

**PASS IT ON!**  
**Health Care Policy, Information & Resources**  
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A publication of the  
Family to Family Health Information & Resource Center of Family Voices-New Jersey @ the  
Statewide Parent Advocacy Network  
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For more information and resources, go to [www.spannj.org](http://www.spannj.org)!

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.

## POVERTY

The National Center for Children in Poverty (NCCP) has developed a profile of how your state is "improving the odds for the healthy development and school readiness of young children." This profile looks across systems to identify if and how your states is promoting health and nutrition, early care and education, and parenting and economic supports. You can view a draft of your state's profile at: [http://nccp.org/ec\\_profiles.html](http://nccp.org/ec_profiles.html).

## EARLY CHILDHOOD

*A Parents Guide to Newborn Screening DVD*-The March of Dimes announces the release of their new DVD on Newborn Screening, *A Parent's Guide to Newborn Screening*. The DVD explains what newborn screening is, its purpose, the testing procedure, and what parents need to do if retesting is necessary. DVD is ideally suited for use with women in their 3rd trimester. Each DVD has 2 segments - one in English and one in Spanish. Runtime for each is approximately 5 minutes. DVD item #09-2099-06 and price = \$20.00/DVD. To order call: 1-800-367-6630. March of Dimes also offers a Newborn Screening pamphlet in English (#09-1976-05) and Spanish (#09-2042-06) that complements this DVD.

**Genetics:** <http://www.nccrcg.org/regional.asp> - In 2004, the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), Genetic Services Branch (GSB) awarded grants to support the Heritable Disorders Program by establishing a national coordinating center (NCC) and seven Regional Genetic and Newborn Screening Services Collaboratives (RCs). The purpose is to fund national and regional activities to improve the health of children and their families by promoting the translation of genetic medicine into public health and healthcare services and to improve access to newborn screening and genetic services and the quality of those services.

The October/November issue of *Preschool Matters*, from the National Institute for Early Education Research, includes an article about the National Center on High Quality Personnel in Inclusive Early Childhood Settings, a new initiative recently launched at the Frank Porter Graham Institute. Go to <http://nieer.org/resources/printnewsletter/OctNov2006.pdf> and see page 3.

**Brief Explores EPSDT's Role in Early Childhood Comprehensive Systems-*Maximizing the Use of EPSDT to Improve the Health and Development of Young Children* reviews research about Medicaid; the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program; and young children and the role of EPSDT in Early Childhood Comprehensive Systems (ECCS). The brief by the National Center for Children in Poverty examines the role of EPSDT in financing early childhood services such as newborn screening, early intervention, home visiting, and early childhood mental health treatment and how ECCS leaders across the country are working to ensure access to health care and a medical home for all young children. State EPSDT performance rates and interagency collaborative efforts to improve EPSDT performance in the context of ECCS are discussed. Tips for states and federal guidance for the EPSDT child health benefit under Medicaid are also presented. The brief is available at <http://nccp.org/media/tst06b.pdf>.**

**Pathways to Early School Success:** Helping the Most Vulnerable Infants, Toddlers, and Their Families - Research demonstrates that all low-income babies, toddlers, and families can benefit from child development and family support programs, such as Early Head Start. However, there are babies, toddlers, and parents who face so many risks that these programs alone may not be enough. This issue brief describes 10 strategies that can help these most vulnerable families and promote early school success even in the face of multiple demographic, economic, and parental risk factors, such as depression and trauma. For more information and to access the report, go to [http://www.nccp.org/pub\\_pew06e.html](http://www.nccp.org/pub_pew06e.html)

**Importance of Play in Promoting Healthy Child Development-**A recent report from the American Academy of Pediatrics (AAP) emphasizes the importance of free and unstructured play for helping children reach social, emotional, and cognitive developmental milestones, as well as helping them manage stress and develop resilience. To see the full press release and access the report online go to <http://www.aap.org/pressroom/play-public.htm>

