

# NJCDD

NJ Council on Developmental Disabilities

# the Council

A publication of the New Jersey Council on Developmental Disabilities

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## Mark Your Calendar

- September 20 – Get Out The Vote Rally – at the New Jersey Self Advocacy Conference, Somerset, NJ.
- October 14th – last day to register to vote.
- October 28th, noon – mail-in deadline for voting via absentee ballot.
- November 3rd, 3 p.m. – in-person deadline for voting via absentee ballot.
- November 4th – Election Day.

## Resources:

NJ Department of State, Division of Elections Maintains a website with information in both English and Spanish, and voter registration forms in 6 languages.

[www.state.nj.us/state/elections/vote\\_doe.html](http://www.state.nj.us/state/elections/vote_doe.html)

[www.njvoterinfo.org/](http://www.njvoterinfo.org/)

## SPECIAL PRE-ELECTION ISSUE



## Get Out the Vote '08

This November, citizens across the country will go to the polls to elect the next President of the United States of America. In New Jersey, voters will also be selecting representatives to Congress – each of New Jersey's 13 seats in the U.S. House of Representatives are up for re-election, as are both Senate seats. In addition, New Jerseyans will be asked to consider several ballot questions.

To better prepare citizens with developmental disabilities for the upcoming election, several statewide organizations have developed Get Out the Vote guides.

The New Jersey Council on Developmental Disabilities has developed a new voting resource that outlines accessibility issues and voting rights. The 18-page guide, *Can I Vote? Sure Can...* can be accessed at: <http://www.njcdd.org/publicationupdates/Votingbook.pdf>.

The Arc of New Jersey's 2008 Get Out The Vote booklet provides general voting-related information, lists all the candidates running in this year's election and explains how to get more information about their positions. Visit the Arc's website at <http://www.arcnj.org/> for a copy.

The New Jersey Self Advocacy Project will be sponsoring a Get Out The Vote rally at their conference on September 20th. New Jersey Public Advocate, Ron Chen, will deliver a short keynote presentation about voting. The League of Women Voters will also be on hand to register people to vote, and representatives from the Presidential and Senate campaigns have been invited. For more information, contact The New Jersey Self Advocacy Project office at 732-926-8010.

*The Council has a new voting guide, Can I Vote? Sure Can..." outlining accessibility issues and voting rights for people with disabilities.*



## Presidential Candidates Participate in Disability Forum

On July 26th - the 18th anniversary of the Americans with Disabilities Act – advocates and their allies gathered in Ohio to participate in a National Forum on Disability Issues, featuring the major party Presidential Candidates.

The event gave each candidate an opportunity to present his vision for the future of disability policy in America to this influential voting bloc — more than 40 million people with disabilities are eligible to vote in the U.S.

Republican candidate, Senator John McCain (AZ) participated directly in the event via satellite link. Democratic candidate, Senator Barack Obama (IL), who was traveling outside the U.S. with a Congressional delegation, was represented by Senator Tom Harkin (D-IA). Participants also briefly heard from one of Obama's senior advisors, who shared a story about his son with autism.

Judy Woodruff, news anchor and journalist from The News Hour with Jim Lehrer, moderated the event.

Candidates were asked prepared questions about their positions on employment, health care, long term services and supports, affordable housing, special education, and voting and civil rights.

The event was supported by more than 80 national, regional and local disability organizations including the Association of University Centers on Disability, the National Council in Independent Living, Self Advocates Becoming Empowered, Epilepsy Foundation, The Arc of the United States and United Cerebral Palsy Association.

The forum was simulcast on the web by Disaboom.com to tens of thousands across the country, many of whom hosted viewing parties.

For more information, including a transcript, and the archived webcast, visit <http://www.aapd-dc.org/News/election/peac2008.php>.

To learn more about each candidate's positions on disability issues, please visit their respective websites:



Democrat Barack Obama

<http://www.barackobama.com/issues/disabilities/>



Republican John McCain

<http://www.johnmccain.com/>



## Budget 2009: Congress to Consider Increases in Federal Funding for Family Support

According to the Association of University Centers on Developmental Disabilities, over 80% of all long-term services and supports are delivered informally, yet little funding is provided to support families and other informal caregivers.

As Congress considers the 2009 Federal Budget, advocates are urging that they increase funding for Family Support.

Although there are several important federal family support programs, funding has not kept pace with growing demands and pressures on families.

The National Family Caregiver Support Program (NFCSP) is intended to provide a variety of supports to a range of caregivers, including those providing care to children and adults with disabilities. Funding for the NFCSP has not kept pace with an aging population and actually received a cut last year. The Consortium for Citizens with Disabilities (CCD) has recommended that Congress increase funding to \$250 million for FY 09.

