

October 10  
Edition

Statewide Parent Advocacy Network  
35 Halsey Street, Newark, NJ 07102 (800) 654-SPAN [www.spannj.org](http://www.spannj.org)

## PASS IT ON HEALTHCARE POLICY

*Pass It on...Health Care Policy* is brought to you by the Family to Family Health Information & Resource Center/Family Voices at the Statewide Parent Advocacy Network (SPAN) to share resources, information, and activities regarding care for children with special health care needs.

### STATE LINKS, INFORMATION, & RESOURCES

SPAN offers many workshops in areas close to you, including our county-based Basic Rights in Special Education; Health Advocacy; and Transition to Adult Life workshops. Check out our website, [www.spannj.org](http://www.spannj.org) for SPAN workshops, and [www.thetrainingcalendar.org](http://www.thetrainingcalendar.org) for workshops and conferences offered by other organizations around the state. Contact Silvia Pavon, Training Administrator, at 973-642-8100 x 116 for more information.

**Emotional Support:** Would you like to speak with a parent of child who has your child's disabilities for emotional support? Call NJ Statewide Parent-to-Parent at 973-642-8100 x 125.

**Health:** Want help for your child with special health care needs? Contact Family Voices at 973-642-8100 x 110.

### CHANGES TO STATE SPECIAL EDUCATION CODE! PARENTS' VOICES MUST BE HEARD!

The NJ Board of Education is considering changes to the state special education code in response to changes in the federal Individuals with Disabilities Education Act. Parents have a chance to make sure that parents and children with disabilities in New Jersey don't lose critical protections, such as short-term objectives; stay-put for students involved in discipline issues; having team members at IEP meetings and making sure changes aren't made without a meeting; etc. The Statewide Parent Advocacy Network (SPAN) has an on-line survey that you can complete at [www.spannj.org](http://www.spannj.org). There is also an on-line petition at [www.StrongIdeaNJ.org](http://www.StrongIdeaNJ.org).

November 16: Public hearing at the NJ Board of Education, 100 Riverview Plaza, Trenton, 3 pm.

December 19: Draft state special education code changes published in NJ Register

December 21: Public hearing on proposed regulations

March 15: Final public hearing on proposed regulations, 100 Riverview

It is VERY IMPORTANT that families participate in these hearings! For more information, contact Martha Brecher at 800-654-SPAN x 114. The action alert can also be found at [www.spannj.org](http://www.spannj.org).

### SAVE THE DATES!

**Parents of young children!** Come to a community meeting for child health and early learning on Saturday, October 15 from 8:30 a.m. to 12:30 p.m. in Newark, New Brunswick, or Camden. Learn more about what's available for your child and how you can help build a better future for all New Jersey children! Contact Denise Bouyer, 973-642-8100x108. The forum is sponsored by the Early Childhood Comprehensive Systems Grant of the NJ Department of Health, whose mission is to implement an accessible, comprehensive, culturally competent early care, health and education system that informs and empowers families and caregivers and supports the needs of young children.

**Train the Trainer on accessing health coverage and health services for children with special healthcare needs**, October 25, 10-2, East Brunswick Public Library. Register with Silvia Pavon at SPAN, 973-642-8100 x 116.

**Train the trainer on the changes to federal and state accountability and monitoring under IDEA 2005** for parent leaders, advocates, and SPAN staff and volunteers ONLY, October 26, 9:30-3, Ramada Inn in East Windsor. Lunch will be provided. Register with Silvia Pavon at SPAN, 973-642-8100 x 116.

**SPAN Annual Statewide Conference:** Friday-Saturday, April 7-9, National Conference Center/Ramada Inn, East Windsor. Stay tuned for more details!

**Annual Conference of SPAN's NJ Inclusive Child Care Project**, Saturday, May 6. More to follow!

**RESOURCES** (Many thanks to the NY Family to Family Health Resource Center/NY Parent to Parent for these resources of interest to families!)

**1. Advocacy 101 - items that help strengthen advocacy skills -**

**(Communication skills, parenting skills, letter writing, speaking with professionals, asking questions)**

<http://hctransitions.ichp.ufl.edu/ddcouncil/> - Health care transition is a process that takes time and planning. This site has been developed as a learning resource for people in the process of transition

<http://ppal.net/> - PAL provides support, education, and advocacy around issues related to children's mental health.

