

Working Toward Sustainable Futures A Call for Action and Solutions

Steve Eidelman, the Executive Director of The Arc of the United States, gave a presentation in Philadelphia on October 21, 2004, as part of the Mini Course Series on Disabilities by Temple's Institute on Disabilities. The Arc and Human Services Research Institute are working together to support and assist state systems to examine what can be done to increase community participation and sustain efforts to include people with disabilities in all communities. The Family Forum brings you his presentation in our first issue of 2005 – a great time to start thinking about the future.

Steve's first gave "A bit of background and history" and then an "Understanding of the challenges we are facing." He worked toward the important question: "What we might do in response," and the inevitable "What are YOU going to do about it?" A great place to start thinking about the future.

Presenting some history by decade, Steve took the audience through segregation in expanding public institutions (1950s and 1960s) all the way to the other end of the scale to the closing of institutions in the 1990s, accelerated community services growth, community reform, and self-advocates speaking up.

We have promised families and people with disabilities so much with the billions of dollars

Steven M. Eidelman is the Executive Director of The Arc of the United States. He has an extensive background in developmental disabilities policy and practice and is deeply

committed to the vision of "Everyday Lives" for individuals with disabilities in Pennsylvania. Mr. Eidelman was the Director of Mental Retardation Services in Philadelphia and Deputy Secretary for the State Office of Mental Retardation, overseeing deinstitutionalization efforts in the Commonwealth. His commitment continues on the national level as he focuses on the tradition of advocacy and the development of innovative programs and cutting-edge policies.

spent (up to \$24 billion in 2002) to provide home-and community-based waiver serves and ICF/MR supports for 877,000 people nationwide. The questions arise: Are we prepared to deliver? Do we have the courage of our convictions? Do we have what it takes? Can it be done?

The challenge facing systems in answering those questions lies in changing what we – not others – have developed. Providers of services and state governments are doing what we, the current generation of advocacy leaders, have asked them to do in the



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Enjoying the Brighter Futures presentations at My City My Place on November 3rd are (from left) Michael J. Covone, Deputy Director, and Arthur C. Evans, new Director, both of Behavioral Health and Mental Retardation Services; and Diane Kiddy, Chair of the Mayor's MH/MR Advisory Board.

Always a big attraction are the resource displays at My City My Place: time for gathering information and networking.



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215-685-4MRS (4677)**

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**MRS Internet Resource Directory
www.MyCityMyPlace.com**

Family Forum's are archived on the web

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SPOTLIGHT

on MR Awareness Month

Mental Retardation Awareness Month is Coming ... Soon!

by Donna Szamatowicz

It's time to begin making preparations to celebrate Mental Retardation Awareness Month this March! For over twelve years, families, individuals and providers have done a fabulous job carrying out many activities that raise awareness about the gifts, challenges, and contributions that people with mental retardation make to society. Check out some of the exciting ideas for March in this article. This is an opportunity to reach out to the community, educate our neighbors, and build bridges. *Imagine what a difference one person can make. Imagine what a difference we can make as a community.*

Here are some ideas for you to plan activities in March to raise public awareness of the contributions people with mental retardation are making to society. Think of other ways to make community an everyday experience for people with disAbilities. *Family Forum* welcomes your ideas and a photo with a caption of your event.

Families – Tell your elected officials how waiver services work for you, why money is needed for those on the waiting list and to raise the salaries of Direct Support Professionals. Start a sibling or dads' support group. Organize computer classes. Invite guest speakers to help families connect to community resources, learn about new programs, funding, and rights. Join the Public Awareness Committee.

Community – Organize an agency Open House and invite neighbors to get involved. Join your

community association, town watch, neighborhood garden club, senior center, or recreation center.

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

Self-Determination – Support someone to attend the local Speaking for Ourselves chapter meetings; help people with disAbilities to participate on committees. Share success stories at community organizations, places of worship, and through radio and television shows.

Spirituality – Ask religious leader to preach about the gifts and contributions of all people. Develop work and volunteer opportunities at your church, invite consumers to be in the choir, or to usher. Help your faith community reach out to include people with disabilities; have a buddy system.

Media – Submit an article to the community newspaper (or invite them to do an interview) highlighting a special achievement or activity involving individuals with disAbilities and their families. Get coverage for an awards ceremony, or video about agency services, individuals' accomplishments.

For our friends in the community – Invite a person with a disability home for dinner or to the movies. Welcome a new group home in the neighborhood. Include folks with mental retardation in your block club or athletic team.

We Rocked the House!

*By Sheila Stasko, Statewide Director
Pennsylvania Waiting List Campaign*

Our mission is to end devastating Waiting Lists for community services and supports for people with mental retardation and their families. We are mothers, fathers, sons, daughters, grandparents, friends, and citizens. We are people who believe that everyone is entitled to health, happiness and a quality lifestyle. We are people with disabilities who continue to wait for community services and supports so that we too can live in our community.

Thank you for your support on October 19! We Rocked the House! People with disabilities, families, friends and providers converged on the State Capitol to make our voices heard. Eight hundred members of the “silent” majority found and raised their voices in unison to bring attention to the need for funding the Emergency Waiting List and a Cost Of Living Adjustment (COLA) in this year’s state budget.

