

**PASS IT ON!**  
**Health Care Policy, Information & Resources**  
**December 12, 2005**

A publication of the  
Family to Family Health Information & Resource Center of Family Voices-New Jersey @ the  
Statewide Parent Advocacy Network  
35 Halsey Street, Newark, New Jersey 07102  
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**This is not intended to serve as a resource for lobbying. It's purpose is to assist families and the professionals working with them to better understand issues and resources related to health care for children and youth with special needs so that they may make informed choice on how to respond in a manner that will best support their needs. Funding for the Family to Family Health Information & Resource Center of Family Voices-NJ @ SPAN comes from the US Department of Health and Human Services Centers for Medicare & Medicaid Services. The views in this publication do not necessarily reflect the views of CMS or SPAN.**

### **Federal Links Information & Resources**

Visit the **Family Voices Legislative Action Center** which can be utilized to send messages to members of Congress. Issues at the present time are the Family Opportunity Act, saving EPSDT and other aspects of Medicaid. It is fast, easy and efficient. If you would like members of Congress to hear from you, visit the Legislative Action Center at <http://capwiz.com/familyvoices/home/>

**Order your 2006 Family Voices calendar today!** Order yours for just \$13 (including shipping) <http://www.familyvoices.org/>

**SURGEON GENERAL RELEASES WEB-BASED FAMILY HEALTH HISTORY TOOL-My Family Health Portrait** is a Web-based tool designed to help families gather and share their health information. The tool, released as part of the U.S. Surgeon General's Family Health Initiative, organizes information into a printout that an individual can use, in partnership with a health professional, to determine whether he or she is at increased risk for six common diseases with a known genetic contribution, and for other conditions that may run in families. Users can highlight certain diseases, such as heart disease or diabetes, and produce personalized diagrams or charts for each family member that can then be used to develop individualized diagnosis, treatment, and prevention plans. The tool is intended for use by individuals, families, and health professionals in understanding the importance of collecting a family health history and in making the process of gathering the information easier and more efficient. The tool is available in both English and Spanish at: <https://familyhistory.hhs.gov>.

**Consumer Guide Available to Assist People with Disabilities in Navigating Medicare Part D Drug Coverage-Understanding Changes in Prescription Drug Coverage for People with Disabilities on Medicare** (Prepared by Jeffrey S. Crowley, Health Policy Institute, Georgetown University, with Bob Williams, Advancing Independence) [www.aapd.com/News/medicaredrugcoverage/downloads/disRxGuide.pdf](http://www.aapd.com/News/medicaredrugcoverage/downloads/disRxGuide.pdf)

**NDSS Invites DS Community to Support The Ringer on Opening Weekend, Dec. 23-25** The National Down Syndrome Society is proud to join the Special Olympics in support of "The Ringer," an upcoming Farrelly brothers film that uses humor to challenge destructive stereotypes of people with intellectual disabilities. "The Ringer" tells the story of Steve Barker, a young man who pretends to have an intellectual disability so he can compete in and "fix" a Special Olympics event. However, Barker's attitude changes as he develops friendships with several of the Special Olympics athletes. He learns, as will moviegoers, that people with intellectual disabilities are more like the rest of us than they are different. The athletes in the film listen to music, play video games, watch the latest movies, and work together toward athletic excellence - all while having fun. Below is a link to an invitation to support "The Ringer" on opening weekend that includes a message from Eddie Barbanell, an actor with Down syndrome who stars in the film.

<http://join.buddywalk.org/site/www.ndss.org/media/pdf/ringer.pdf>

**Testing Accommodations Manual Available:** The Council of Chief State School Officers has just issued a testing accommodations manual. You will find this to be a tremendous resource. a quick review of the contents page will show you how valuable this could be for both you and your school

<http://www.ccsso.org/content/pdfs/AccommodationsManual.pdf>

**No Child Left Behind Act: Improved Accessibility to Education's Information Could Help States Further Implement Teacher Qualification Requirements. GAO-06-25, November 21.** -

<http://www.gao.gov/cgi-bin/getrpt?GAO-06-25> Highlights -

<http://www.gao.gov/highlights/d0625high.pdf>

**Emergency Management and People with Disabilities: Before, During and After-**Congressional Briefing - November 10, 2005 Hosted by The National Council on Disability, the National Council on Independent Living, the National Organization on Disability, the National Spinal Cord Injury Association and the Paralyzed Veterans of America. Read minutes from meeting:

[http://www.ncd.gov/newsroom/publications/2005/transcript\\_emergencymgt.htm](http://www.ncd.gov/newsroom/publications/2005/transcript_emergencymgt.htm)