Two reports from the Commonwealth Fund examine strategies for improving the delivery of developmental services to children in their first three years of life: ***Beyond Referral: Pediatric Care Linkages to Improve Developmental Health*** explores how pediatric practices link young children and their families to community-based developmental services and support. It describes promising strategies undertaken by a variety of primary care practices, as well as by community and statewide programs, to help providers identify children with developmental needs and link them to appropriate services. ***State Policy Options to Improve Delivery of Child Development Services: Strategies from the Eight ABCD States*** provides guidance on how states can improve policy to promote developmental services and highlights strategies to improve coverage, reimbursement, and performance by physicians and others who provide developmental services to young children. [http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=430649&#doc430649](http://www.cmwf.org/publications/publications_show.htm?doc_id=430649&#doc430649)  
[http://www.cmwf.org/publications/publications\\_show.htm?doc\\_id=434687&#doc434687](http://www.cmwf.org/publications/publications_show.htm?doc_id=434687&#doc434687) .

**Rotavirus Vaccine Now Recommended for Infants**-Will now be included in the lineup of routine immunizations given to all infants. [http://www.kidshealth.org/research/rotavirus\\_vaccine.html](http://www.kidshealth.org/research/rotavirus_vaccine.html)

**The CDC has launched a new initiative involving child care providers in a public awareness campaign to identify children with possible problems in child development.** The campaign is called "Learn the Signs - Act Early." Learn more about the campaign and order a FREE Child Care Provider Resource Kit at [www.cdc.gov/actearly](http://www.cdc.gov/actearly).

## **HEALTH COVERAGE & HEALTH CARE**

**A High-Performing System for Well-Child Care: A Vision for the Future**-In the new Commonwealth Fund report, [A High-Performing System for Well-Child Care: A Vision for the Future](#), Stanford University's David Bergman, M.D., and colleagues present a model for effective, efficient well-child care, as well as a guide for future policy and research efforts. Their ideal well-child system would include advanced access to services, such as systems to allow parents to make same-day appointments, as well as team-based care and individualized developmental and behavioral screening. As envisioned by the authors, each child's care would be coordinated through a "medical home," aided by tools for information and knowledge transfer. These would include a personal health record that each family could use to engage in secure electronic communications with their clinicians, view test results and visit summaries, input health information, and share information with other health care professionals.

**Estimating the Impact of State Implementation of the Family Opportunity Act**-Passed as part of the Deficit Reduction Act of 2005, the Family Opportunity Act (FOA) allows states the option of extending income eligibility and creating a buy-in program to expand Medicaid coverage to children with severe disabilities who have family incomes up to 300% of the Federal Poverty Level (FPL). The Catalyst Center has just released a technical brief— [Methodology for Estimating the Impact of State Implementation of the Family Opportunity Act](#)—to be included when sharing first round estimates on FOA implementation with policy makers and key stakeholders in your state. The [Catalyst Center](#) is a national center funded by the Maternal Child Health Bureau to help the Bureau achieve measurable progress towards the national goals related to children and youth with special health care needs (CYSHCN) by ensuring that all families of CYSHCN have access to adequate public and/or private insurance to pay for the services they need. Visit their [website](#) to learn more. Look for their FAQ on FOA to be posted there soon!

**The Emergency Medical Services for Children (EMSC) Program** is pleased to announce the launch of its new website located at: <http://mchb.hrsa.gov/emsc>. Special features of the new site include: (1) a toolbox highlighting information about specific topics, such as pediatric pain management, pediatric disaster preparedness, and pre-hospital education; (2) up-to-date EMSC News items; and (3) a navigation bar providing quick links to helpful information, such as state activities, funding opportunities, and EMSC products and resources. Take time today to visit the new website and to see all the information now available to support grantees, health professionals, and families regarding pediatric emergency care issues. Please note that the old EMSC website ([www.ems-c.org](http://www.ems-c.org)) no longer exists. All individuals linking to the old address will be automatically transferred to the new site.

**Medicaid & SCHIP**-To compare your state's Medicaid program and the population it serves to other states and the nation, visit Kaiser's interactive online State Medicaid Fact Sheets tool. State Medicaid Fact Sheets - <http://www.kff.org/mfs/index.jsp>.

