed competent to control his or her health care records in the absence of a legal finding that a guardian is necessary. Thus, a family member who does not have guardianship cannot control access to their relative's health care information. However, nothing prevents the individual (regardless of cognitive limitations) from authorizing release of health care information to a family member.

If an individual (or his personal representative) requests his records, a covered entity may request that he sign an authorization for the release. HIPAA regulations address the content of the authorization and require that it include, among other things, an expiration date or event. Accordingly, an individual (or his representative) can execute an authorization that governs future requests for information so long as an expiration date is included in the authorization.

Who Ya Gonna Call?



Philadelphia MRS

701 Market Street, Suite
5200, 19106-1532

Reception & Information

215-685-5900

Registration Unit for New Registrations

Ileana Rodriguez (secretary)
(V) 215-685-4MRS (4677)
(F) 215-685-4617
ileana.rodriguez@phila.gov

Your Supports Coordination Organization

If you have not received a letter informing you which agency will be providing Supports Coordination to you, contact
Marianne Roche
(V) 215-685-5930
(F) 215-685-5959
marianne.roche@phila.gov

MRS Supports Coordination

Elayne Blender, Acting Mgr.
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(F) 215-685-5956
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Connie Falcone, Supvsr,
Individual Supports
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The Consortium

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Partnership for Community Supports

8217 Castor Avenue, 19152
(V) 215- 350-4777
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The Disability Odyssey Continues

By Steve Gold, *Brown v. Board of Education - Information Bulletin # 66 5/04*

May 17, 2004 marks the 50th anniversary of the *Brown v. Board of Education* decision in which the Supreme Court held that school districts violated the Fourteenth Amendment by racially segregating children in schools.

What follows is a review of segregation of children based on disability.

The latest data from the U.S. Department of Education, which annually collects this data state by state and submits it to Congress, presents the following data for the 5,594,431 students between the ages of 6 and 18 with disabilities:

- ❑ A composite of “All Disabilities” shows that more than 1,236,373 children – 22% of the total with disabilities – remain in segregated settings, i.e., they are either entirely in “Separate Schools and Facilities,” or spend more than 60 percent of their time “Outside Regular Classes,” in separate classes for children with disabilities. (These are the definitions used by the U.S. Dept. of Education.)
- ❑ * The flip side shows that only 2,742,219 – less than half of all children with disabilities – are “integrated” in their schools, i.e., they spend less than 21 percent of their time Outside Regular Classes or, in clearer terms, they spend more than 79% of their time in “regular” classes with children who are not disabled.
- ❑ * The middle 29% are children with disabilities who spend between 21 - 60% of their school hours “Outside Regular Classes,” presumably in

“resource rooms” only for children with disabilities. Obviously, the more time they spend “OUTSIDE regular classes,” i.e., closer to 60% than 21% of time, the more they are segregated. A snap shot by specific disability classification shows:

- ❑ For children who have only an “orthopedic impairment” (these children have no other disabilities), 30.2% are in segregated settings (i.e., spend more than 60% of their time outside regular classes).
- ❑ For children who have either only a “hearing impairment,” 37% are segregated and for children who have only a “visual impairment,” 27.6% are segregated.
- ❑ By far the most segregation occurs for children classified as having “Mental Retardation.” 57.3% of this population are segregated.

A breakdown by State – not local school

districts – and by disability, graduation rates, drop out rates, etc., can be found at www.ideadata.org/PartBDataMeeting2004.asp. Just click on your State.

School and education advocates have for too long been primarily parents of individual

disabled children. As with housing and Olmstead issues, the SCHOOL segregation of children with disabilities in schools and educational settings must become an issue that goes far beyond the direct participants. A truly inclusive society and educational system can and should integrate children with disabilities.

While education is a “local” issue, and your local school districts should be held accountable for segregating children with disabilities, your State Department of Education can and should as a policy issue review why such

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Social Security Income No Longer Disqualifies Some Children with Disabilities from Medical Assistance

Children with disabilities that meet the Social Security disability criteria are usually eligible for Medical Assistance regardless of their parent's income. This is known as the "disabled child" provision or "loophole." However, only parental income is excluded under the loophole.

Income in the child's name is counted (except for court-ordered child support). If it exceeds \$796 a month, the child is ineligible for Medical Assistance. The most common type of income in the child's name is Social Security (not to be confused with SSI that includes Medical Assistance automatically).

We are talking about the kind of Social Security for which a child is eligible because one of his/her parents has died (survivors), retired, or has become disabled themselves. That has resulted in the situation where a child with two parents earning \$200,000 can qualify for Medical Assistance, but if one parent dies, the child might lose his MA

Disability Odyssey Continues

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segregation exists in your local school district. Advocates should review the extent of disability segregation school district by school district.