**Still Going Strong: Head Start Children, Families, Staff, and Programs in 2004** by Katie Hamm and Danielle Ewen. As Congress considers legislation to reauthorize the federal Head Start program, this new policy brief from the Center for Law and Social Policy (CLASP) examines the latest data from the Program Information Reports that all Head Start grantees must submit to the U.S. Department of Health. In 2004, Head Start continued to provide early education services and medical, dental, and mental health screenings for poor children, as well as comprehensive supports for families. The number of teachers with degrees grew substantially in 2004—65 percent of teachers had an Associate's Degree or higher. Less than half of eligible children, however, receive Head Start services. The full report is available online at

[http://www.clasp.org/publications/headstart\\_brief\\_6.pdf](http://www.clasp.org/publications/headstart_brief_6.pdf)

**Families of children with disabilities play a central role in interventions and practitioners need certain skills and knowledge to work effectively with them.** From the FPG Child Development Institute, *Essential Skills for OT Practitioner During Intervention*, sheds light on the expansion of practitioners' roles, the importance of family-centered approaches to intervention, and practitioner skills—including positive communication—that result in successful intervention. Available online at

<http://www.fpg.unc.edu/~images/pdfs/snapshots/snap26.pdf>

**THE CIVIL RIGHTS OF INSTITUTIONALIZED PERSONS ACT: HAS IT FULFILLED ITS PROMISE?"** Published by the National Council on Disability, this report examines the U.S. Department of Justice's (DOJ) enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA), which was enacted by Congress in 1980 to protect the rights of people in state-run nursing homes, mental health facilities, institutions for people with intellectual and developmental disabilities, and correctional facilities for children and adults. For more information, go to <http://www.ncd.gov/newsroom/publications/2005/personsact.htm>

**POPULATION IN STATE INSTITUTIONS ON A STEADY DECLINE ACCORDING TO A NEW STUDY** A 2004 survey of developmental disability agencies and state institutions in the U.S. revealed a steady decline in residents, according to a new study published in the journal, *Mental Retardation*. Read more at [http://www.aamr.org/Reading\\_Room/pdf/LakinMarch05MR.pdf](http://www.aamr.org/Reading_Room/pdf/LakinMarch05MR.pdf)

**NEW STUDY PROBES WHY INSTITUTIONS AND NURSING HOMES ARE MORE PREVALENT IN SOME U.S. STATES THAN OTHERS**—The results of this recent study conclude that a state's political culture determines the prevalence of the use of institutions and nursing homes in the care of persons with developmental disabilities. The study can be found at <http://www.uic.edu/orgs/rrtcamr/NursingHomeStudy.pdf>

**COMMUNITY FOR ALL TOOL KIT**—This tool kit was developed at the request of volunteers, advocates, self-advocates, and professionals concerned that the remarkable progress made towards the inclusion of people with cognitive, intellectual and developmental disabilities into the fabric and mainstream of community life in America was at risk. This tool kit provides the philosophy, policy and research rationale that supports community supports and services for all people with disabilities, in the context of their families, their communities and their country. For more information, go to <http://thechp.syr.edu/toolkit/>

**Home Sick: How Medical Debt Undermines Housing Security**—Nearly half of the low- and moderate-income taxpayers surveyed in seven cities nationally reported having medical debt, which threatened their housing security. That's according to a new report from the Access Project. [http://www.accessproject.org/medical.html#md\\_housing](http://www.accessproject.org/medical.html#md_housing)

**The Public Health Informatics Institute** has recently updated the project webpage for a project designed to advance public health's ability to develop integrated child health information systems that support program goals and objectives. These programs include newborn dried blood spot screening, hearing screening, vital records, and others. Some of the useful resources available from the website include a framework for public health practitioners to assist in more effectively integrating their child health information systems and a checklist to assist project managers in assessing which of the principles and core functions are incorporated into their integrated information system and where they need to be focusing their efforts. <http://www.phii.org/CoreFunctions.html>

**Medicaid's Fragile Beneficiaries:** On Capitol Hill, the debate over cutting the nation's social programs is framed in sums so vast as to become abstract. But barely two miles away, within the small, bright, preschool classrooms of a childhood development center, there is no dispute about the usefulness of every federal dollar. *The Washington Post*, 11/18/05

## Other Activities, Opportunities and Information

From *Reuters*: **Heavy Teen Girls Risk Metabolic Syndrome**, 11/25/05 - Researchers report in *Pediatrics* that adolescent girls who carry excess weight around the middle and who have high levels of harmful triglycerides are at increased risk of developing the so-called metabolic syndrome--a cluster of heart disease and diabetes risk factors such as excess body weight, high blood pressure, high blood sugar, and high cholesterol levels.