**Understanding why Medicaid is so important to children with disabilities-Kaiser Commission on Medicaid and the Uninsured is Profiles of Medicaid's High Cost Populations** See the full report at <http://www.kff.org/medicaid/upload/7565.pdf>

**Services for Younger Grandparent Caregivers-** The Older Americans Act Amendments of 2006 amended the Caregivers Support Program of the Social Security Act to lower the age limit for grandparent caregiver programs from 60 to 55. The program provides Federal support for State programs that provide older caregivers training, respite care, and other services through the National Family Caregiver Support Program (NFCSP) and gives priority to caregivers caring for children with severe disabilities. The text of the Act is available at [http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109\\_cong\\_bills&docid=f:h6197enr.txt.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_bills&docid=f:h6197enr.txt.pdf).

**Maternal and Child Health: History, Legacy and Resources for Education and Practice**-The Maternal and Child Health Bureau, in collaboration with the University of South Florida, Johns Hopkins University, and the University of Washington, developed a new Web site, Maternal and Child Health: History, Legacy and Resources for Education and Practice. The site traces the history of maternal and child health in the US, and provides in-depth modules on topics such as the Maternal and Child Health Systems of Care and Infant Mortality. Narratives provide an overview of the topic, including historical perspectives, current issues, and rich reading and web resources. The site also allows you to search for topical areas of interest. To learn more, please go to: <http://www.mchb.hrsa.gov/timeline>.

**Approving Quality and Achieving Equity: The Role of Cultural Competence in Reducing Racial and Ethnic Disparities in Health Care** The Commonwealth Fund presents a new report addressing cultural competency in health care. To learn more visit: [www.cmwf.org/usr%5Fdoc/Betancourt%5Fimprovingqualityachievingequity%5F961.pdf](http://www.cmwf.org/usr%5Fdoc/Betancourt%5Fimprovingqualityachievingequity%5F961.pdf).

**The Maternal Oral Health Resource Guide** comprises journal articles, materials, and organizational information aimed at improving oral health guidance and care for women who are pregnant. The guide, published by the National Maternal and Child Oral Health Resource Center, is divided into three sections. The first section lists journal articles appearing in the published literature between 2004 and 2006. The second section lists materials, including books, reports, surveys, manuals, pamphlets, and brochures. The third section lists advocacy organizations, federal agencies, policy centers, professional associations, resource centers, and voluntary organizations that may serve as resources. The guide is available at <http://www.mchoralhealth.org/PDFs/maternalguide.pdf>.

**Medicaid Commission Report:** In May 2005 the Secretary of the Department of Health and Human Services, Michael O. Leavitt, established a Medicaid Commission to advise the Secretary on ways to modernize the Medicaid program so that it can provide high-quality health care to its beneficiaries in a financially sustainable way. On December 29, 2006 the Commission issued its final report, which can be found at <http://aspe.hhs.gov/medicaid/122906rpt.pdf>.

### **The Medicare Medicaid Relationship-**

[http://www.cms.hhs.gov/MLNProducts/downloads/Relationship\\_Brochure.pdf](http://www.cms.hhs.gov/MLNProducts/downloads/Relationship_Brochure.pdf)

**Social Security Benefits for Children with Disabilities-** <http://www.ssa.gov/pubs/10026.html>

**Career Planning Begins with Assessment: A Guide for Professionals Serving Youth with Educational & Career Development Challenges.** This guide is for the workforce development system as it assists youth in making decisions and choices based on appropriate assessments that focus on their individual talents, knowledge, skills, interests, values, and aptitudes. It covers selecting career-related assessments, determining when to refer youth for additional assessment, and issues such as accommodations, legal issues, and ethical considerations. Administrators and policymakers will find information on developing practical and effective policies, collaboration among programs, and interagency assessment systems. It can be downloaded in Adobe PDF at <http://ncwd-youth.info/assets/guides/assessment/AssessGuideComplete.pdf> and in Microsoft Word at <http://ncwd-youth.info/assets/guides/assessment/AssessGuideComplete.doc>.

**Social Security Information-**Information about the Supplemental Security Income (SSI) disability program is at <http://www.socialsecurity.gov/notices/supplemental-security-income/>.

Information about Social Security disability is at <http://www.socialsecurity.gov/disability/>.

Electronic forms to help in applying for either program are at

<http://www.socialsecurity.gov/applyfordisability/>. The final rule establishing a new disability determination process is available at [www.socialsecurity.gov/disability-new-approach](http://www.socialsecurity.gov/disability-new-approach).