Disability advocates must make education more than an individual child's issue; we must organize around education. Pretend every child with a disability is your own; would you accept a segregated educational system for your child?

Tell your school boards and state educational officials that Jim Crow education for children is NOT acceptable, whether based on race or disability.

eligibility once he starts to receive Social Security on his deceased parent's account.

After advocating for years for DPW to change this discriminatory policy, DPW has agreed to a partial change to the policy. From now on, if a child (under 21) – *who is already on MA* – starts to receive Social Security on a deceased, retired, or disabled parent's account, their Social Security will NOT be counted in determining the child's continuing eligibility for Medical Assistance. This new policy was issued on January 28, 2004, in Operations Memorandum OPS 040107.

It should be noted that this new policy does NOT apply to children who were not already on Medical Assistance at the time they start receiving Social Security. Apparently this is because the Administration felt covering children who were not already on Medical Assistance would be too costly.

For further information, contact the PA Health Law Project at 1-800-274-3258.



Campaign to Help Increase Access to Polling Places for Americans with Disabilities

United Cerebral Palsy has launched <www.DontBlockMyVote.org> to advance equal access for voters with disabilities. This website has been created by the UCP to assure Americans with disabilities, their families, and supporters have the access they need to fully participate in elections. Through DontBlockMyVote.org, UCP is encouraging eligible voters to participate in this year's election while building support for full funding for the Help America Vote Act (HAVA).



How Ironic

By Yvette Clark, Vision for Equality

I have been a full-time monitor at Vision for Equality for five years. I became involved in doing this work because I have a ten-year-old son, Calah, who has Down Syndrome.

I go into homes of people with disabilities, visiting CLAs, ICFs, boarding homes – just a variety of residential environments. We get the names of people to speak to about their lives from Mental Retardation Services. Many of them have lived in big institutions for a large portion of their lives. After I interview individuals, I do follow-ups with families. Unfortunately, lots of times I find there is no family contact. How terrible that is, I'd think.

Well, can you imagine my surprise when I found out that my own family – which is HUGE, believe me – had had no contact for years with my second cousin, Olin Johnson (my great uncle's son's son!)

New Name & Location for Police & Fire Association

The Philadelphia Police & Fire Association for Handicapped Children has changed its name to Philadelphia Police & Fire Association (Serving People with Special Needs) and is now based in center city. Group chair, Harry Magee, feels the move is a good one so they can recruit new members and get more people involved with the board. With a \$75,000 grant, secured by the organization's attorney, Ed Titterton, Magee said they hope to begin offering services dropped due to lack of funding, such as equestrian and physical/occupational therapies.

Now located at 718 Arch Street, 6th fl North, Philadelphia, PA 19106, the Association can be reached at 215-627-7088. Source: Northeast Times article.



who has mental retardation. Growing up in North Philadelphia, we all went to the Open Door Baptist Church, where Olin's father was pastor. The church is still there at 26th and Cecil B. Moore Avenue, and family still attend. I remember Olin as being "different," but didn't know why. When Olin's mother passed seventeen years ago, he was placed in a home in Montgomery County, and I never knew what happened to him. How ironic that my family was one of "those" families who had no contact with their family member with disabilities.

Then, about four months ago, Olin's father passed – and there was Olin at the funeral! I was so happy to see him. He was there with his direct care staff, and before the day was over, I made sure I got all his contact information. I found out that the staff didn't know he had around a hundred relatives within spitting distance, including a sister, Qunda, who is an actress in New York.

About seven months ago, I decided that I had to take on the mantle of keeping our huge family in touch since the older members were passing, and there was danger of our all going our separate ways. So, I started a monthly family dinner and, of course, Olin got invited. He has come to the last three dinners, and now, because we have a competitive family here, he is being invited to other family gatherings and holiday celebrations. His sister has also re-established contact with him.

When Olin was making his first visit, I asked his staff if he had any special needs or arrangements. They told me he's pretty independent, but he only speaks in one word sentences and doesn't really interact. Well, I'm here to tell you since he's been back with his family, he speaks in sentences, and I can have an actual conversation with him when I call. His staff are commenting on how he's starting to open up, and they're seeing another side of him. That makes me so happy and so glad that, even though it was through the loss of his father, Olin's family has found him again.

Hispanic Father Shares. . .

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would check him, and see if he was okay. As parents, we did everything for Joel. Now he was with many other children, children like him, and we could tell that Joel was happy. In addition, the school would send with Joel resources and information on Mental Retardation Services and, at that time, Base Service Units.

FF- So after Joel was registered, how did you feel about the services?