From *HealthDay News*: **Parental Control Affects Teen's Depression**, 11/25/05 - British researchers report in the journal *Child Development* that parental discipline, life events, and social interactions can all contribute to a teen's risk for depression, regardless of his or her genetic makeup.

From *WebMD*: **Neglected Tots: Brain Hormones Lowered**, 11/21/05 - According to a study published in the *Proceedings of the National Academy of the Sciences*, neglected babies may have lower levels of brain hormones tied to social bonding. But those children can still develop satisfying relationships, researchers stress.

**The Fine Art of Helping At-Risk Kids**-Powerful emotions like anger can become a major roadblock to learning. Art therapy is one approach to helping kids manage those feelings and be successful. Letitia Star reports on an art therapy program in Chicago.

<http://www.connectforkids.org/node/3729>

**Let's Connect Web Site**-<http://www.letsconnect.org/> This web site was created by young people with chronic illnesses for young people with chronic illnesses. It provides forums, links to information about conditions and programs, and Dear Connect where users can write to the site's creators, and more.

**Handling Your Child's Medical Issues:**

<http://specialchildren.about.com/od/medicalissues/index.htm?nl=1>

**Handling Your Child's Behavior Issues:**

<http://specialchildren.about.com/od/behaviorissues/index.htm?nl=1>

**Handling Your Child's Developmental Issues:**

<http://specialchildren.about.com/od/developmentalissues/index.htm?nl=1>

**Handling Your Child's Learning Issues:**

<http://specialchildren.about.com/od/learningissues/index.htm?nl=1>

**Handling Your Child's Mental Health Issues:**

<http://specialchildren.about.com/od/mentalhealthissues/index.htm?nl=1>

**Programs Aim to Stop 'Cyber Bullying'** -Laura Ascione, eSchool News, November 29, 2005

<http://bridges4kidsnewsdigest.c.topica.com/maaehi4abmBqwcjcSyFbafpLKt/>

Schoolyard bullies are becoming increasingly high tech, as a growing number of students now engage in "cyber bullying" by spreading rumors through web sites or harassing students through text messages.

**Free Downloadable Letter of Intent Form - An 88 Item Checklist Showing Parents How to Communicate their Wishes and Knowledge about their Son or Daughter with a Disability to Future Caregivers**-Attorney L. Mark Russell

<http://bridges4kidsnewsdigest.c.topica.com/maaehi4abmBq5cjcSyFbafpLKt/> How can you, as a parent, be assured that your son or daughter will lead as complete a life as possible after your death? What can you do to make sure your hopes and aspirations are realized? Writing a letter of intent is a critical step in the planning process. This critical document permits parents to communicate vital information about their son or daughter to future caregivers.

**Free Bullying Prevention and Youth Safety Webinars**- On **December 15**, at 1 pm ET, the National Youth Violence Prevention Resource Center will sponsor a webinar entitled "**Keeping Kids Safe.**" The webinar will focus on the primary causes of injuries and death among children and youth ages 10-24, and ways to prevent these occurrences.

<http://genesys.on24.com/r.htm?e=16402&s=1&k=BB78A419F9B99E832D8AAFC41A870B3A>

## Upcoming Events

For information on additional events, go to [www.thetrainingcalendar.org](http://www.thetrainingcalendar.org).

### DECEMBER, 2005

December 14, 10:15-noon, 684 Hoes Lane West, Piscataway. Dr. Susan Hammerman presents **Self-Direction in Developmental Disabilities Services: Implications for Public Health**. Understand the basis for shifting disability services towards self-direction in community living; become familiar with the NJ systems change towards self direction through Real Life Choices for people with developmental disabilities; identify some of the impacts of self-direction on health and social services. Register online at

<https://ophp.umdnj.edu/wconnect/wc.dll?acecode%7EGroupCatalog%7EGROUP%7EEMPHS%7EPublic+Health+Seminar+Series%7ESEM>.

December 15. **Research to Practice: Building the Evidence-Base for Systems of Care for Children's Mental Health**. Register at

[http://gucchd.georgetown.edu/programs/ta\\_center/tacalls.html](http://gucchd.georgetown.edu/programs/ta_center/tacalls.html)

December 16-20, Marriott Wardman Park Hotel, Washington DC. **Annual Head Start Parent Training Conference**. December 15-16 **Enhanced Building Blocks for Father Involvement**.

December 17-18 **Parent Involvement Conference**. December 19-20 **Intensive Head Start Governance Training**. Check out [www.nhsa.org/training/parent/index.htm](http://www.nhsa.org/training/parent/index.htm).

### JANUARY 2006

January 3, 10-12, Perinatal Cooperative, 2600 Mount Ephraim Avenue, Suite 401. **Welcome to Early Intervention** seminar. RSVP to Southern Regional Early Intervention Collaborative, at 856-768-6747.