[http://www.ldsuccess.org/parent\\_guide.html](http://www.ldsuccess.org/parent_guide.html) - This guide is based on over 20 years of research conducted by the Frostig Center in Pasadena, California. The research traced the lives of individuals with learning disabilities in an attempt to identify factors that predicted successful life outcomes.

**2. Financing issues - health insurance and other ways to finance the costs of needed services (including Grievances, denials and appeals - i.e. Strategies for Appealing Health Plan Decisions)**

<http://hschange.org/CONTENT/776/> - Initial Findings from HSC's 2005 Site Visits: Stage Set for Growing Health Care Cost and Access Problems

<http://coveringkidsandfamilies.org/> - The Covering Kids & Families Communications Team offers materials, free of charge, to assist in your efforts to enroll children in NJ's Medicaid and Family Care programs.

**3. 504 Accommodation Plans related to Health Conditions (i.e. what are the legal obligations of schools to provide health-related services and therapies? Accommodations needed for equal access)**

<http://jeffcoweb.jeffco.k12.co.us/isu/504/5042.html> - overview of Section 504

<http://www.advocatesforchildren.org/pubs/504guide.doc> - Q&A for parents about Section 504

**4. Who helps with what? Which state agencies are involved in health care and health coverage? What do medical and managed care terms mean? What should families look for in selecting a provider? What questions should families ask?**

[WWW.HOSPITALCOMPARE.HHS.GOV](http://WWW.HOSPITALCOMPARE.HHS.GOV) - Consumers across the U.S. will be able to see more about how well their local hospitals are performing with new information now available at the Hospital Compare.

<http://www.medicare.gov/> The consumer-oriented website will now report on steps that hospitals take to prevent surgical infections and will reflect up to four quarters of data from 2004. The website has been updated and improved by the Centers for Medicare & Medicaid Services and the Hospital Quality Alliance (HQA).

<http://www.cms.hhs.gov/medicarereform/factsheets.asp> - fact sheets on different programs available to families.

<http://www.cms.hhs.gov/partnerships/news/mma/qsandas.pdf> - info on Medicare prescription drug coverage.

**5. Parent-to-parent support skill-building (How can parents provide support and assistance to families without substituting their judgment? Understanding and respecting cultural diversity. How can parents be culturally competent in working with diverse families? How can parents emotionally support, inform, and educate parents so that they are strong, knowledgeable, and confident in caring for their child?)**

<http://www.lib.uchicago.edu/~rd13/hd/coping.html> - coping with caregiver grief

<http://massfamilyties.org/healthcorner/tenminut.html> - making the most out of the 10 minute office visit.

**6. Keeping Records is a learned skill. Parents will learn what kinds of records are important and how to record necessary information. Your child's health care providers rely on your records to help them make sound medical recommendations.**

<http://www.aap.org/advocacy/blankform.pdf> - Blank Emergency form from American Academy of Pediatrics

[http://www.fifionline.org/images/PDF Files/fifi\\_emsc\\_form.pdf](http://www.fifionline.org/images/PDF%20Files/fifi_emsc_form.pdf) - record keeping for emergencies

**7. Parent-professional collaboration strategies. How can families work with their health care provider to secure quality care and coverage for their child? How can health care providers and families communicate more effectively? What are effective health advocacy strategies? What is a "medical home" and how can parents access it for their child with special health needs?**

<http://massfamilyties.org/healthcorner/medhome.html> - fact sheet on what a medical home is

<http://www.kidsource.com/NICHCY/parents.groups.dis.all.3.1.html> - article on how vital the support of parents supporting parents is.

**8. Understanding Medicaid funded Waiver Services (Including the philosophy of individual and family-centered supports)**

<http://www.cms.hhs.gov/map> - The Centers for Medicare & Medicaid Services website has a chart of the benchmark plans that dual eligible people with both Medicare and Medicaid coverage will be auto assigned to

<http://www.lhcr.org/html/bene/rights.shtml> - understanding your rights under Medicare

[http://www.kff.org/medicaid/benefits/state\\_main.jsp](http://www.kff.org/medicaid/benefits/state_main.jsp) - Medicaid benefits compared by State.

[http://www.kff.org/medicaid/benefits/service\\_main.jsp](http://www.kff.org/medicaid/benefits/service_main.jsp) - Benefits by service - you can click on a selected service to learn how it compares across all states.