EP- First, I was delighted with all the services Joel could utilize. Coming from having no services, and now having him registered, having a case manager, getting FDSS funding, going to I.E.P meetings, and Joel being happy was great. What is funny was that I thought that being registered was to meet the case manager (Support Coordinator) once a year, fill out the paper work receive the funding and that is it.

FF- What happened that now you are a strong advocate and involved with Public Awareness and other advocacy groups in our system?

EP- It all happened in 2000. I had an accident at my job and was unable to work. During that time, I started reading literature that my son brought home and other MRS literature. The more I read, the more I realized that I needed to get involved. It was not that Joel was not getting services; Joel was and is happy. I just noticed that I, as a parent, needed to learn the system. I concluded that in order to do that I had to be part of the system – especially in the Hispanic community, which is where my desire is. I also met many people who inspired me in our system like Ms. Freda Egnal, who welcomed me and got me involved. Now I do the Spanish translation for the Family Forum.

FF- Now that you feel somewhat knowledgeable about our system, what do you see for yourself in the future?

EP- I first want to say is that as a parent to see that my son Joel happy brings satisfaction to me and my wife. Therefore, I know that what I have learned was worth that smile. In addition, to me the future is now. What I mean is that I co-started a parents' group at St. Christopher Hospital for non-English-speaking Hispanic people. We meet once a week. In addition, this fall I will start at Community College and, hopefully, major in social work. Like I said before, and always say, "Knowledge is power, and I like to learn."

Note: To contact Emilio's parents' group for non-English-speaking Hispanic people, call 1-800-459-1838 ask for Español or press #8.

Un padre Hispano Comparte sus Conocimientos

Entrevista por: Julio Nieves, Health Care Technical Assistance Specialist Philadelphia Coordinated Health Care.

Emilio Pacheco vive en Philadelphia desde 1998, con su esposa Ana y su hijo Joel, quien tiene impedimentos mentales y físicos. Emilio ha estado traduciendo para la población Hispana, la sección "¿Sabía Usted?" De la publicación "Family Forum" para la oficina de Retardación Mental de Philadelphia.

FF- ¿Por qué motivo ustedes dejaron su hogar en Puerto Rico? ¿Porque escogieron vivir en Philadelphia?

EP. Mi familia y yo estuvimos viajando por varios años de Puerto Rico hacia Boston. Cuando mi padre quien vive en Philadelphia supo de mi situación y nos invitó a que viniéramos aquí. Mi padre y yo realmente no teníamos ninguna relación, así que pensé que esto sería una buena oportunidad para conocernos mejor. Desafortunadamente después de algunos años la relación no trabajo, y desde entonces mi familia y yo luchamos por nosotros mismos

FF-¿Como son los servicios para las personas con Retardación Mental en Puerto Rico?

DID YOU



► **Philadelphia Home Improvement Loans** – If you own and live in your home in Philadelphia and are credit-worthy, low-interest loans (PHIL) are available from several local banks. Each bank sets its own terms and conditions. For more information, visit <www.philaloan.com>. The banks are: PNC (888-256-9378), Fleet (215-561-5014), Wachovia (267-321-4278), and Citizens (800-649-1114).

► **Préstamos para mejoras en el hogar en Philadelphia**-si usted es dueño y vive en su propia casa en Philadelphia y tiene buen crédito, préstamos con bajos intereses (PHIL) están disponibles en algunos bancos locales. Cada banco establece sus propios términos y condiciones. Para más información, visite<www.philaloan.com>. Los bancos son: PNC (888-256-9378), Fleet (215-561-5014), Wachovia (267-321-4278), y Citizens (800-649-1114).

► **Find Government Homepages** – Want to find the website homepage of a local government? Or looking for ideas on new places to go without breaking the budget? Check out <www.FirstGov.gov> new America's Hometowns page. Click on a state to find information and links to hundred of cities, counties, and towns. To go directly to the Hometown page: <www.firstgov.gov/agencies/local_government/cities.shtml>.

► **Encuentre las páginas principales del gobierno**-¿desea encontrar la página principal del gobierno local en los sitios de la Internet? ¿O busca ideas de nuevos lugares para salir sin que le afecte en su presupuesto? Verifique esto. <www.FirstGov.gov> new America's Hometowns page. Oprima en 'state'para encontrar información y enlaces a cientos de ciudades, países y pueblos. Para ir directo a: "the Hometown page" <www.firstgov.gov/agencies/local_government/cities.shtml>.

► **Baby Bargains and Toddler Bargains** – are two books that advertise to save you at least \$250 – and come with a

KNOW?

money-back guarantee if they don't. The books cover about every facet of child-rearing, offering secrets to saving 20-50% on items such as strollers, carriages, diaper bags, and much more. To order, the books are at local bookstores, or call 800-888-0385, or visit www.babybargainsbook.com. The website also has an e-newsletter you can sign up for.