Prior to the rally a meeting was held with the Department of Public Welfare Secretary, Estelle Richman, and Budget Secretary, Michael Masch. Three families were present to share their intimate stories of life on the Waiting List. Secretary Masch and Secretary Richman listened intently as families spoke through tears and movingly presented the struggle and reality of our long wait. Secretary Richman reissued her commitment to end the wait.

People, many who made extraordinary sacrifices to attend, poured into the Rotunda from all regions

of the state. By the time the event was scheduled to start people were primed and ready to rally. The enthusiasm and spirit of the crowd was so intense it spilled into every space of the Capitol. Reporters told us we made an indelible impression. Our voices were definitely heard. END THE WAIT and FUND THE COLA echoed through the halls of Harrisburg!

Nancy Murray, from The Arc-Allegheny, was one of several parents and family members who spoke out about their wait. Nancy’s daughter has been waiting for services 16 years. Nancy reminded all of us that we need to be in contact with our legislators. We need to thank them for last year’s support and remind them that we need their support this year. She also adamantly questioned why Governor Rendell wasn’t “here” at the rally since he had been invited.

The rally participants were reminded about how many times and years we have heard the Governor and legislators say it was a “bad” budget year for the state – but also said that they could always find money to fund other interests that were “important” to them. They need to make the Waiting List for Mental Retardation Services equally “important.”

Ending the Waiting List is the greatest movement for the mental retardation system today. Our people – our sons and daughters – are counting on the support of the Rendell Administration and the Legislature to make this issue a top priority. Become passionate about Ending the Wait. Take this passion and meet with your legislators now!



Jody Saitsky (seated, holding banner) sent Family Forum this photo of the excitement at the Rally.

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Working Toward Sustainable Futures

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past. They are not the enemy. They must be helped to change. We bear some responsibility to help them through this change. Changing is not optional. Complacency is the enemy. Inaction is the enemy.

Let's look at the challenges ahead. Working Toward Sustainable Futures is an action-agenda anchored in values and committed to making the changes necessary to secure the best outcomes possible for people with developmental disabilities and families.

Let us continue to build on the foundation of values that we have learned ... and resolutely search for "value." Take the action pathway – resolutely pursue principles of person-centered supports – self-determination. There is a need to assure that individuals with disabilities, and their families, have the opportunity to be the decision makers concerning the supports that are needed, and how they best can be provided. Regardless of who is the "self" in self-determination – family-directed, state-directed, self-directed, provider-directed, broker-directed – good support is the resolution.

Things we can do for "good support" include: placing the individual in a meaningful position of power where his/her opinion is taken seriously (assume competency) and planning for meaningful supports to counterbalance the effects of intellectual disability; listening well to the individual, including having a third-party listener; providing the person with good information and useful assistive technology; building in quality and performance with outcome measurement and bench-marking and

having effective and efficient quality management, with good use of information technology.

We know so much, yet we don't take that knowledge and apply it. Complacency is the enemy. Inaction is the enemy. If all supports and services in Pennsylvania today were as good as the best that are available today in Pennsylvania, the quality of life for Pennsylvanians with disabilities would improve more than all the progress in the past fifty years. This would move advocacy from quantity and access to quality and outcomes. Now we come to the challenges for advocacy with and by consumers and families in the 21st century. What are these challenges?

There are problems with the quality of services and supports. Despite enormous progress, the gains are uneven. Many people are not getting what they want or need. Almost one million adults live with parents over 65. The quality of supports and

services is highly variable. Most adults are not productively employed. Community services are a necessary, but not sufficient, part of a good life.

Federal policy for supports and services still has a bias toward

congregate settings. Mainstream institutions still discriminate. Government and "cookbook" programs cannot do it alone. We must involve busy people in comprehensive advocacy programs: some time-limited on specific issues; develop advocacy leaders with broad perspectives; and tackle the adversarial nature of issues, such as special education.

Positive changes must be made in "The Industry." In what other industry could you sell people something they do not want to buy, use someone else's money to pay for it, charge a lot for it, and

In what other industry could you sell people something they do not want to buy, use someone else's money to pay for it, charge a lot for it, and be surprised when they don't like it?

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be surprised when they don't like it? We need to get options for people to buy what they want to buy with self-directed dollars. The voice of families, consumers, and concerned citizens must be strong.

Getting down to the bottom line, what are you going to do about these challenges? What traditions, commitments, and vision define us? What assets can we count on, and what leverage do we have? What alliances can we forge? What opportunities will we create? What changes do we need to make to achieve the best possible outcomes for people and families going forward?

The fundamental issues to overcome are:

- ❑ Technical – Can we figure out ways to make the structure work in a technical sense?
- ❑ Political – Do we have the will to make changes to the flow of money?
- ❑ Tradition – Can we abandon program (slot) driven approaches? Can we move from supply-centered to demand-centered systems?

Concluding Thoughts!
Change imposes choice.
Choice imposes ambiguity.
Ambiguity promotes discussion.
Discussion promotes deliberation.
Deliberation forms opinion.
Opinion leads to action.
If not us, then who?

Remember: Complacency is the enemy.
Inaction is the enemy.
Changing is not optional!