**9. Legal information - what are the rights of children to medical coverage under Medicaid, SCHIP, fee-for-service coverage. How can families use complaint, arbitration, and grievance procedures to resolve disputes? What are the legal obligations of schools to provide health-related services and therapies?**

E-MAIL: [mkogan@hrsa.gov](mailto:mkogan@hrsa.gov) - from Michael Kogan, Maternal and Child Health Bureau, you can e-mail him directly and request hard copies of the journal supplement, in limited quantities on HEALTH CARE NEEDS . The National Survey of Children with Special Health Care Needs: Using State-Level Data to Improve Systems of Care for Children, a special supplement to the June 2005 issue of the Maternal and Child Health Journal, includes articles from 11 states about how they have used the 2001 survey findings to improve programs or policies for children with special health care needs (SHCN). The issue also includes articles that examine (1) whether rates of functional limitations are associated with access to care, (2) methods for comparing state outcomes for children with SHCN, and (3) the use of survey data in meetings with program managers and policy makers.

<http://www.healthinschools.org/ejournal/2005/apr1.htm> - Courts Say States Must Improve Services to Medicaid Children

### Other links

<http://www.usd.edu/cd/autism/Autism%20Handbook.pdf> - an extensive, informative handbook that should not be limited to Autism. Is useful for many different children with special needs.

[http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=275484](http://www.cmwf.org/publications/publications_show.htm?doc_id=275484) - Preventive Care for Young Children: Problems and Solutions-A new report reveals that just 57 percent of parents with young children report ever discussing their child's development with a pediatrician. Its authors call for national standards for preventive care, enhanced reimbursement, better provider training, and parent education.

<http://www.efmoody.com/directory2.html> - yellow pages of websites for families with someone/any family member with any type of special needs

<http://www.cgc.state.ny.us/newsletter/news1.htm> - Commission on Quality of Care and Advocacy for Persons with Disabilities Newsletter

### Upcoming Workshops & Support Groups of Interest

Bereavement support group for families who have experienced the loss of a baby or a young child; Third Wednesday of every month, 10-12, at NJ Dental School, 110 Bergen Street, Room B 839, Newark. Contact Jan Hader, LSW, 800-545-7437, or Gladys Martinez, LSW, 973-972-5458.

#### OCTOBER, 2005

October 1 and for seven consecutive Saturdays, 10 am - 12:30 p.m., Lawrenceville, Mercer County. Free Family education course, Visions for Tomorrow, for caregivers and family members of children and adolescents with emotional, behavioral, and/or brain disorders. FREE. Call 609-799-8994.

October 3 and for seven consecutive Mondays, 7-9:00 pm, NAMI Burlington County Visions for Tomorrow family education course for caregivers and family members of children and adolescents with emotional, behavioral, and/or brain disorders. FREE. 774 Eayrestown Rd., Lumberton. Register with Kathy Burke, Family Support Organization, 609-265-8838.

October 5 and for seven consecutive Wednesdays, 7-9:30 pm, NAMI Burlington County Visions for Tomorrow family education course for caregivers and family members of children and adolescents with emotional, behavioral, and/or brain disorders. FREE. 774 Eayrestown Rd., Lumberton. Register with Kathy Burke, Family Support Organization, 609-265-8838,

October 10 and for seven consecutive Mondays, 7-9:30 pm, NAMI Hunterdon County Visions for Tomorrow family education course for caregivers and family members of children and adolescents with emotional, behavioral, and/or brain disorders. FREE. 91 Center Street, Clinton. For more info or to register, contact Ino at 908-236-8619.

October 11, 2-3:30 p.m. What Families need to know about behavior problems and positive behavior support: Demanding quality supports for our sons & daughters. Featuring Sue Swenson of National ARC & Nancy Weiss of TASH. Register online at <http://www.tash.org/teleconferences/pbs/index.htm>. \$25.

October 11, 7:30 p.m., Coleman Elementary School Library, 100 Pinelynn Road, Glen Rock. Math Disabilities & Coping Strategies for Elementary School Students, presented by the Special Services Advisory Council of Glen Rock. Featuring Dr. Teresa Montai, Fairleigh Dickinson University. Free.

October 11th, 6:30 p.m. – 8:30 p.m., Seabrook Village Senior Center, Town Square Music/ Classroom (second floor), 3000 Essex Road. SPAN Peer Consultant Training. To Register, contact: Lynn Muller-Guiser at 732-933-1202, [lmullerguiser@spannj.org](mailto:lmullerguiser@spannj.org) or Janet Kimble at 732-928-4142, [janetkimble@spannj.org](mailto:janetkimble@spannj.org).

