

**NJCDD**

NJ Council on Developmental Disabilities

the **Council**

A publication of the New Jersey Council on Developmental Disabilities

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**P&A Files Waiting List  
Action in Federal Court**

New Jersey Protection and Advocacy (NJP&A) has filed a lawsuit in Federal District Court against the New Jersey Department of Human Services (DHS) alleging that DHS has failed to meet its legal responsibility to provide housing for people who want or need to live outside of their family homes.

NJP&A partnered with the private law firm, Lowenstein Sandler, in drafting and filing the action.

Several individuals served by NJP&A are named anonymously in the suit. In addition, the New Jersey Association of Community Providers, The American Association on Intellectual and Developmental Disabilities, and The Alliance for the Betterment of Citizens with Disabilities, are named as interested parties.

*continues on page 4***Funding for Lifespan Respite  
Program Advances**

Earlier this spring, the U.S. Senate unanimously passed an amendment to the Senate Budget Resolution reserving \$53 million for Lifespan Respite. Senators Hillary Clinton (D-NY) and John Warner (R-VA) offered the amendment.

Although the resolution is non-binding and, therefore, does not guarantee an appropriation, it will make it easier to secure funding during the FY09 appropriations process because it sets parameters that must be followed when considering spending bills.

Congress passed the Lifespan Respite Care Act in 2006 to make respite more accessible and affordable to family caregivers. The bill authorized \$289 million during the next five years for states to provide respite services to an estimated 50 million families. To date, Congress has provided no funding.

New Jersey Representative Mike Ferguson (R-7), who sponsored the measure in the House, has asked other members of Congress to sign onto a letter to the House Subcommittee on Labor, Health and Human Services, and Education urging full funding (\$53.3 million) for the Lifespan Respite Care program.

Sixty national organizations and more than 135 state and local organizations also sent letters to House and Senate members urging funding for the program.

In 2005, approximately \$207 billion was spent on professional long-term care services; 49 percent paid for by Medicaid and 20 percent

*"Voluntary family care giving accounts for 80 percent of the overall long-term care provided in the United States, at a savings of more than \$300 billion annually."*

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# Self-Advocates and Family Members Can Help Shape the Future

Do you want to have a say in what services and supports for people with developmental disabilities will look like in the future?

The state Division of Developmental Disabilities (DDD) is looking for self-advocates and family members to be part of a committee workgroup that will be planning for people who are leaving state institutions.

‘Path to Progress’ is New Jersey’s plan to transition people with developmental disabilities out of developmental centers (DCs) into the community over the next 8 years. The Plan addresses the requirements of state laws, as well as an important U.S. Supreme Court decision, known as ‘Olmstead,’ which requires states to develop a plan to help people who want to move out of institutions.

New Jersey’s Olmstead Implementation and Planning Advisory Council has five workgroups examining different parts of the system. As a member of one of these workgroups, the Self-Advocacy and Family Partnership Workgroup, you can help make suggestions

to DDD about how the “Path to Progress” Olmstead Plan is working, and help make sure that the information that families and self-advocates need gets to them in a way that they understand.

The group meets as often as needed, and the meetings are held at accessible locations and times. You will be compensated for your time and travel.

## **We need your voice to be heard!**

For more information, please contact one of the workgroup’s co-chairs:

Tom Baffuto: The Arc of New Jersey, 732-246-2525 ext. 17, [tbaffuto@arcnj.org](mailto:tbaffuto@arcnj.org)

Alison Lozano: New Jersey Council on Developmental Disabilities, [alison.lozano@njddc.org](mailto:alison.lozano@njddc.org)

Ann Martinelli: 908-586-9257, [joeysmom45@aol.com](mailto:joeysmom45@aol.com)

To learn more about Olmstead in New Jersey, go to [http://www.state.nj.us/humanservices/ddd/nofa\\_bg.htm](http://www.state.nj.us/humanservices/ddd/nofa_bg.htm)



## Resource Desk: HealthHelp for New Jersey Families

The Arc of New Jersey has announced a new resource for families. “HealthHelp for New Jersey Families,” is a laminated pamphlet that lists, in both English and Spanish, important resources for any New Jersey parent or family member who knows or believes their child has a developmental disability.

This resource is the result of the dreams and work of Arc member Robert Hage, an ambassador from the Arc’s Family Advocacy Program. Robert and his wife, Odette, have twin daughters, both of whom have significant physical and developmental disabilities. When their girls were born, the Hages experienced a great deal of frustration searching for the help they needed. Working with staff from the Arc, Hage was able to transform this frustration into a simple idea that has now become a viable, statewide project.

The American Academy of Pediatrics/New Jersey Chapter has endorsed the project, which was funded with generous support from The Horizon Foundation. The Academy is helping to distribute HealthHelp to pediatric offices across the state, with a letter urging pediatric health professionals to make it widely available to parents and families. Copies are also being sent to hospitals, public health facilities, community organizations and any other entity that may have contact with families who could benefit from this resource.