We Rocked the House

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WHAT TO DO NOW

We must be seen and heard! We need to get the job done. If your Legislator doesn't know about the Waiting List, you need to do a better job! Remember – The TOTAL NUMBER of people waiting across the state as of October 1, 2004, for EMERGENCY services is 2,130. For CRITICAL services the number is 7,842 and for PLANNING services it is 10,411.

Flood Governor Rendell's office with calls and emails encouraging him to *End the Wait* and fund the COLA. Until the state budget is passed in February, it is important that Governor Rendell be the primary person to contact. Governor Rendell's email is governor@state.pa.us. His telephone number is 717-787-5962. You can write to him at 225 Main Capitol, Harrisburg, PA 17120.



Your Legislators also must be contacted. Go to www.pawaitinglistcampaign.org and click on "State Controls." Enter your Zip+4 and your Pennsylvania Representative and Senator will display. Call Sheila Stasko at 1-877-372-WAIT, or email her at info@pawaitinglistcampaign.org if you have questions.



END THE WAIT!

Help Save Medicaid – Share Your Story

This request for help is from Families USA. Do you know a senior, a child, a person with a disability, or working family in your state that has Medicaid coverage? If so, Alexandra Zavala, Communications Outreach Coordinator, at 800-593-5041 ext. 3614, or at azavala@familiesusa.org wants to hear from you. They are starting a campaign to protect Medicaid from federal cuts. Your voices can and should be heard in Washington, DC, by Senators who can put a stop to any attempt to cut Medicaid funds. They are looking for people who can speak to reporters to talk about their fears of losing Medicaid benefits. They want children who did not choose to become sick, to seniors who cannot be blamed for living a long life.

WAIVER WIZARD'S Corner



By Vanessa Williams
MRS Program Analyst

What's Available to Me While I Wait for Waiver Services?

If you or a family member is on the waiting list for services, the first thing you need to do is set up a meeting with your supports coordinator. The supports coordinator will help you explore available supports and services and will assist you in developing a FDSS plan.

- ❑ Use generic community resources. Check the website – MyCityMyPlace.com.
- ❑ Contact LIHEAP for utility assistance: 215-684-6100 (see page 11).
- ❑ Check out after school programs, the Free Library, community arts centers and neighborhood recreation centers for daytime activities.
- ❑ Explore services through The Philadelphia Corporation for the Aging (PCA) by calling 215-765-9000. Service options include DOM Care (residential), Meals on Wheels, Senior Centers, and in home services.
- ❑ To find help with employment after a person graduates from school, call OVR at 215-560-1972. The State Employment service, Pennsylvania Career Link, 215-560-5482, and Networks for Training and Development, 215-546-4111, are good resources.
- ❑ Health related issues can be addressed at your District Health Center, or through your HMO. PCHC can provide medical consultation; they can be reached at 215-546-0300.
- ❑ Contact the Office of Behavioral Health (OBH) at 215-685-5400 and Community Behavioral Health (CBH) at 215-413-3100 for mental health services.

- ❑ Join a support group to network with people who have similar circumstances – a great place to learn about resources, get ideas, and support. You can contact Parent to Parent, Vision for Equality, your Supports Coordination Advisory Committee, or review resources posted on the <www.MyCityMyPlace.com> website.

If I Have an Emergency . . .

- ❑ Be persistent and clear when stating the nature of an emergency.
- ❑ Inform the supports coordinator of the nature of the emergency.
- ❑ Use generic community resources such as the American Red Cross for housing needs.
- ❑ Contact the Delegate line at 215-685-6440 for emergencies after regular office hours.
- ❑ Things We Can Do Right Now
- ❑ Use a circle of supports or team members to access resources and develop a long term plan and short term goals.
- ❑ Seek supports from churches and the faith community as well as family and friends.
- ❑ It is always a good idea (and often necessary) to advocate for yourself, your family members and others who are waiting for services.
- ❑ Contact the Supports Coordinator as soon as an issue arises, do early planning and save some of your FDSS allocation for emergencies.
- ❑ Make sure that a PUNS has been completed for the person who needs services and keep the PUNS updated to reflect changes.
- ❑ Keep medical records updated.
- ❑ Maintain waiver eligibility information at home, such as copies of your bank account information, insurance policies, and burial reserve accounts.
- ❑ When thinking about long-term planning, you will want to involve your supports coordinator and circle of support. The first option is for family members to remain at home using Day and In-Home Supports. If residential services are needed, options to explore include, a CLA, Life Sharing, Companion Living, and Supported Living.

Major Change in MA Coverage for Children

As of October 18, 2004, children with disabilities who apply for Medical Assistance (MA) will no longer be rejected because they receive Social Security Disability Benefits as a result of the death, disability or retirement of a parent.

In Pennsylvania, children with disabilities have been enrolled in Medical Assistance (MA) without regard to the amount of their parent's income for many years. Income in a child's name, however, did count against them in determining MA eligibility. If the child began receiving SSDI, the child would become ineligible for MA. This was a serious problem for children who lost the income of a parent and had major uncovered medical expenses.

In January 2004, DPW issued a rule that a child who was currently on MA in the "disabled child" category would not be thrown out as a result of the receipt of these benefits. But the rule did not apply to children who were applying for MA.