October 12, 7-9 p.m., Ellen DeRosa of NJ Department of Banking & Insurance presents to Parents of Special People on the Mental Health Parity Act, what insurance companies are required to do by law, and what your rights and responsibilities are as a member of your insurance company. 1 Crest Way, Aberdeen. Directions at <http://www.marsd.org>.

October 12, 1:30-3 p.m., Evaluating English Learner Services & Results for Accountability & Instructional Improvement Online Webinar, WestEd's English Learner Evaluation & Accountability Support program. Powerpoint presentation & conference call. Participate via web telecast or teleconference. (Web telecast requires access to an internet connection & phone line at the same time.) Sign up at <http://wested.schoolsmovingup.net/>. Click on "Events" tab at top of page, choose appropriate session, and select "Sign up." For more information, call Julie Duffield at 415-615-3213 or [jduffie@wested.org](mailto:jduffie@wested.org), or Kenwyn Derby at 510-302-4265 or [dwilson@wested.org](mailto:dwilson@wested.org).

October 14, 8:30-noon, Middlesex County Fire Academy, 1001 Fire Academy Drive, Sayreville. Middlesex County Mobilizing for Action through Planning & Partnership Coalition 1<sup>st</sup> Annual Kick-Off Event addressing public health issues. Breakfast will be served. Contact Padma Arvind at 732-745-3140 or [padma.arvind@co.middlesex.nj.us](mailto:padma.arvind@co.middlesex.nj.us).

October 14, 2-3:30 pm. Advocating to eliminate the use of aversives, seclusion, and the inappropriate use of restraint. Featuring Pat Amos of the Family Alliance of NJ, Jane Hudson, Pat Hunt, and Jamie Ruppman of TASH. Register online at <http://www.tash.org.teleconferences/pbs/index.htm>. \$25.

October 15, 9 am to 2 pm, Collingswood Community Center. Public Policy Advocacy training and the New IDEA. Featuring Peg Kinsell. \$15. Call Dianne Malley at 856-858-5675 or email at [dislicpa@aol.com](mailto:dislicpa@aol.com).

October 18, 19 & November 29: Essential Lifestyle Planning II: Process Facilitation and Plan Writing. 9:30 am - 3:30 p.m. each day. New Brunswick. Free. Register at 732-235-9325 or <http://rwjms.umdnj.edu/boggscenter>.

October 19-20, all day, NJ Coalition for Inclusive Education presents a clinic featuring Carol Tashie on Facilitating Friendships at the Unitarian Society, 176 Riders Lane, East Brunswick. \$130; discounts for teams featuring a parent & educator or two or more educators. Download registration form at [www.njcie.org](http://www.njcie.org) under "Workshops." Fax the registration form to 732-390-7697 to reserve a space. Call NJCIE at 732-613-0400.

October 19, Transition from School to Adult Life, 7-8:30 p.m. Merchantsville, NJ Sponsored by Family Support Organization. Contact Sue Doherty-Funke, 856-662-2600.

October 20. Expanding Partnerships in Systems of Care: Substance Abuse and Mental Health Working Together. Register at [http://gucchd.georgetown.edu/programs/ta\\_center/tacalls.html](http://gucchd.georgetown.edu/programs/ta_center/tacalls.html).

October 20, Arc of Monmouth, 1158 Wayside Road, Tinton Falls. Transition from HS to Adult Life: Find your Future. Featuring Lorraine D'Sylva Lee, DDD Director of Transition, on what's happening within DDD including traditional services and self-directed services. Students are encouraged to attend for workshops on Preparing a Resume & Basic Interview Skills and Where Am I Going? How am I getting there? RSVP to Joan Nufrio, 732-493-1919 x 663.

**October 22 Conference for parents of children with disabilities.** The Montclair Community Pre-K is sponsoring *Abling & Empowering Parents of Children with Learning Disabilities* on Saturday, October 22 at 22 Valley Road from 8:30 am-noon. There will be workshops for parents of children from pre-school age through eighth grade on a variety of topics including how to tell if your child has a learning disability, navigating the school system, advocacy and political action and parenting children with learning disabilities. The conference fee is \$10.00/person for Montclair Community Pre-K families, \$15.00/person for the general public and \$10.00/child for childcare. Contact Patty Dow at 973-509-4500 x29 or [pdow@montclairprek.com](mailto:pdow@montclairprek.com).