► **"Baby Bargains" y "Toddler Bargains"**-son dos libros que anuncian que usted puede ahorrar hasta \$250- y ofrece la garantía de que se le devolverá su dinero si usted no ahorra esta cantidad. Los libros cubren cada faceta de la crianza de un niño, ofreciendo secretos para ahorrar del 20 al 50% en artículos como coches, carruajes, bolsas de pañales y mucho más. Para ordenar, el libro está en librerías locales o llame 800-888-0385 o visite www.babybargainsbook.com. Este sitio de la Internet también tiene un boletín informativo en el cual usted puede suscribirse.

► **Reflections from a Different Journey, What Adults with Disabilities Wish All Parents Knew** – edited by Stanley Klein and John Kemp – is a great book according to Jackie Golden, a Project Leadership member. She writes that it is filled with stories from some amazing advocates with

disabilities on what they want parents to know about raising a child with a disability. The most important thing she says she

got from reading the book was simply: this child is a child, treat them the way you would any other child, support them and love them, but most of all include them! Available at local bookstores and <www.amazon.com>.

► **"Reflections from a Different Journey, What Adults with Disabilities Wish All Parents Knew"** – Editado por Stanley Klein y John Kemp-es un gran libro, de acuerdo a Jackie Golden, miembro de los líderes del proyecto. Ella

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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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escribe que está lleno de historias de algunos asombrosos consejeros con impedimentos sobre lo que ellos quieren que los padres sepan acerca de criar niños con impedimentos. Lo más importante que ella dice que obtuvo leyendo el libro fue simple: "este niño es un niño, debe tratarlo de la manera en que usted trataría cualquier otro niño, apoyarlo y amarlo, pero más que todo incluirlo!" disponible en las librerías locales y en www.amazon.com.

► **Keeping Track of Medicaid Waivers** – The National Association of State Medicaid Directors keeps track of waiver programs. This very informative website contains all sorts of information, data, and statistics. It also contains data on children enrolled in MR/DD 1915c waivers by state, age and program. <http://www.nasmd.org>.

► **Siguiendo el paso de los "Waivers" de Medicaid.**-La Asociación Nacional de Directores Estatales del "Medicaid" mantiene seguimiento e información de los programas del Waiver. Esta página en la Internet es bien informativa y contiene toda clase de información, data y estadísticas. También contiene información de niños matriculados en "MR/DD 1915c Waivers por estado, edad y programas <http://www.nasmd.org>.

► **Free Art Classes** – The City of Philadelphia's Mural Arts Program holds free mural arts classes at 18 sites throughout the city, beginning in October through August. The program is divided into four sessions and takes place after-school hours, three times a week. At the conclusion, students participate in large-scale summer murals or mosaic projects, in exchange for a stipend (as an introduction to job skills). Contact the Mural Arts Program Big Picture Program at 215-685-0751.

► **Clases de Arte Gratis**-El Programa de Artes Murales de la Ciudad de Philadelphia ofrece gratis clases de artes murales en 18 lugares a través de la ciudad, comenzando en octubre hasta agosto. El programa está dividido en cuatro secciones y se ofrece en horas después de la escuela, tres veces en semanas. Al finalizar los estudiantes participaran en el verano en murales a grand escala o en un proyecto de

*Thanks to Emilio Pacheco for
the Spanish translation.*

mosaicos a cambio de remuneración económica (como introducción a destrezas de trabajo). Puede contactar el programa de artes murales llamando al 215-685-0751.

► **"Chapter 15 Children"** – are children who may need special accommodations in school, but not formal special education. Children covered under Chapter 15 of the state regulations can include those with epilepsy, asthma, diabetes, muscular dystrophy, depression, or other mental, physical or health impairments, which substantially limits one or more "major life activities." Major life activities include learning, walking, seeing, hearing, speaking, breathing, and caring for one's self. For instance, if a child with diabetes cannot attend school unless someone is monitoring his or her blood sugar level, he/she will be protected by Chapter 15 and entitled to that service from the school district. To obtain an information publication from the Education Law Center, call 215-238-6970, or visit www.elc-pa.org.

► **"Niños Del Capítulo 15"** – son niños que podrían necesitar especial acomodo en la escuela, pero no educación especial formal. Los niños cubiertos bajo las regulaciones estatales del Capítulo 15 pueden incluir aquellos con epilepsia, asma, diabetes, distrofia muscular, depresión, y otros impedimentos como mental, físico o de salud, el cual sustancialmente limite 1 o más de sus actividades de vida mayores. Actividades de vida mayores incluyen aprendizaje, caminar, visión, audición, habla, respirar, o el cuidado de sí mismo. Por ejemplo, si un niño con diabetes no puede ir a la escuela a menos que alguien esté monitoreando su nivel de azúcar, el o ella estará protegido bajo el Capítulo 15 y tiene derecho a ese servicio a través del distrito escolar. Para obtener publicación informativa del " Education Law Center, llame al 215-238-6970, o visite www.elc-pa.org.