As a result of concerns about this, raised by the Disabilities Law Project, the Pennsylvania Health Law Project, and others, DPW has now issued a new rule to cover those children who were previously excluded – those who are applying for MA in the "disabled child" category. The Operations Memo states: Effective October 18, 2004, disregard Social Security benefits (Retirement, Survivors' or Disability) as income for a child with a disability applying for or currently active in the PH-95 category.

There is some question of whether the "disabled child" category includes people between the ages of 18 and 21. If you know a young person with a disability between those ages who is unable to get MA as a result of SSDI benefits, please contact Pennsylvania Protection and Advocacy at 800-692-7443. Source: PP&A announcement

MH Law for Minors Makes Access to Services Easier

Rep. Stephen Maitland's (R-Gettysburg) legislation (Senate Bill 137) clarifying issues of consent regarding mental health treatment for minors aged 14 through 18 has been signed into law. Previously, parents of these children were unable to ensure that their child would receive appropriate mental health services if the child refused his or her consent.. Many simply chose to give up and face the dilemma of seeing their child forego treatment rather than face court commitment proceedings. The new law allows the parent or guardian of a child who is less than 18 years of age to consent to voluntary mental health examination and treatment for their child. The new law also permits minors 14 years of age or older to seek outpatient mental health treatment without the consent of a parent or legal guardian. Along with ensuring that these adolescents can have simple access to needed care, it also will reduce problems associated with the need for parental consent when parents are divorced and one parent refuses to agree. Source: press release from Representative Maitland's office. Visit www.repmaidland.com.

Assistive Technology Act Signed

Millions of people with disabilities rely on assistive technologies, such as wheelchairs, communication devices and adapted computers, to pursue their education, obtain and maintain a job, participate in their community and leisure activities. Passage of the AT Act of 2004 assures that people with disabilities, educators, employers, service providers will have access to the technology they need.

AT Programs, established under the Technology-Related Assistance Act of 1988, have been responsible for increasing access to assistive technology devices and services for people with

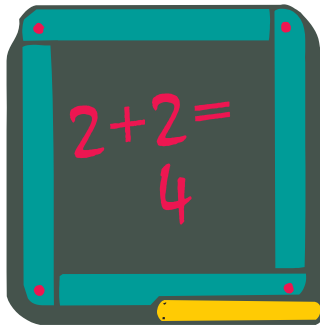
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DID YOU

▶ Toy Industry Publishes Special Needs Guide – The Toy Industry Association has created Let's Play: A Guide to Toys for Children With Special Needs in cooperation with the American Foundation for the Blind and the Alliance for Technology Access. It has more than 25 pages of toys, organized by toy type. The booklet is free by calling 212-875-1141. It also can be downloaded at <www.toy-tia.org>.

▶ La Industria de Juguetes publica su guía para necesidades especiales. La Asociación Industrial de Juguetes en cooperación con la Fundación Americana para los Ciegos y la alianza para el acceso tecnológico, han creado "Vamos a Jugar" una guía de juguetes para niZos con necesidades especiales. La guía contiene más de 25 páginas con juguetes, organizadas de acuerdo a los tipos de juguetes. La guía es gratis y la obtiene llamando al 212-875-1141. También la puede obtener en la siguiente página de Internet. www.toy-tia.org>.

▶ Start A Child Care Provider Program – A fund has been created by the Philadelphia Commerce Department to assist home-based Philadelphia child care providers who would like to start child care businesses, or expand their current operations. This program is administered by the Women's Business Development Center. The City will provide funding to qualified applicants for the following license and permit fees only: Business Privilege License, Family Child Care License, Zoning Permit, Use Registration Permit, Preparing and Serving Food License, and Certificate of Occupancy. To get started, applicants can call either the Women's Business Development Center at 215-790-9232, or any one of these participating child care agencies: Northwest Interfaith Movement (19119), 215-843-5600, ext.213 – Preschool Project (19125), 215-634-3325 ext.116 – West Philadelphia Child Network (19104), 267-531-5245 – YMCA of Philadelphia Family Child Care Program (19103), 215-963-3786.



KNOW?

▶ Comience un programa de proveedor de cuidado de niZos. Un fondo ha sido creado por el Departamento de Comercio de Filadelfia para asistir aquellos que les gustaría comenzar o expandir un negocio basado en el hogar, proveyendo cuidado de niZos en Filadelfia. El programa es administrado por: "The Women's Business Development Center". La Ciudad proveerá fondos a aquellos solicitantes que

cualifiquen, solamente para las cuotas de las siguientes licencias y permisos: Business Privilege License, Family Child Care License, Zoning Permit, Use Registration Permit, Preparing and Serving Food License, and Certificate of Occupancy. Para comenzar, los interesados deben llamar a Women's Business Development Center al 215-790-9232, o cualquiera de las siguientes agencias de cuidado de niZos participantes: Northwest Interfaith Movement (19119), 215-843-5600 ext.213, Preschool Project (19125), 215-634-3325 ext.116, West Philadelphia Child Network (19104), 267-531-5245, YMCA of Philadelphia Family Child Care Program (19103), 215-963-3786.

▶ The Family Village – <www.familyvillage.wisc.edu> – a website from the University of Wisconsin, is a site with many connections and a lots of resources. There are discussion board and chat rooms for people with disabilities; matching programs for siblings, parents and fathers. You can look up specific diagnoses or general information. The Family Village can be emailed at <familyvillage@waisman.wisc.edu>.