October 22, 8:45 am - 3:30 pm, 9<sup>th</sup> Annual Cherry Hill Free Fall Conference for Parents of Children with Special Needs, Cherry Hill Community Center, 820 Mercer Street, featuring workshops on recent changes to special education laws; transitions from early intervention to preschool, preschool to elementary school, elementary to middle school, middle to high school, and HS to adult life. Free breakfast and lunch. For information or to register, call 609-488-7868.

October 24, 1 pm, Monmouth Library, 125 Symmes Drive, Manalapan, Department of Human services Central Regional Budget forum.

October 24, 7:30 p.m. Education Funding. Hosted by Cando Parents, Harrison School Building, Gray Road, Caldwell. Contact Pam Donovan at 908-403-5789.

October 25, all day, Tenth Annual Conference on Guardianship, NJ Law Center, 1 Constitution Square, New Brunswick. Sponsored by the Guardianship Association of New Jersey. \$40 for family members. Contact GANJI at 877-GUARDNJ (973-927-5714) or [www.ganji.org](http://www.ganji.org).

October 27, 10 am, UMDNJ, School of Osteopathic Medicine, Academic Center, East Laurel Road, Stratford. Department of Human Services Southern Regional Budget Forum.

October 28, 8 am - 4 p.m., Hilton Woodbridge Iselin, ASPEN Fall Conference, It's Not Just Academic: Effective Intervention Strategies for Parents and Teachers of Students with Asperger Syndrome and Related Disorders, featuring DR. Ross Green, author of *The Explosive Child*, Rebekah Weinrichs, author of *Perfect Targets*, and Dr. Robert Hendren. See [www.aspennj.org](http://www.aspennj.org) for additional information and registration form.

October 31, 10 am, Morris County Cultural Center, 300 Mendham Road, Mendham, Northern Regional Department of Human Services budget forum.

## NOVEMBER, 2005

November 1, 2-3:30 p.m. Schoolwide approaches to positive behavior supports. Featuring Rob Horner. Register online at <http://www.tash.org/teleconferences/pbs/index.htm>. \$25.

November 3-4, Family Support Center Annual National Family Caregivers Conference, Taj Mahal, Atlantic City. Contact Jaqueline Moskowitz, 800-372-6510 or visit [www.fscnj.org](http://www.fscnj.org). An annual event that focuses on caregiving, respite, education, autism, family supports, mental health and much more. This conference will host over 30 workshop sessions, informational exhibits and inspirational speakers. Scheduled keynote speaker for Thursday, Nov. 3rd will be author Lee Ann Thieman, author of "Chicken Soup for the Caregiver". Keynote speaker for Friday, Nov. 4th will be Trisha Meili, better known as "The Central Park Jogger". For more information, go to [www.NationalCaregiversConference.org](http://www.NationalCaregiversConference.org) today!

November 5, 8 am to 2 p.m., Summit Overlook Hospital. Social Skills Training & Frustration Management for Preschool to HS Students with Autism Spectrum Disorders & Social-Behavior Problems, featuring Dr. Jed Baker, Director of the Social Skills Training Project. Contact 908-522-2000. Register by October 29. Email Beth at [bethsklarbaker@aol.com](mailto:bethsklarbaker@aol.com) for more information.

Sunday, November 6, 2 p.m., Fall Advocacy Training Workshop featuring Rachelle Milstein, Esq. Logos Chapel, Rutgers Community Christian Church, 71 Cedar Grove Lane, Somerset. Free. Contact Chinese Autism Resource Center at 848-391-5668.

November 15, 7-9:30 p.m., Bloomfield Town Hall, 1 Municipal Plaza, Council Chamber, 2<sup>nd</sup> Floor, Bloomfield. SPAN's Basic Rights in Special Education, featuring Penny Dragonetti. Register on line at [www.spannj.org/training](http://www.spannj.org/training) or call Silvia Pavon at 973-642-8100 x 116. FREE!

November 16. Transition from School to Adult Life. 7-8:30 p.m. Gloucester Township Branch Library. Hosted by Family Support Organization. Contact Sue Doherty-Funke at 856-662-2600.

November 16, 7-9 p.m., NJ Law Center, 1 Constitution Square (off Ryders Lane), New Brunswick, Everything You Always Wanted to Know about Special Education: Parents' & Schools' Rights & Responsibilities. Featuring Rebecca Spar, Michaelene Loughlin, and David Giles, Esq. Contact Florence Nathan, NJ Bar Foundation, at 1-800-FREE LAW or [www.njsbf.org](http://www.njsbf.org).