The Disability Rights Commission (DRC) has released the first comprehensive study of the accessibility of a wide array of Web sites. The 56-page report – "The Web: Access and Inclusion for Disabled People" – is available in printed, PDF (56 pp.), audio, Braille, and other formats. Go to www.drc-gb.org/publicationsandreports/report.asp.

Gardening to “Grow” Your Bones

A recent study at the University of Arkansas suggests an alternative to weight training as a way to strengthen bones: gardening! Researchers found that gardening was better at building bone than walking, jogging, swimming, or aerobics. Gardeners’ movements include pushing, pulling, carrying, turning, lifting, and squatting – all good for increasing bone density. And because they enjoy it, gardeners tend to spend more time at it, even into their senior years. Researchers also found that gardening improved balance and muscle strength, decreasing the frequency of falls.

The Trees of Philadelphia



The Fairmount Park Commission has jurisdiction of all park and street trees in Philadelphia. Before any planting, removal, pruning, or other work on street trees is performed, contact the Fairmount Park Commission. The Commission provides inspection, planting, removal, and pruning. For service, contact the Fairmount Park Commission District Arborist by phone (general information 215-685-0000) or mail (4231 N. Concourse Drive, 19131). The office is open from 7 a.m. to 3:30 p.m., Monday-Friday. Ask for the District Arborist who handles your zipcode to have a tree inspector visit and evaluate your tree. You can download a Tree Maintenance Service Request form at <www.phila.gov/fairpark/trees>.

Vision for Equality has two open positions for a full-time and a part-time monitor. Independent Monitoring for Quality (IM4Q) teams interview people with disabilities who are living in the community, using a survey called Essential Data Elements. After the interview the team completes a short questionnaire and the Monitor writes a short report listing the Signs of Quality and any Considerations the team would like to address. If you enjoy meeting people and can travel independently throughout the city and suburbs, fax your resume to 215-923-8055, or mail to 718 Arch St, 6th fl North, Philadelphia, PA 19106, attn: IM4Q.



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New Child Advocacy Web Site – www.capp4kids.org

The site has been developed with the specific goal of making professionals, (Pediatricians, Family Practitioners, Social Workers, Teachers, etc) who take care of families and children, better Social Workers by having a comprehensive, adaptable, accessible web site that lists most of the major advocacy organizations in the Philadelphia area. This site addresses issues in Pediatrics that include: poverty, homelessness, literacy, truancy, mental health, unemployment, immigration, malnutrition, teen pregnancy, child abuse, and domestic violence. The ultimate goal is to link families in need with the most appropriate resources for their needs. – Dan Taylor, D.O., Assistant Professor Drexel College of Medicine, Pediatrician, St. Christopher’s Hospital for Children

EP- Puerto Rico es una isla hermosa y es mi hogar, pero cuando se trata de servicios de Retardación Mental, los recursos son bien limitados... casi nada... y eso es si usted vive cerca del área metropolitana. Si usted vive en área rural o en el campo, los servicios son cero, nada.

FF-¿Cómo fue para ti y para Ana cuando su hijo comenzó en la escuela aquí en Philadelphia?

EP-Estábamos muy ansiosos, no sabíamos cómo reaccionar. En Puerto Rico, Ana llevaba a Joel a la escuela por la mañana y lo recogía en la tarde. Ahora un autobús escolar con personas extrañas recogía a Joel por la mañana en la casa y lo entrega por la tarde. Las horas que Joel pasaba en la escuela eran las horas mas largas del día, llamábamos por teléfono a la escuela varias veces al día, cuando el regresaba en la tarde, nosotros lo mirábamos y verificábamos que todo estuviera bien. Nuestra vida corre alrededor de Joel, Ana y yo como padres tenemos la encomienda de buscar para Joel todo lo que el necesita. Ahora Joel comparte en la escuela con otros niños con o sin impedimentos y podemos decir que Joel lo disfruta mucho y es bien feliz en la escuela.

FF- ¿Cómo se sienten con el servicio después de registrar a Joel en el sistema?