▶ La Villa Familiar <www.familyvillage.wisc.edu> es una página en la Internet de la Universidad de Wisconsin, es un sitio con muchas conexiones y un montón de recursos. Ahí encontrará discusiones de comités y secciones para charlar para personas con impedimentos; programas que combinan hermanos, padres y papás. Usted puede buscar un diagnóstico en específico o información general. El correo electrónico de La Villa Familiar es <familyvillage@waisman.wisc.edu>

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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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▶ **Choosing Naia: A Family's Journey** – chronicles the roller-coaster emotional ride of Greg and Tierney Fairchild, an interracial couple who, early in their long-awaited first pregnancy, heard the words that all expectant parents fear: “I think we have a problem here.” This is the true story of how the Fairchilds cope with the diagnosis, their struggle to deal with complex moral and medical issues, and the resources they draw on to allay their fears and strengthen their resolve. It follows them from their pregnancy and Naia's birth through her third birthday and the birth of her little brother. By Mitchell Zuckoff, Beacon Press.

▶ **Eligiendo a Naia: Un Viaje Familiar**, narra la carrera emocional de montaña rusa de la familia Greg and Tierney Fairchild, una pareja interracial que a principios de su largo y agudo primer embarazo, escucharon las palabras que todos los padres temen escuchar: ‘Creo que tenemos un problema aquí’ Esta es una historia real de cómo los Fairchilds le hicieron frente al diagnóstico, su lucha para lidiar con el complejo moral y la situación médica, y los recursos a los que ellos recurrieron para apaciguar sus temores y fortalecer sus resoluciones. Éstos se mantuvieron durante el embarazo, el nacimiento de Naia hasta su tercer cumpleaños y durante el nacimiento de su pequeño hermano. Por Mitchell Zuckoff, Beacon Press.

▶ **The Riot** – is an on-line newsletter for self-advocates. The writers promise entertainment, good information, and to help self-advocates speak-up. They actively solicit articles and stories. Visit <www.hsri.org/leaders/theriot> to read the paper. You can sign up to receive it directly as well. The Riot is supported by Human Services Research Institute.

▶ **The Riot** es una hoja informativa en la Internet para los que abogan por sí mismos. Los escritores prometen entretenimiento, buena información y ayuda para que los que abogan por sí mismos puedan ser escuchados. Ellos enérgicamente solicitan artículos e historias. Visítelos <www.hsri.org/leaders/theriot> para leer los artículos. Usted puede suscribirse para recibirlo directamente. The Riot es respaldado por “Human Services Research Institute”.

*Thanks to Emilio Pacheco for
the Spanish translation.*

▶ **The Arc's Sibling Support Project** – is creating a web page titled “Siblings Who Have Made a Difference” and is seeking siblings of all ages for inclusion on the web page. They'd like to hear about siblings who are students, homemakers, volunteers, or are filling any other roles in our communities. Send a one-paragraph description (120 words or less) and a way to contact the sibling to Don Meyer at donmeyer@siblingsupport.org, or call 206-297-6368. Don can accept a high-resolution jpg or gif head shot of the nominee.

▶ **“The Arc's Sibling Support Project”** esta creando una página en la Internet titulada

▶ **“Siblings Who Have Made a Difference”** (Hermanos que han hecho la diferencia) y están buscando hermanos o hermanas de todas las edades para incluirlos en la página. A ellos les gustaría escuchar acerca de hermanos que estudian, trabajan en el hogar, voluntarios, o que desempeñan otros roles en la comunidad. Envíe su historia en un párrafo (120 palabras o menos) y como contactar al hermano o hermana. Envíelo a donmeyer@siblingsupport.org, o llame al 206-297-6368. Don puede aceptar alta resolución jpg o una foto del rostro del nominado gif.

▶ **The 2005 Disability Policy Seminar** – co-hosted by The Arc, UCP, AAMR, NACDD and AUCD, will be held on February 28 through March 2 in Washington, DC. Learn about top priority national disability public policy priorities and help spread our message with our elected officials in the new 109th Congress. Look for more details on The Arc's website <www.thearc.org>.

▶ **“The 2005 Disability Policy Seminar”** co-patrocinado por UCP, AAMR, NACDD y AUCD, se llevará a cabo del 28 de Febrero al 2 de Marzo del 2005 en Washington, DC. Aprenda acerca de cual es la más alta prioridad en las prioridades de la política pública nacional en impedimentos. Ayude a difundir el mensaje con nuestros oficiales electos en el nuevo 109vo Congreso. Encuentre más detalles en la página de la Internet de ARC. <www.thearc.org>.

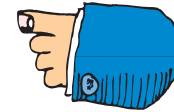
**Visit www.MyCityMyPlace.com
for resources**

PGW Will Accept LIHEAP Applications Until March 24

The Philadelphia Gas Works (PGW) is now signing up eligible customers for Low Income Home Energy Assistance (LIHEAP) grants at neighborhood Customer Service Centers. LIHEAP is a federally funded program administered by the state to help low-income households with home heating bills. Applications for this winter's program will be accepted until March 24, 2005. Applicants do not have to be on public assistance to be eligible for LIHEAP. Grants are also available for renters, as well as for homeowners.