November 17. Research to Practice: Setting the Context for Evidence-Based Practices in Systems of Care. Register at [http://gucchd.georgetown.edu/programs/ta\\_center/tacalls.html](http://gucchd.georgetown.edu/programs/ta_center/tacalls.html).

November 18-20, Transforming Systems through Youth and Family Leadership, Annual Conference of the Federation of Families for Children's Mental Health. Renaissance Hotel, Washington DC. \$300. SPAN will send up to 2 staff people to this conference. Penny Dragonetti, Alice Hunnicutt, and Dorothy Taylor will represent SPAN at this conference.

## 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/>

**New Fact Sheet Describes Wide Variation in Child Poverty Rates Among States, Racial Groups, and Age Groups.** The second fact sheet in National Center for Children in Poverty's new series portrays the 12 million children who live in families with incomes below the federal poverty level and the 5 million children who live in families with only half that income and how rates differ widely across the states. [Read the fact sheet.](#)

**New Resource on Transportation and Youth/Adults with Disabilities-** "Impact: Feature Issue on Meeting Transportation Needs of Youth and Adults with Developmental Disabilities" is a new publication from the Institute on Community Integration, University of Minnesota that offers strategies for meeting these and other transportation needs of youth and adults with disabilities. This summer issue of the quarterly newsletter is available online at <http://ici.umn.edu/products/newsletters.html#various>.

**A child-friendly version of the new MyPyramid Food Guidance System** was unveiled by Agriculture Secretary Mike Johanns. Resources for MyPyramid for Kids are available at: <http://www.mypyramid.gov/>

**Social Security Benefit Eligibility Screening Tool for SSI & SSDI.** The Social Security Administration provides a simple web-based tool to see if a child might be eligible for benefits. The Benefit Eligibility Screening Tool (BEST) is a tool that you can use to find out if you could be eligible for benefits from any of the programs Social Security administers. This tool will give you eligibility information based on answers you give to the questions on the following pages; however, BEST is not an application for benefits. <http://www.ssa.gov/best>

**CMS writes: We need your help to reach people with Medicare.** The Centers for Medicare & Medicaid Services (CMS) is implementing Medicare prescription drug coverage that will begin on January 1, 2006. After 40 years of providing dependable coverage for doctor visits, hospital stays and life-saving surgeries, Medicare now covers new preventive screenings and in a few short months, dependable coverage for prescription drugs. Links to publications that may be printed or ordered with general background information on Medicare prescription drug coverage [http://www.cms.hhs.gov/medicarerereform/91007\\_MedicareBrochure.pdf](http://www.cms.hhs.gov/medicarerereform/91007_MedicareBrochure.pdf)  
<http://www.cms.hhs.gov/medicarerereform/11142IntroMedRx.pdf>  
<http://www.cms.hhs.gov/medicarerereform/DrugCovisavailEnglish.pdf>

A link to a series of fact sheets and tip sheets on specific topics:  
<http://www.cms.hhs.gov/medicarerereform/factsheets.asp>

**Alliance for Participation Medicaid Document-Going Forward, Medicaid Policy Must Statement of Principles:**  
[http://join.buddywalk.org/site/R?i=A3WFGZOTrBqjHK2\\_w9mlA..](http://join.buddywalk.org/site/R?i=A3WFGZOTrBqjHK2_w9mlA..)

**Make A Difference: A Guidebook for Person-Centered Direct Support-**By John O'Brien & Beth Mount with contributions from Peter Leidy & Bruce Blaney. Can be ordered from Inclusion Press for course adoption, in-service training, team quality improvement, supervision, & self-study. [http://join.buddywalk.org/site/R?i=LfA2IOE-TOAI\\_haTySdv8w..](http://join.buddywalk.org/site/R?i=LfA2IOE-TOAI_haTySdv8w..)