January 3, 1-3, Perinatal Cooperative, 2600 Mount Ephraim Avenue, Suite 401. **Transition to Preschool** seminar. RSVP to Southern Regional Early Intervention Collaborative, at 856-768-6747.

January 9-11, Washington DC. **National Leadership Summit on Eliminating Racial & Ethnic Disparities in Health**, sponsored by US Department of Health & Human Services Office of Minority Health. Contact [www.OMHSummit2006.org](http://www.OMHSummit2006.org).

January 11, **Forum on Community Engagement**, sponsored by the Maternal & Child Health Bureau, US Department of Health and Human Services. CyberChat 1/16-1/20/06. Call 202-966-5557 x 206 for more information or RSVP with name, phone, email, and organization to [joleary@geneticalliance.org](mailto:joleary@geneticalliance.org).

January 11, 7-9 p.m. 100 Edgewood Road, Linden. Linden Educational Association for Parents and Professionals Presents **NCLB workshop** by SPAN. Contact Joann Fruciano at 908-486-2615 or [jmfm24@comcast.net](mailto:jmfm24@comcast.net) or Tirrell Martin, 908-275-0773 or [autism\\_advo@yahoo.com](mailto:autism_advo@yahoo.com).

January 11, 7:30-9:30 pm, Presbyterian Church of W. Caldwell, 31 Fairfield Avenue (corner of Ravine), W. Caldwell. Creating Choices for Children of Caldwell presents Gary Mayerson, Author of **How to Compromise with your School District without Compromising Your Child**. RSVP by 12/10 to Janine 973-403-7887, [jjnovak@comcast.net](mailto:jjnovak@comcast.net) or Pam 973-364-0717, [Pamela.Donovan@us.kline.com](mailto:Pamela.Donovan@us.kline.com).

January 23, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, **Managing Behavior During Daily Routines**. Presented by Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

January 26-28, **Health Action 2006 Grassroots Conference** presented by Families USA: The Voice for Healthcare Consumers. Mayflower Hotel, D.C.

## FEBRUARY 2006

February 6, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, **Increasing Independence in your Child with Autism**. Presented by Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

## MARCH 2006

March 8-9, Portland Marriott Downtown Waterfront. **National Conference on Post-School Outcomes for Youth With Disabilities**. Check out [www.psocenter.org](http://www.psocenter.org).

March 13, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, **Improving Social Skills of your Child with Autism**. Presented by Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

March 19-21, Historic Mills House, Charleston, SC. **Accommodating Students with Disabilities on state Assessments: What Works?**, Sponsored by the College Board, National Institute for Urban School Improvement, Council for Exceptional Children, and Educational Testing Service.

March 26-29, Chicago, Family Support America's 11<sup>th</sup> Biennial International Conference. For more information, go to [www.familysupportamerica.org](http://www.familysupportamerica.org) or 312-338-0900.

#### APRIL 2006

*April 7-8, Ramada National Conference Center, East Windsor, 8:30-4. Advocacy for Children is not a Spectator Sport! Annual Conference of the Statewide Parent Advocacy Network. Go to [www.spannj.org](http://www.spannj.org) for more information.*

April 24, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, **Making the Most of Play Time for your Child with Autism**. Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

April 28, 29, 30, May 1, 2006: Washington, DC Metro Area, **Infancy and Early Childhood Training Course**. Taught by Stanley I. Greenspan, M.D. and Serena Wieder, Ph.D. Brochure and registration materials available in January, 2006. For more information call 301-320-6360 or visit <http://www.stanleygreenspan.com/>.

#### MAY 2006

*May 6, 8:30-4, Ramada National Conference Center, East Windsor. Annual Conference of the NJ Inclusive Child Care Project. Contact Denise Bouyer at 973-642-8100 x 112 or go to [www.spannj.org](http://www.spannj.org) for more information.*

May 8, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, **Autism and Sibling Relations**. Presented by Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

#### JUNE 2006

June 28-29, Montgomery High School (near Princeton), **Summer Inclusion Conference 2006" The Keys to Inclusion: Unlocking the Doors for Children with Mild to Significant Disabilities**, NJ Coalition for Inclusive Education. Contact 732-613-0400 or [njcie@comcast.org](mailto:njcie@comcast.org).

#### JULY 2006

July 12-15, Orlando, Florida. **2006 National Training Institutes of the National TA Center for Children's Mental Health**. For more information, go to [http://qucchd.georgetown.edu/programs/ta\\_center/index.html](http://qucchd.georgetown.edu/programs/ta_center/index.html). Alice Hunnicutt will attend.

#### NOVEMBER 2006

November 10-12, ICDL (The Interdisciplinary Council on Developmental and Learning Disorders) **10<sup>th</sup> Annual Conference**.