To be eligible, an individual could have an annual income of \$12,569. A household with two members could earn up to \$16,862, and a home with three occupants could have a total income of as much as \$21,155. Income levels for four or more household members may be determined by adding an additional \$4,293 for each additional occupant.

Applicants must provide proof of income and proof of social security numbers for all members of their household, as well as their most recent heating bill. Additional information is available through PGW's LIHEAP Hotline, 215-684-6100, or on PGW's Web site <www.pgworks.com>.



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Ronald Bruce Nipon Assoc. has two well-appointed rooms for rent at 6445 Castor Avenue, 19149, Monday through Friday, use of kitchen and office space available. 215-537-1540, or email rbnipon@aol.com.

Just a note to let you know how great it is that you've created the website and have posted The Family Forum on it. Had two questions this week. Both were solved because The Family Forum was on the website now. Thanks for everyone's efforts that allowed this to happen.

Brenda Golden, ChildLink/PHMC



Grandmother needs a mattress bed, box spring, and dresser for her 8-year old granddaughter,, with special needs, who just came to live with her. To donate these items, call Marianne Roche, MRS, 215-685-5930.

Oral-B Crossaction Power & Powermax Toothbrushes Dangerous

Recently there have been three reports received by the company that makes the Oral-B CrossAction Power and PowerMAX toothbrushes concerning instances where the brush head of these toothbrushes has become loose in the mouth during brushing. The head of the toothbrush can unlatch and can be caught in the throat, or swallowed. The company will replace them with a toothbrush that is better suited for people with disabilities. Call 800-496-6557 during weekday hours, and Oral-B will send you a prepaid mailing envelope to return either toothbrush. Once received, they will send you an Oral-B Advance Power 400 battery toothbrush. The article about these incidents can be found at <www.oralb.com/home.asp>.

Supports Coordination Training: Respond, Respect, Communicate

By Donna Szamatowicz, Networks for Training

In preparing for a new way of supporting people with disabilities, Philadelphia Mental Retardation Services (MRS) reorganized Supports Coordination, effective July 1, 2004. If you are a person who receives mental retardation services in Philadelphia, you were given an opportunity to select from among four new Supports Coordination entities. This, however, wasn't the only new change. MRS, in collaboration with several training agencies, individuals, family members, provider agencies, and Supports Coordinators planned for and developed a training curriculum consisting of sixty hours of formal training that all Supports Coordinators will receive. These trainings focus on coordinating, supporting, identifying, and locating resources for the individual and family – not just “managing a case.”

The curriculum includes: Values and the Role of Supports Coordination, Person Centered Planning, ISP Development, Understanding Mental Retardation, Understanding the Mental Retardation System, Self-Determination, Outcomes, Working with Families/Cultural Diversity, and Assistive Technology.

Beginning this past August, individual and family members who use the services shared in the role of facilitating the trainings with other trainers. This process will continue throughout the sixty hours of training.

The first training module, Values and Role of the Supports Coordinator, included a panel of families and self-advocates who engaged in open dialogues with Supports Coordinators, sharing their positive and negative experiences with the system and the expectations they have for quality coordination of supports. This honest engagement fostered relationship-building throughout the two-day sessions. Supports Coordinators expressed their

frustrations dealing with paperwork and not having enough resources to offer families. Sometimes families just wanted someone to listen to them and return phone calls. Families and individuals want someone who will not judge them, to be an advocate, to know the system, connect them to the community, and to think out of the box. Other times, self-advocates wanted someone to call them, or just to care. Supports Coordinators wanted all to know that sometimes they get overwhelmed, and that there isn't enough time in the day. Families and self-advocates experience the same frustration. Overall, the consistent theme of this training module was A Partnership that is Responsive, Communicative and Respectful.

We are moving forward with a “new” way of doing things ... we are in this together as families, individuals, and professionals working together toward a Partnership that focuses on a consistent way of thinking, responding to each other, respecting one another, and communicating.

To contact Donna Szamatowicz, email her at <donnas@networksfortraining.org>.

Assistive Technology

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disabilities. AT Programs are responsible for implementing training and technical assistance, with a special emphasis on assistance for individuals with disabilities transitioning from school-to-work, or continued education, conducting public awareness activities, information and referral services, and coordination and collaboration with public and private entities that are responsible for programs, services, policies or funding of assistive technology services.

Source: Association of Assistive Technology Act Programs (ATAP) <www.ataportg.org>, or 518-439-1263.

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, Vision for Equality, 6N 718 Arch, Bill Krebs, 267-257-0109

☆ 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

Wednesdays

☆ Every Wed. free legal advice and representation on general legal problems, Liberty Resources. Call for appt. 215-204-1800

Thursdays

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

Fridays

☆ Every Fri. 1-3p, Skills Training on Accessing Public Transportation, Liberty Resources, for appt. call 215-204-1800, Debbie at x255

☆ 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

To Elwyn Institute Staff, from Ms. Willa Mae Coleman, Robin's Mother.