Continued next page

**How to Find Your Disability Rights and Information**-<http://www.disabilityinfo.gov/>,  
<http://dir.yahoo.com/Government/Law/Disability/>, <http://www.access-board.gov/>  
National Business & Disability Council: <http://www.nbdc.com/>  
Alliance for Human Research Protection: <http://www.ahrp.org/>

**SUPPLEMENTAL EDUCATIONAL SERVICES TOOL KIT**-The Supplemental Educational Services (SES) Quality Center recently published a free tool kit for parents and community leaders to inform them of the opportunities for getting extra academic help for children. Under No Child Left Behind, children from low-income families in Title I schools that have not made adequate yearly progress for three years may sign up for supplemental educational services. The SES in Action tool kit provides strategies, tips and tools for finding free tutoring services for eligible children. The SES in Action tool kit is available online at <http://join.buddywalk.org/site/R?i=oLf-s-Rcmz6VAuxX7hPaIq..> or by calling toll-free (866) 544-8686, while supplies last

**Web-based Health Care Transition Training Program for Youth and Families**-We are pleased to announce that Health Care Transition Training Program for youth and families has been completed and is now available on the Web at <http://join.buddywalk.org/site/R?i=-NiEh25Nos1wjIz9ckKQww..> . This site has been developed by the Institute for Child Health Policy with funding from the Florida Developmental Disabilities Council to help young people with disabilities and their families with the process of planning for and successfully completing a transition to adult oriented medical services.

**The National Center of Medical Home Initiatives for Children with Special Health Care Needs**-Extreme Web site Makeover - Checkout the New Features at <http://www.medicalhomeinfo.org/>

**The Center for Personal Assistance Services** provides research, training, dissemination and technical assistance on issues of personal assistance services (PAS) in the United States. Personal assistance services (PAS) refer to help provided to people with disabilities to assist them with tasks essential for daily living. These tasks include bathing, dressing, getting around, toileting, eating, shopping, remembering things, and other activities. PAS, along with assistive technology such as wheelchairs, text readers, and hearing aides, help people with disabilities to participate in activities at home, at work, and in the community. A PDF version of this newsletter can be found at <http://join.buddywalk.org/site/R?i=TcgF1wSOWCRZ9tkKRdr8Qg..>

**The Social Security Administration (SSA) published a final rule addressing the reinstatement of entitlement to disability benefits.** This rule implements a provision of the Ticket to Work and Work Incentives Act of 1999 (TTWWIA), allowing the reinstatement of eligibility for people whose entitlement benefits have been terminated because of employment but are unable to work at the Substantial Gainful Activity (SGA) level. The new regulation becomes effective on October 31 and can be read at:  
<http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/pdf/05-19529.pdf>.

**Beach Center on Disability Fall 2005 Newsletter** - Human Genome Project. The Beach Center on Disability announces the arrival of its fall 2005 e-newsletter, which focuses on the Human Genome Project. You'll also find Interviews, Groups, and Books, as well as Tips. The Fall '05 Newsletter is available here:  
<http://www.beachcenter.org/news/default.asp?id=68>

Continued next page

**Family Voices National [Families Helping Families - Hurricane Relief Fund](#)** In the aftermath of Hurricane Katrina, children and youth with special health needs and their families face unique and difficult challenges. The Centers for Disease Control has estimated that there are at least 99,000 children with special health care needs in Mississippi, 193,000 in Louisiana, 488,000 in Florida, and 152,000 in Alabama. Donate through [PayPal](#) or send your donation through the mail to Family Voices, 2340 Alamo SE, Suite 102, Albuquerque, NM. Family Voices will funnel your dollars to our volunteer family leaders "on the ground" in the affected states. We promise that 100% of your donations will go to help families and their children and youth. Your donations will pay for items and services our leaders have learned are needed - things such as anti-bacterial wipes, diapers, phone cards, medical care, cash for medications, gas and food, rent, toys, and clothing. Or send your contribution to SPAN for our Katrina Evacuee Project, providing training and one-on-one support and technical assistance to families living in New Jersey who have been displaced from Louisiana and Mississippi. Send your tax-deductible contribution to SPAN, 35 Halsey Street, Newark, NJ 07102, and mark it "Katrina Project."

The latest edition of the *State of the States in Developmental Disabilities* study by David L. Braddock contains a detailed analysis of mental retardation and developmental disability spending, including a 4-page statistical profile for each state on trends in spending, trends in revenue, trends in residential services, and individual and family support. visit <http://www.responsetrack.net/lnk/aamr563910/?11S9N02X4E1>

**WHAT WORKS IN TRANSPORTATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL ISSUE OF A NATIONAL NEWSLETTER.** Transportation is one of the most pressing concerns of people with disabilities. The latest issue of *Impact*, a quarterly newsletter from the Institute on Community Integration in Minnesota contains success stories from around the country on what has worked in transportation of adults with developmental disabilities. <http://www.responsetrack.net/lnk/umn563914/?11S9N02X4E1> to read the newsletter.