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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.

### The Economics of Caregiving

- The economic value of informal caregiving is valued at over \$350 billion a year.
- American businesses lose between \$17.1 and \$33.6 billion annually in lost productivity costs due to family members providing informal supports.

*(Source: National Family Caregivers Association & Caregivers Alliance, 2006)*

The Lifespan Respite Care Act is intended to provide competitive grants to states to assist states in developing statewide respite systems to make quality respite available to family caregivers regardless of age or disability, but it has not yet received any funding. CCD has recommended that Congress provide funding at the full authorization level of \$53.3 million for FY 09.

Title II of the Developmental Disabilities Act authorizes the Family Support Program to promote and strengthen systems of family support services to families with relatives with developmental disabilities. Currently, only 21 states receive funds through this Act. CCD has recommended that funding for family support be increased from approximately \$7.2 million to \$17 million to allow every state and US territory to receive grants.

Advocates can make their views known by contacting their Congressperson and asking that family support programs be funded at the levels recommended by the Consortium for Citizens with Disabilities (CCD). Members of Congress can be reached by calling the Capitol switchboard at: (202) 224-3124. Advocates may also go to <http://www.c-c-d.org/> for more information and guidance.

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## September is Emergency Preparedness Month

The New Jersey Council on Developmental Disabilities has launched a campaign to better prepare people with disabilities for emergency situations. The month-long effort coincides with National Preparedness Month, co-sponsored by the U.S. Department of Homeland Security and the American Red Cross to encourage individuals to take simple steps to prepare for emergencies.

The initiative includes half-day emergency preparedness training seminars across the state for people with developmental disabilities. Trainers will travel to locations designated by provider agencies. The Council will provide ‘Go Bags,’ supply kits and all training materials. “By taking the time to develop a disaster plan, assemble a supply kit and put together a ‘Go Bag’, individuals will be better prepared when an emergency strikes,” said Jane Dunhamn, Training Coordinator for Emergency Preparedness at the Council.

In addition, the Council has produced a new guide, *Getting Ready for An Emergency*. The 8-page guide can be found at the Council’s website: <http://www.njddc.org/>

For more information, readers should contact Jane Dunhamn, or Frank Latham, at 609-292-3745.

### New Report Available

A new report by the Association of State and Territorial Health Officials addresses the needs of people with disabilities in pandemic situations. *At-risk Populations and Influenza Pandemic: Planning Guidance for State, Territorial, Tribal and Local Health Departments* is a 126-page document with links to resources offering guidance including how to partner with “at-risk” populations and providers, identifying at-risk populations in the community, and involving people with varying abilities in preparedness planning and data. See the document at: [www.astho.org/pubs/ASTHO\\_ARPP\\_Guidance\\_June3008.pdf](http://www.astho.org/pubs/ASTHO_ARPP_Guidance_June3008.pdf).



## Resource Desk

### Family Care Navigator: State-by-State Help for Family Caregivers

For people providing care to a family member or friend with disabilities, navigating the long-term care system can be difficult and confusing. Programs vary from state to state and community to community. Caregivers can spend hours on the phone trying to locate appropriate services. Until now, there has not been one central site for families to find help in their communities. The Family Caregivers Alliance, which takes thousands of calls each year from family caregivers looking for specialized support, has created a new web-based feature to guide them to services and programs designed to help.

The National Center on Caregiving at Family Caregiver Alliance has launched the Family Care Navigator, a first-of-its-kind comprehensive online guide intended to help families in all 50 states and the District of Columbia locate government, nonprofit, and private caregiver support programs.

The resource is at: [http://caregiver.org/caregiver/jsp/fcn\\_content\\_node.jsp?nodeid=2083](http://caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083).

The Navigator lists programs for family caregivers as well as resources for older and disabled adults living at home or in a residential facility. It also includes information on government health and disability programs, legal resources, living arrangements, disease-specific organizations, FAQs, a glossary and more. There is no charge to use the Navigator.

The Family Care Navigator is the newest feature on Family Caregiver Alliance’s website at [www.caregiver.org](http://www.caregiver.org). The site offers caregiving advice, newsletters, fact sheets, research reports, policy updates and discussion.