They [Elwyn staff] have concern and show interest in people in the program. She received a "china pin" from the company she works for, Team China DC. I also would like to thank Veronia Gordon, her job coach. She stays on top of things. I would refer anybody to Elwyn Institute. Editorial Note: Mrs. Coleman requested this note, which has been edited for space, to be printed in Family Forum. Family Forum is always interested in hearing from consumers and families.

Services/Supports Directory Available

The 3rd edition of the Directory of Services and Supports – published by Philadelphia Mental Retardation Services' (MRS), was launched at the Brighter Futures Award event on November 3rd. Copies are available upon request to Shalisha Anderson at shalisha.anderson@phila.gov, or 215-685-5915.

This resource for people with disabilities, their families and professionals provides information to identify, plan and use services and supports from the Philadelphia Mental Retardation system.

The Directory includes:

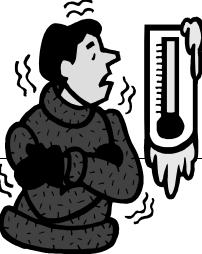





- ❑ Philadelphia Mental Retardation System description
- ❑ Information about 73 provider agencies, cross-referenced by services and State Office of Mental Retardation Service Definitions used in the development of the Individual Support Plan (ISP).
- ❑ Quality Management section with descriptions of Personal Outcome Measures, Independent Monitoring for Quality (IM4Q) and guides for selecting services and supports
- ❑ Appendix with MRS' phone list, acronyms, Q & A about the Waivers, and Fair Hearing forms.

This Directory is also online at www.MyCityMyPlace.com Internet resource directory. We welcome suggestions on information you would find useful in the directory or website.




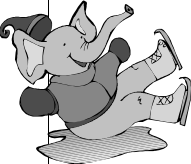
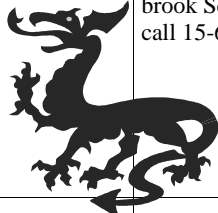





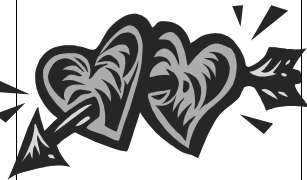
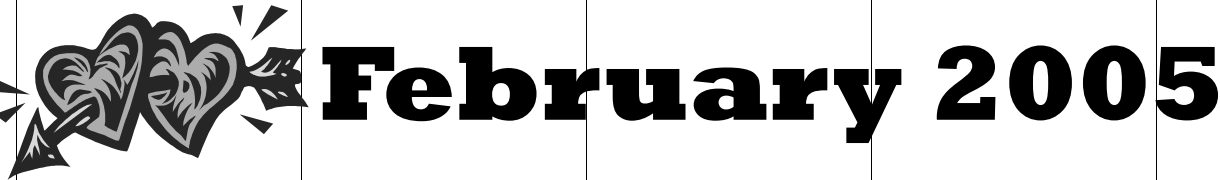


**For Expanded Dates
More Resources
The Family Forum
On-Line**

**Visit [www.
MyCityMyPlace .Com](http://www.MyCityMyPlace.Com)**

Sun	Mon	Tue	Wed	Thu	Fri	Sat	
 <h1>January 2005</h1>						Mental Wellness Month National Birth Defects Awareness Month	1 HAPPY NEW YEAR'S DAY!!! -AAMR national congress meeting 202- 387-1968
2 	3 * Speaking for Ourselves 	4 Overwhelm your senses at the Living Loft Puppet Museum \$5 215-222-6979 3114 Spring Garden Street	5 * Legal Advocacy Disney On Ice presents Finding Nemo at the Wachovia Center 7:30pm 215-389-9543	6 3 Kings Day 	7 *Easter Seals Martin Luther King III & Christoph Eschenbach for a discussion of King's life and beliefs. FREE, at Phila. Library 19th & Vine	 8 * Disabled in Action Pennsylvania Academy of Fine Arts 200th Bicentennial Celebration at Broad and Cherry Streets 215-972-7600	
9 ASL interpreted CATS 2pm at the Walnut Street Theater, \$52, 215-574-3550 	10 *Mayor's Commission on People w/ Disabilities	11 * TAMW Forum on Supports Coordination at Temple Kiva Auditorium, State OMR, 215-204-1000	12 * Legal Advocacy Bugs, bugs, bugs! The Insectarium has them all. \$6, 10a-4p 215-338-3000 8046 Frankford Ave.	13 * SEPTA 14-15 Language & Behavior Interventions for Autistic Children workshop at Bucks County Comm. College 215-598-8175	14 *Skills Taring "A Spoon Full of Sugar" Psychotropic Medication Issues in Mental Retardation, Friends Hospital 1800-899-0548 	15 Stuart Davis & American Abstraction exhibit at Phila. Museum of Art -Live the Dream Family Day, 12-4 Academy of Fine Arts, 215-972-2061	
16 Healthy Weight Week Philadelphia Home Show PA Convention Center adm. \$9	17 Martin Luther King, Jr. Day -Public Schools Closed 	18 Philadelphia Beauty-Showcase National Historical Museum where homage is paid to Philadelphia as the center of beauty product development \$7, 510 S. 52nd Street 215-474-7533	19 *Legal Advocacy 	20 Visiting Artist Lecture , FREE, PA Academy of Fine Arts, 11:30a-1p, Broad & Cherry Streets 215-972-7600	21 *Skills Taring *Easter Seals *Consumer Connection	22 Sibshops, an opportunity for children to spend time with other siblings of children with special needs Children's Hospital of Phila. RSVP 215-590-7443	
23 	24 1/24-26 Health Assistance Partnership Annual Conference, Wash. DC 202-737-6340	25 Four Day Outcomes Training at Hall Mercer to register call 215-685-9437	26 - Training: The IDEA has changed at the Education Law Center 9:30a, 215-238-6970 x 301	27 Quality Progressions 6-8pm at Vision 267-675-2012 - 27-29 Health Action 2005 Conference in Wash. DC, Families USA 202-628-3030	28 Deadline for the POT Award nominations, send to Shalisha Anderson, 215-685-5933 (fax) -Christine Whitman former secretary of the EPA talks about her book, Free Library, 7pm	29 Philadelphia Jewish Sports Hall of Fame at the Gershman Y, 215-446-3016, 401 S. Broad 	
30 Shoe Fetish? Temple U Shoe Museum can handle it! 8th & Race, by appt. only 215-625-5243 Come see a collection of shoes from around the world! 	31						