**Families Make Connections Count** - You can find ideas here on how to participate in the national family week celebration as a family, or with a group of neighbors or friends. <http://www.nationalfamilyweek.org/families.htm>

**The Covering Kids & Families Communications Team** offers materials, free of charge, to assist in efforts to enroll children in your state's Medicaid and State Children's Health Insurance (SCHIP) program. <http://coveringkidsandfamilies.org/>

**Medicaid Benefits Online Database-** [http://www.kff.org/medicaid/benefits/service\\_main.jsp](http://www.kff.org/medicaid/benefits/service_main.jsp)

**National Center on ADHD-**has a wealth of information for families and providers to access: <http://help4adhd.org/index.cfm>

**IDEA 2004 Resources-**<http://www.ed.gov/policy/speced/quid/idea/idea2004.html> Continued next page

## **ACTIVITIES, OPPORTUNITIES and OTHER**

### **Medical Research News for Parents - ADHD Can Impair Kids' School, Social, and Family Lives**

According to the Centers for Disease Control (CDC), about 8% of U.S. children have been diagnosed with attention deficit hyperactivity disorder. ADHD doesn't just interfere with schoolwork - it can affect a child's family life, mental health, and overall well-being. [http://www.kidshealth.org/research/ADHD\\_kids.html](http://www.kidshealth.org/research/ADHD_kids.html)

**"Baby-Friendly" Hospitals Boost Newborn Breastfeeding Rates**-Despite the benefits of nursing, many new moms don't do it, so some hospitals and birthing centers across the United States have taken steps to encourage breastfeeding in new mothers. [http://www.kidshealth.org/research/baby\\_friendly\\_hospitals.html](http://www.kidshealth.org/research/baby_friendly_hospitals.html)

**Internet Safety**-The Internet can be a wonderful resource for kids. They can use it to research school reports, communicate with teachers and other kids, and play interactive games. Any child who is old enough to punch in a few letters on the keyboard can literally access the world. But that access can also pose hazards to your children. [http://www.kidshealth.org/parent/positive/family/net\\_safety.html](http://www.kidshealth.org/parent/positive/family/net_safety.html)

**Homework Overload?** Having trouble getting a handle on all of your homework? Get your work space set, your schedule organized, and your studying done with the help of this article.

[http://www.kidshealth.org/teen/school\\_jobs/school/homework.html](http://www.kidshealth.org/teen/school_jobs/school/homework.html)

**Good Friends**-This section offers advice on how to help friends with problems from cutting, addictions, eating disorders, and more. [http://www.kidshealth.org/teen/school\\_jobs/index.html](http://www.kidshealth.org/teen/school_jobs/index.html)

**What Kids Say About: Handling Stress**-A KidsPoll was done to find out what kids do when they feel upset and stressed. See what they had to say. [http://www.kidshealth.org/kid/talk/kidssay/poll\\_stress.html](http://www.kidshealth.org/kid/talk/kidssay/poll_stress.html)

**Cystic Fibrosis**-There was an article about CF in Sept. 12 issue of Newsweek Magazine. The article is available on line: <http://www.msnbc.msn.com/id/9189605/site/newsweek/>

**"Moose: A very special person"** In this book a father tells the true story of his son, who was born with Down Syndrome. <http://www.qualitymall.org/products/prod1.asp?prodid=2299>

**"Just Another Kid"** This book tells the story of the children with autism and other disabilities. The story is told by their teacher, Torey Hayden <http://www.qualitymall.org/products/prod1.asp?prodid=2300>

**Halloween Costumes for Children Who Use Wheelchairs**-this is a really neat website that has many costumes that can be made for kids...have a look

[http://www.bridgeschool.org/about/about\\_halloween.html](http://www.bridgeschool.org/about/about_halloween.html)

**Publication from NY to help families understand Section 504-**

<http://www.advocatesforchildren.org/pubs/504guide.doc>

**Learn Something New: Osler-Weber-Rendu Syndrome** also known as Hereditary Hemorrhagic Telangiectasia (HHT) <http://bridges4kidsnewsdigest.c.topica.com/maad4qyabkYnUcjcSyFbafpLKt/>

**Promoting father involvement in early childhood-**

[http://www.friendsnrc.org/downloads/Male\\_participation\\_in\\_Early\\_Childhood.pdf](http://www.friendsnrc.org/downloads/Male_participation_in_Early_Childhood.pdf)