For more information, or to receive more copies, please contact The Arc of New Jersey at 1-877-272-0277, ext. 42, email [healthhelp@arcnj.org](mailto:healthhelp@arcnj.org), or visit [www.arcnj.org](http://www.arcnj.org).

## Auto-defensores y miembros de la familia ¡Ayude a formar el futuro!

¿Quiere opinar acerca de cómo serán los servicios y apoyo futuros para las personas con discapacidades de desarrollo en Nueva Jersey?

La División de Discapacidades del Desarrollo (DDD) del estado está buscando auto defensores y miembros de familia para que participen en un comité que ayudará a las personas que salen de las instituciones del estado.

El “Camino hacia el Progreso” (Path to Progress) es el plan que tiene Nueva Jersey para ayudar a personas con discapacidades de desarrollo al salir de los centros de desarrollo (DC) e insertarse en la comunidad en los próximos 8 años. El Plan aborda los requisitos de las leyes estatales y un importante fallo de la Corte Suprema de los Estados Unidos llamado ‘Olmstead,’ que exige que los estados desarrollen un plan para ayudar a las personas que quieren mudarse de las instituciones.

El Consejo Asesor de Planificación e Implementación de Olmstead en Nueva Jersey tiene cinco grupos de trabajo que se encargan de distintas partes del sistema. Como miembro de uno de estos grupos de trabajo, el Grupo de Trabajo de Auto Defensoría y Sociedad Familiar, usted

puede ayudar a dar sugerencias al DDD acerca de cómo está funcionando el Plan “Camino hacia el Progreso” de Olmstead, y ayudar a asegurar que la información que necesitan las familias y auto defensores les llegue de tal manera que la comprendan.

El grupo se reúne las veces necesarias en lugares y horas accesibles. Se le compensará por su tiempo y traslado.

### ¡Necesitamos escuchar su opinión!

Para mayor información, comuníquese con uno de los co-presidentes del grupo de trabajo:

Tom Baffuto: The Arc of New Jersey, 732-246-2525 ext. 17, [tbaffuto@arcnj.org](mailto:tbaffuto@arcnj.org)

Alison Lozano: Consejería sobre Discapacidades de Desarrollo de Nueva Jersey, [alison.lozano@njddc.org](mailto:alison.lozano@njddc.org)

Ann Martinelli: 908-586-9257, [joeysmom45@aol.com](mailto:joeysmom45@aol.com)

Para conocer más acerca de Olmstead en Nueva Jersey, visite:

[http://www.state.nj.us/humanservices/ddd/nofa\\_bg.htm](http://www.state.nj.us/humanservices/ddd/nofa_bg.htm)



## Mostrador de Recursos – HealthHelp

La Asociación para Ciudadanos con Retraso Mental de Nueva Jersey (Arc of New Jersey) ha anunciado la emisión de un nuevo recurso para las familias. “HealthHelp para las Familias en Nueva Jersey”, es un panfleto que enumera, tanto en inglés como en español, recursos importantes para cualquier padre o miembro de familia en Nueva Jersey que sabe o piensa que su hijo tiene una discapacidad de desarrollo.

Este recurso es producto de los sueños y el trabajo de Robert Hage, miembro de Arc, un embajador del Programa de Defensa de la Familia de Arc. Robert y

su esposa, Odette, tienen hijas mellizas, las dos con una significativa discapacidad física y de desarrollo. Cuando sus hijas nacieron, los Hage sufrieron una gran frustración al buscar la ayuda que necesitaban; pero el trabajo de Hage con el personal de Arc le permitió transformar esa frustración en una idea simple que actualmente se ha convertido en un proyecto factible a nivel estatal.

La Academia Americana de Pediatría/Capítulo de Nueva Jersey ha avalado el proyecto, el cual ha sido financiado

*sigue la página 5*



## P&A Files Waiting List Action in Federal Court

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The suit alleges that the Department of Human Services has violated the Americans with Disabilities Act and Federal Medicaid Law in its use of waiting lists, and its failure to:

- provide prompt services,
- assess the needs of individuals on waiting lists,
- provide services to wait-listed individuals,
- inform individuals of their right to choose integrated, less restrictive services, and
- properly use Medicaid Home and Community-based Waivers for qualified individuals who are seeking less restrictive services.

The full text of NJP&A's waiting list complaint is available in pdf format online at [www.njpanda.org](http://www.njpanda.org) on NJP&A's litigation page. NJP&A is the designated federally funded protection and advocacy system for the State of New Jersey, and provides information and referral, technical assistance and training, legal and non-legal advocacy, and outreach and education on behalf of the rights of people with disabilities in New Jersey.

### **The complaint asks the Court to require that the NJ Department of Human Services:**

- declare the rights of the affected individuals under the ADA, Section 504 of the Rehabilitation Act, and federal Medicaid law;
- inform individuals with developmental disabilities who are eligible for services from DDD that they may be eligible for community services, that they have a right to those community services and they will provide them in accordance with specified reasonable timelines;
- promptly determine the eligibility of all current and future individuals on the waiting list for community services, including placement in community residences, and inform them of it in writing;
- develop a community-based infrastructure responsive to individual needs through the use of individualized care plans that afford eligible individuals the freedom to choose to reside in a preferred living arrangement in their community of choice;
- identify all eligible individuals at least six months prior to their graduation from high school, and provide necessary information, referrals and linkages to services as they transition to adult services;
- provide necessary services and supports for aging persons with developmental disabilities that afford continuity of care through the lifespan and maintain preferred living arrangements in their communities; and,
- eliminate the waiting list within three years and establish a plan with reasonable timelines for providing Waiver services, including placement in community-based residences.