EP-Primero, estábamos contentos, viniendo de un lugar donde no había servicios, pensábamos que reunirnos con el coordinador de apoyo una vez al año y firmar por FDSSera todo lo que había que hacer, Nadie nos oriento en relación a los servicios que Joel podía utilizar. Ahora Joel esta registrado en una unidad de servicios, tiene un coordinador de apoyo, recibe fondos del Waiver, del "FDSS" una vez al año, tenemos reuniones de IEP, somos realmente parte de la comunidad y Joel esta contento en la escuela.

FF-¿Que pasa ahora que tu eres un fuerte consejero para la comunidad Hispana y estas envuelto con el Comité de Conciencia Publica de La Oficina de Retardación Mental de Philadelphia, El Grupo de Consumidores y Familias con Determinación Propia en

PA., el grupo de apoyo en el hospital y otros comités a través de la Ciudad?

EP-Todo comenzó en el año 2000. Tuve un accidente en mi trabajo que me impidió trabajar por un tiempo. Durante ese periodo yo comencé a leer literatura que se recibía en el hogar por correo o Joel la traía a casa. Mientras más leía, mas notaba que necesitaba involucrarme en el sistema. No era simplemente que Joel podía recibir más servicios, Joel era y es un niño muy feliz, solo note que como padre necesitaba conocer el sistema. Llegue a la conclusión que para hacer esto, tenia que ser parte del sistema-especial mente en la comunidad Hispana donde esta mi deseo de colaborar en especial con los que tienen la barrera del lenguaje. También conocí gente en el sistema que me inspiraron, como Freda Egnal, quien me dio la bienvenida y me meayudo a relacionarme con el sistema. Ahora estoy traduciendo para la publicación "Family Forum."

FF-¿Ahora que tienes mas conocimientos acerca del sistema, que ves para ti en el futuro?

EP-Primero quiero decir que como padres ver a nuestro hijo Joel feliz, nos trae mucha satisfacción. Yo se que lo que he aprendido realmente vale la sonrisa de Joel. Y para mi el futuro es ahora. Yo ayude a formar un grupo de padres Hispanos que no hablan Ingles, que tienen niños con necesidades especiales en el hospital de Niños "St Christopher, para compartir con ellos lo aprendido y que ellos también puedan utilizar el sistema. En adición en este otoño comienza la realización de un sueño, fui aceptado en "Community Collage" de Philadelphia con la esperanza de completar una carrera en Trabajo Social con el fin de trabajar en el sistema de Retardación Mental específicamente con la comunidad Hispana. Como dije antes, y siempre diré, "conocimiento es poder" y a mí me gusta aprender.

Nota: Para contactar el grupo de apoyo de Emilio, favor de llamar al 1-800-459-1838 preguntar por Español o marcar el numero 8.



REPEATABLES

These activities are marked on the calendar with an asterisk. Although the items have been checked, it is best to call before going.

Mondays

- ☆ 1st Mon 6:30-9p Speaking for Ourselves, St. Joseph's College, McShane Hall, 5600 City Line, 610-825-4592
- ☆ 2nd Mon 1:30p Mayor's Commission on People w/ Disabilities, Municipal Services Bldg, 1401 JFK Blvd., 16th fl, 215-686-2798

Tuesdays

- ☆ 2nd Tues 10a-12p That All May Worship (TAMW), Vision for Equality, 718 Arch St, 6N, 215-923-3349 x137

Thursdays

- ☆ 2nd Thurs 1:30p SEPTA Advisory Committee on Accessible Transportation, 1234 Market St, 11th fl, 215-580-7145

Fridays

- ☆ 1st & 3rd Fri 7-9p Easter Seals Teen Social Club, 3975 Conshohocken Ave, Kendra Brooks 610-565-2353 x 231
- ☆ 3rd Fri 1-3p Consumer Connection, Liberty Resources, 1341 N. Delaware Ave, 215-634-2000 x320

Saturdays

- ☆ 2nd Sat 1-4p Disabled In Action, American Friends Ctr., 1501 Cherry, 215-627-7255

Wanted - Tales of Creative Solutions to Disability Discrimination The authors of the forthcoming book, *Everyday Law for Individuals with Disabilities*, are seeking examples of situations where people developed creative solutions to disability discrimination issues using the principles of self-advocacy. Specifically, the authors are looking for stories concerning employment, access to facilities, education (including post-secondary), reasonable accommodations, transportation, housing, and voting. The book is being written to help people to obtain their rights under the federal disability discrimination statues by using the principles of self-advocacy. If you have a story that you are willing to share, please e-mail Adam Milani at milani_a@mercer.edu.

Free Computer Basics for Beginners

Computer Basics for Beginners Classes will be held every Wednesday, from noon to 3 p.m., at the Independence Branch Library, 18 South















7th Street. The course begins the first Wednesday of every month and is approximately four weeks long. The classes will continue as long as they have a teacher. The classes include introduction training in very basic Internet and Word Processing skills.