## Recurso

### Family Care Navigator (Navegador de Cuidado Familiar): Brinda ayuda estado por estado para cuidadores familiares

Para las personas que brindan cuidados a un familiar o amigo con impedimentos, navegar a través del sistema de cuidados a largo plazo puede ser difícil y confuso. Los programas varían de estado a estado y de comunidad a comunidad; los cuidadores pueden pasarse horas en el teléfono tratando de encontrar los servicios apropiados. Hasta este momento, no ha existido ningún lugar central para que las familias encuentren ayuda en sus comunidades. La Family Caregivers Alliance (Alianza de Cuidadores Familiares), que atiende miles de llamadas cada año de cuidadores familiares en búsqueda de apoyo especializado, ha creado una nueva opción basada en la Web a fin de guiarlos a servicios y programas diseñados para brindar ayuda.

El National Center on Caregiving (Centro Nacional de Cuidados a Pacientes) de la Alianza de Cuidadores Familiares ha lanzado el Navegador de Cuidado Familiar, una guía integral en línea, primera en su clase, dedicada a ayudar a las

familias en los 50 estados y el Distrito de Columbia a ubicar programas de apoyo de cuidadores del gobierno, sin fines de lucro y privados. El recurso se encuentra en [http://caregiver.org/caregiver/jsp/fcn\\_content\\_node.jsp?nodeid=2083](http://caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083). El Navegador presenta las listas de programas para los cuidadores familiares así como los recursos para adultos mayores o discapacitados que viven en su hogar o en un servicio residencial. También incluye información sobre programas de salud y discapacidad del gobierno, recursos legales, alojamiento, organizaciones de enfermedades específicas, preguntas frecuentes, un glosario y más. No hay cargos por utilizar el Navegador.

El Navegador de Cuidado Familiar es el programa más reciente del sitio Web de la Alianza de Cuidadores Familiares en [www.caregiver.org](http://www.caregiver.org). El sitio ofrece asesoría, boletines, folletos, informes de investigación, actualización de políticas y debates sobre cuidado.

## Guidance on “Reasonable Modifications” Under the Fair Housing Act

The Departments of Housing and Urban Development (HUD) and Justice (DOJ) have released new guidelines that reinforce the right of people with disabilities to modify buildings in which they live - including common areas - so that they can fully enjoy the premises. The guidance is designed to help housing providers and homeowners' associations better understand their obligations, and help people with disabilities better understand their rights.

The federal Fair Housing Act (FHA) prohibits discrimination in housing based on disability, race, color, religion, national origin, sex and familial status. HUD and DOJ share responsibility for enforcing the law. HUD is the agency with primary responsibility for investigating individual complaints of discrimination.

One type of discrimination that is prohibited is the refusal by housing providers or homeowner associations to permit a structural alteration of existing premises, occupied or to be occupied by a person with a disability, when the modification is necessary to afford the person full enjoyment of the premises. Although the housing provider must allow the modification, the tenant (or prospective tenant) must pay the cost. Examples of reasonable modifications include widening doorways or installing a ramp.

The guidelines are available online at both [www.usdoj.gov/fairhousing](http://www.usdoj.gov/fairhousing) and [www.hud.gov/offices/ftheo/disabilities](http://www.hud.gov/offices/ftheo/disabilities).



# Community Calendar

- September 20 Get Out the Vote Rally, afternoon event at the New Jersey Self Advocacy Conference, Doubletree Hotel, Somerset, NJ. Contact the New Jersey Self-Advocacy Project, 732-926-8010.
- September 25 Public Meeting of the New Jersey Council on Developmental Disabilities, 10:00 am. Lafayette Yard Marriott, Trenton, NJ. Contact NJCDD, 609-292-3745. [www.njcdd.org](http://www.njcdd.org)
- September 26 State Interagency Coordinating Council Meeting, 11:00 a.m. to 1:30 p.m., Medical Society of New Jersey, 2 Princess Road, Lawrenceville, NJ. Contact Terrie Goeke, 609-730-1522, or email [tegoeke@comcast.net](mailto:tegoeke@comcast.net).
- October 8 Meeting of the New Jersey Council on Affordable Housing. Meetings start at 9:30 a.m. , New Jersey Housing and Mortgage Finance Agency, 637 South Clinton Avenue, Trenton.
- October 16 New Jersey State Special Education Advisory Council Meeting, 9:30 a.m., National Conference Center, Holiday Inn, East Windsor, NJ.
- October 23 Ann Klein Advocate Awards Dinner; Community Health Law Project. Contact CHLP, 973-275-1175.
- October 29th National Caregivers Conference: Changing the Face of Caregiving, Sponsored by the Family Support Center of New Jersey, Woodbridge Hotel and Conference Center, Iselin, New Jersey. Keynote: Lee Woodruff, freelance writer and wife of Bob Woodruff. Contact the Family Support Center of New Jersey, 732-528-8080.

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