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## Respite Program Advances

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paid for by Medicare. However, voluntary family care giving accounts for 80 percent of the overall long-term care provided in the United States, at a savings of more than \$300 billion annually.

According to Eric Joice, Director of Caregivers of New Jersey, respite care decreases the need for professional long-term care, resulting in significant savings for the health care system and taxpayers.

“Access to respite services has also been shown to improve caregiver health and well-being, promote family stability, avoid or delay more costly out-of-home placements and reduce the likelihood of abuse and neglect,” said Joice.

In New Jersey alone, over 900,000 unpaid caregivers support a family member.

The House Labor/HHS/Education Appropriations Subcommittee could take action on the FY09 funding bill as soon as late May and the corresponding Senate committees as early as June.

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## Mostrador de Recursos – HealthHelp

*seguido de la página 3*

con el generoso apoyo de la Fundación Horizonte (The Horizon Foundation). La Academia ayuda a distribuir el panfleto de HealthHelp en oficinas de pediatría en todo el estado con una carta instando a los profesionales a poner este servicio a disposición de padres y familias. También se envían ejemplares a hospitales, instalaciones de salud pública, organizaciones comunitarias y cualquier otra entidad que tenga contacto con familias que se puedan beneficiar con este recurso.

Para mayor información, o para recibir más ejemplares, comuníquese con la Asociación para Ciudadanos con Retraso Mental de Nueva Jersey al 1-877-272-0277, extensión 42, correo electrónico [healthhelp@arcnj.org](mailto:healthhelp@arcnj.org), o visite [www.arcnj.org](http://www.arcnj.org).

## Caregivers Conference Scheduled

On Wednesday, October 29, the 2008 National Caregivers Conference will take place at Woodbridge Hotel and Conference Center formerly the Sheraton, Iselin NJ. The annual event focuses on respite, family supports, care giving, mental health and prevention of abuse and neglect. It is a place where professionals, parents and individuals come together to learn and discuss new approaches to care giving issues. The conference will host workshop sessions, informational exhibits and inspirational speakers.

This year the keynote speaker is freelance writer, Lee Woodruff, wife of journalist Bob Woodruff who was critically injured in Iraq while anchoring a broadcast for ABC News. Together they authored the New York Times bestseller *In an Instant: A Family's Journey of Love and Healing*, about their family's difficult journey during his recovery.

For more information, visit [www.nationalcaregiversconference.org](http://www.nationalcaregiversconference.org)

## Remembering Leila Gold

Former Council member and life-long advocate Leila (Gold) Simon died in late March at her home in West Orange. She was 74.

Simon was active with the parents' group at Hunterdon Developmental Center, where her son David lives and was an outspoken advocate for the needs of adults with developmental disabilities.

Her work will be profiled in the next issue of the Council's magazine, *People and Families*.



# Community Calendar

- May 13 DD Lecture Series, Transition Matters: Equipping Youth with Disabilities for Life After High School, featuring Erik Carter, Ph.D., 9:30 AM – 12:30 PM. Mt. Laurel, NJ. Sponsored by the Boggs Center on Developmental Disabilities. For more information go to: <http://rwjms.umdnj.edu/boggscenter/>, or call 732-235-9300.
- May 22 Public Meeting of the NJ Council on Developmental Disabilities (NJCDD), 10:00 AM to 4:00 PM, Trenton, NJ. 609-292-3754.
- May 30 Pubic Meeting of the Statewide Interagency Coordinating Council (SICC) 11 AM – 1:30 PM. Lawrenceville, NJ. 609-730-1522.
- June 4 Health Care Advocacy in the Managed Care Environment Teleconference. 12:00 NOON – 1:30 PM. Sponsored by SPAN. Register on line at <http://www.spannj.org> or by calling 973-642-8100.
- June 13 Positive Behavior Support Conference: Enhancing Quality of Life for Individuals with Developmental Disabilities and Their Families, 8:00 AM – 4:00 PM, Somerset, NJ. Sponsored by the Boggs Center UAP, with NJ DHS, DDD. Go to: <http://rwjms.umdnj.edu/boggscenter/conferences/index.htm> or call 732-235-9314.
- June 14 Men's Health Conference, sponsored by the NJCDD Men with Disabilities Health Care Task Force, Trenton Marriott at Lafayette Yard, Trenton, NJ. Go to: <http://www.njddc.org/calendar.htm>.

The Council is a publication of the New Jersey Council on Developmental Disabilities.

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The Council is a compilation of news from various sources, organized to inform people with disabilities about policies, programs, laws, trainings and events. This publication and others published by NJCDD are available in alternate accessible formats. Please call the Council for more information.

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