Best Wishes for a Happy and Healthy New Year!

Sun	Mon	Tue	Wed	Thu	Fri	Sat
		1 Mental Health Consumer Month National American Heart Month Black History Month	2 *Legal Advocacy 	3 Public Schools Closed - The Fabric Workshop hosts exhibition called "Experiments with Truth" which explores the world of filmmaking and video. 10a-6p 215-568-1111	4 Nat'l give Kids a Smile Day *Easter Seals Networks: Accepting the Challenge & Learning to Lead workshop with Lynn Seagle 9:30a-4p 215-546-4111 - Public Schools Closed	5 Anniversary of the Constitution 
6 Philadelphia Auto Show at the Pennsylvania Convention Center thru Feb 13. - 21st Annual Celebration of Black Writing: Telling Our Stories thru 2/20 at the Arts Sanctuary 215-232-4485	7 * Speaking for Ourselves - Blue Cross RiverRink open at the Festival Pier/ Penns Landing	8 Fat Tuesday * TAMW 	9 Ash Wednesday Chinese New Year 	10 * SEPTA 2/10-11 Two Day Intro to Outcomes session at Overbrook School for the Blind call 15-685-9437	11 *Skills Training Award winning opera AIDA by Giuseppe Verdi now playing at The Academy of Music thru 2/27. 215-893-1999	12 * Disabled in Action Music in the Galleries: Woodwind Quartet, Phila Art Museum., Students of Curtis Inst. Perform, 1:30-3p. Free with museum admission
13 	14 Valentine's Day -Have-A-Heart Day *Mayor's Commission on People w/ Disabilities	15 Escape the winter weather with a trip to the tropical gardens of Fairmount Park West Horticulture Center 215-686-0096, open 9a-3p Mon-Fri.	16 *Legal Advocacy Peter Benchley marine conservationist, author of JAWS gives performance at Academy of Natural Science, \$12, includes a ticket to Lewis & Clark exhibition. 215-299-1000	17 Salvador Dali exhibit opens at the Philadelphia Museum of Art, through May.	18 National Women's Heart Day *Easter Seals *Consumer Connection 	19 Make buffalo & bear masks at the Academy of Natural Sciences, with this craft team it will look like the real thing, 11a-3p
20 Ortleib's Jazzhaus' presents world-class jazz 7 nights a week. 847 N. 3rd Streed, 215-922-1035 	21 President's Day -Public School Closed	22 "A Higher Place in Heaven" performed by the People's Light & Theater Company 8pm, 610-644-3500 play focused on family crisis,	23 *Legal Advocacy 	24 Quality Progressions 10a-12p, Mt. Olive Holy Temple 1469 N. Broad St, 267-675-2012	25 *Skills Training Smuckers Stars on Ice at the Wachovia Center, 7:30p. Tickets 215-389-9543 	26 UPENN Archeology Museum offer a view into the Aboriginal world through the paintings of contemporary Australian artists. 215-898-4000
27 	28 2/28-3/2 2005 Governmental Affairs Seminar in Wash, DC. Co-hosted by ARC, UCP, AAMR, NACDD, AUCD					

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5th Points of Transformation Awards—March 18, 2005

Look for an invitation coming soon to the **5th Points of Transformation Awards**, to be held on March 18, 2005, at the Philadelphia Wyndham at Franklin Plaza. Philadelphia MRS will recognize Direct Support Professionals whose dedication make community real for the people they support. These DSPs are building an inclusive, welcoming community following “the individual path suggested by the unique gifts, preferences, and needs of each person supported, and walk in partnership with the person ... toward a life of opportunity, well-being, freedom and contribution.” (National Alliance for Direct Support Professional Mission Statement)

We need your help in finding these extraordinary people. A nomination form is enclosed in this issue of Family Forum. If you don't receive one, call 215-685-5915, or email familyforum@phila.gov, to request a form. Direct Support Professionals include workers in the MR system who have direct, hands-on contact. They may be employed by a provider agency, hired directly by the individual/family, or paid through a Supports Broker. Regardless of their title, they are the ones on the front line who are making community participation, self-determination, and choice for people with mental retardation an everyday occurrence.