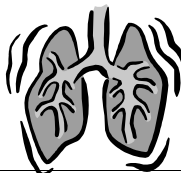




To register for the program call the Library at 215-685-1633. The slots have been filling up quite quickly and there is a waiting list as of now, but you can still sign up and the librarian will contact you when the classes have open slots.

SEPTA Offers Bus Familiarization Classes

SEPTA CCT will be conducting a Bus Familiarization program on the second Wednesday of each month during the summer and fall for riders who have not used the fixed-route system. The class will be a half-day and will cover ADA regulations and conditional eligibility; current fixed-route riders everyday experiences; how to obtain bus schedules, fares; SEPTA accessible bus demonstration. At the end of the session a rider survey and two SEPTA tokens will be distributed. When the survey is returned, SEPTA will send an additional five tokens to the rider.

To join a class, send your name, ID #, address, and telephone number to SEPTA, CCT Connect, 1234 Market Street, 4th fl, Philadelphia, PA 19107, Attention: L. Keehfuss. Upon receipt of your information, SEPTA will contact you with the date and time of your class.

| Sun | Mon | Tue | Wed | Thu | Fri | Sat |
|--|--|---|---|---|---|--|
| SEPTEMBER | | | | | | |
| 2004 | | | | | | |
|  | | | 1 Baby Safety Month - Cholesterol Education Month Healthy Aging Month - ADA Award Ceremonies in NY City 4p-7p  | 2 The Haitian Revolution: Celebrating the First Black Republic art exhibit, African American Museum 215-574-0380  | 3 *Easter Seals -Photo Contest– submit a photo w/ ice cream theme Bredenbecks Bakery 215-242-2712 -Philly Fringe Festival starts 7th year of artist produced shows, & performances Tickets: 215-413-9007 | 4 National Action Partnership “No Room for Poverty” National Rally 9a-1p 1-800-416-9157 Washington DC, The Ellipse |
| 5 Come check out the Franklin Institute this week for lots of hands on fun! 222 N. 20th St., 215-448-1200  | 6 LABOR DAY  | 7 First Day of Public School (Elementary & Secondary) - 9/8 - Healthcare in Crisis Roundtable Discussion 2-4p Drexel U.  | 8 The ARCH National Respite Conference in Atlantic City, NJ info 732-528-8080 9/8-9/10 - 9/8-12 National Alliance for Mentally Ill Annual Convention 703-524-9094 685-5697 | 9 *SEPTA One Day Outcomes Training (location TBA) 215-685-5980  | 10 The Philadelphia Bluegrass Band fundraiser for the Phila. Fair Food Project at the White Dog Café 6:30p \$30 215-386-9224  | 11 * Disabled in Action - The restored art works of N.C. Wyeth in a re-creation of his home at the Brandywine River Museum 610-388-2700 |
| 12 National Grandparents Day - Mexican Independence Day Festival at Penns Landing Great Plaza  | 13 *Mayor’s Commission on Disabilities -Phashion Phest show at Hyatt Regency Hotel 215-670-4323 for tix. - Two Days In Depth Intro to Outcomes 9/13-14 215-685-5980 | 14 *TAMW - Six week Voter Power training at Liberty Resources 1-4p every Tues. 215-634-2000 x 225 - Disabilities Employment Law training with Maryland Works, Inc. 8:30a-12p 410-381-8660 | 15 Farewell exhibit of Rebekah Wostrel’s works. Asymmetrical compositions and an interactive sound sculpture entitled “Ping”. The Cay Studio 12-6p 215-925-3453  | 16 Rosh Hashanah - Public Schools Closed  | 17 * Easter Seals * Consumer Connection - The Para Olympic Games begin 9/17-9/28 - Public Schools Closed  | 18 2004 American’s w/ Disabilities Convention in Wash., D.C 609-449-2000 FREE Admission! No Registration. - South Phila. Mural Trolley Tour w/Lunch 215-685-0754 \$40  |
| 19 Comic genius Steve Martin presents his play “The Underpants” at the Arden Theater 215-922-1122 6:30p \$24  | 20 9/20-23 Four Day Outcomes Training at TAIG 215-685- 5980 - 5:30-8p Networks: Person 2 Person– Shopping on a Budget 1888-683-3651 | 21 Take a Loved One to the Doctor Day - 5:30p-8p Networks: Developing Your Professional Self 866-683-3651  | 22 Former fashion model Birgitta Ara collection of her sculpture, which she began 30 yrs ago, at American Swedish Historical Museum 215-389-1776 | 23 First meeting of Philadelphia I.U Local Task Force 10a-noon 215-229-4550 x 2789 (location to be announced) | 24 The Creative Collective presents “The Fair” to showcase jewelry, glass, wood, fabric etc. Head House Square 215-790-0782  | 25 Yom Kippur |
| 26 Puerto Rican Day Parade Ben Franklin Pkwy  - The Voice of Phila. Features best known poets & spoken-word artists 7p-9p at Painted Bride \$18 215-925-9914 | 27 Family Health & Fitness Day 2004 Freedom March - Von Steuben Day Parade at Logan Circle - 9/27-30 Four Day Outcomes Training at 1845 Walnut St. 215-685-5980 | 28 10a-2p Networks: Responsibilities of Managers & Supervisors 215-546-4111 - Farmer’s Market at South and Passyunk Ave. 2p-7p | 29 -Cliveden Park farmer’s Market Chew and Johnson Ave. 2p-6p  | 30 -A Slave Ship Speaks: The Wreck of the Henrietta Marie historical exhibit at the African American Museum 215-574-0380 |  | Note: Entries with an * are Repeatable Dates— See Page 13 |

|  | Mon | Tue | Wed | Thu | Fri | Sat |
|---|--|---|--|---|---|--|
| 3 Fire Prevention Week -Mental Illness Awareness Week | 4 Child Health Day Collective Advocacy Workshop at OVR in Reading, PA 10a & 1p 800-684-3695 \$6  | 5 "Playing the Field" a retrospective exhibition of a furniture trend that became full blown in the 80's and 90's. Philadelphia University 10a-4p 215-951-2581 | 6 "Mondo Mangia" at the Walnut Street Theater Independence Studio 3, \$10 215-592-9560  | 7 Keystone Mental Health Dinner Theater 6p. \$30 717-558-8450 x 125 - Clark Park Farmer's Market 43rd & Baltimore 3p-7p | 8 Toshiko Takaezu weavings & ceramics exhibit at the Philadelphia Museum of Art 215-684-7500 10a-5p  | 9 * Disabled in Action -Hazardous waste collection in SW Phila. 9a-3p. 3033 S. 63rd St. |
| 10 10/12-15 Four Day Outcomes Training at RHD 215-685-5980  | 11 National School Lunch Week - Columbus Day * Mayor's Commission on People w/ Disabilities | 12 * That All May Worship - 12th Street Farmer's Market 12th & St. James 3p-7p  | 13 Breast Cancer Awareness Day Chester County Hospital provides info, giveaways, and latest research on Breast Cancer 610-431-7000  | 14 * SEPTA Where Are They Now? Insightful exhibit of former graffiti writers, Thomas Eakins House 1729 Mt. Vernon St.  | 15 * Easter Seals * Consumer Connection 10/15-16 Learning Disabilities Assoc. of PA Conference 610-458-8193 | 16 World Food Day  |
| 17 10/17-20 No Parent Left Behind Conference in King of Prussia, PA 570-455-8196 | 18 Collective Advocacy Workshop at Delaware County IU Intermediate Unit 10a & 1p \$6, 800-684-3695 | 19 Annual Closing the Gap Conference for computer technology, 507-248-3294 St. Paul, Minnesota  | 20 Disability Mentoring Day - West Oak Lane Farmer's Market Ogontz & 71st 2p-6p - Commission on HR Lunch 11:30a ,215-686-4675 | 21 One Day Outcomes Training (location TBA) 215-685-5980 - That All May Worship Conference Wilkes Barre, PA 202-293-5960 | 22 20th Annual Phila Alliance Breakfast , 8-10am, Crystal Tea Rm, Wanamaker Bldg, tim@philalliance.org - Roxborough Farmer's Market Ridge Ave & Lexington | 23 "African Art, African Voices: Long Steps Never Broke a Back" represents from various African cultures at the Phila. Museum of Art 215-684-7500  |
| 24 Respiratory Care Week  | 25 "Uncovering the Past" 10a-5p at the Atwater Kent Museum . Archeological display of Philadelphia Sites such as the Commuter Tunnel and First African Church \$5 215-685-4830 | 26 "Cabaret" Tony Award winning musical at the Media Theater 2p & 8p \$23 610-891-0100  | 27 - Two Day In-Depth intro to Outcomes 10/27-28 at KenCrest 215-685-5980 | 28 Chris' Jazz Café provides world class live jazz six nights a week with gourmet dining 6p-untill 215-568-3131  | 29 10/29-30 National Research Conference on innovations in the field of disabilities. Cleveland, OH 800-233-8611x3074 | 30 "Gemini: The Musical" at the Prince Theater 2p & 8p \$30 215-569-9700  |
| 31 Halloween Daylight Savings Time Ends  | | Note: Entries with an * are Repeatable Dates— See Page 13 | | | | |

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