### **ADOLESCENCE/TRANSITION TO ADULT LIFE**

**All-Youth Task Force for the Youth Information, Training & Resource Center, KASA-Family Voices:** KASA is looking for teens with disabilities between the ages of 13 and 18 to serve on the KASA Task Force. The KASA Youth Information, Training and Resource Center Task Force gives advice and opinions to the KASA Advisory Board and staff about what information and training youth with disabilities need. We review documents to make sure young people can understand them and to make sure they are helpful. The Task Force learns new skills on monthly calls from community members, and from each other. We help KASA educate society about issues that affect young people with disabilities. If you have any questions, or would like more information please contact Naomi at 520-881-4672, or email at: [naomiortiz01@msn.com](mailto:naomiortiz01@msn.com).

**The National Adolescent Health Information Center** has released two updated fact sheets containing the most recent available data on suicide and mortality among adolescents and young adults (ages 10-24). The 2006 fact sheets, produced with support from the Maternal and Child Health Bureau, highlight key findings and present data on mortality and suicide rates (in color-coded figures and text) by age, gender, cause, and race and ethnicity. Information about the data sources and other notes are also included. The 2006 Fact Sheet on Suicide: Adolescents & Young Adults is available at <http://nahic.ucsf.edu/download.php?f=/downloads/Suicide.pdf>; the 2006 Fact Sheet on Mortality: Adolescents & Young Adults is available at <http://nahic.ucsf.edu/download.php?f=/downloads/Mortality.pdf>. A list of other NAHIC-produced briefs and fact sheets is available at [http://nahic.ucsf.edu/index.php/data/article/briefs\\_fact\\_sheets](http://nahic.ucsf.edu/index.php/data/article/briefs_fact_sheets).

**E-adolescence-The National Initiative to Improve Adolescent Health** by the Year 2010 (NIIAH) provides a listing of online resources for state maternal and child health professionals who are working to improve the health of adolescents. To learn more visit:  
[www.cdc.gov/HealthyYouth/NationalInitiative/index.htm](http://www.cdc.gov/HealthyYouth/NationalInitiative/index.htm).

**Annual Review Reports for State Vocational Rehabilitation Agencies:** The Rehabilitation Services Administration (RSA) has published the Annual Review Reports for fiscal year 2005. Visit this link and click on Annual Review Reports for FY 2005 to view reports on all 80 state VR agencies.  
[http://wdcrobcolp01.ed.gov/CFAPPS/RSAMIS/de.cfm?form\\_id=107&mode=list&fy=2005](http://wdcrobcolp01.ed.gov/CFAPPS/RSAMIS/de.cfm?form_id=107&mode=list&fy=2005)

**Youth with Mental Health Needs:** The National Conference of State Legislators and National Collaborative on Workforce and Disability for Youth has issued "A Difficult Passage: Helping Youth with Mental Health Needs Transition into Adulthood" on current state strategies for improving outcomes for youth with mental health needs; it's available at  
<http://www.ncsl.org/programs/health/forum/youthmentalneeds.htm>.

**The National Initiative to Improve Adolescent Health by the Year 2010 (NIIAH)** provides a listing of online resources for state maternal and child health professionals who are working to improve the health of adolescents. To learn more visit:  
[www.cdc.gov/HealthyYouth/NationalInitiative/index.htm](http://www.cdc.gov/HealthyYouth/NationalInitiative/index.htm).

**Ready by 21, a Forum for Youth Investment initiative,** has released an action brief on preparing youth for work. The brief highlights work related disparities related to family income, race, and education. Attention is given to states with innovative programs which have aligned business and higher education communities with high school standards and workforce skills demands; which are holding high schools accountable for job readiness; which have collocated and integrated youth services and alternative schools for easier access to career development and career ladder programming. Information about the project and the brief can be found at  
[http://www.forumforyouthinvestment.org/catdisp\\_page.cfm?LID=93C0AD70-FCEC-4F38-837E17F6DE20DC7F](http://www.forumforyouthinvestment.org/catdisp_page.cfm?LID=93C0AD70-FCEC-4F38-837E17F6DE20DC7F).

**Special Needs Trusts:** Benefits issued by the government cannot always provide for the basic necessities of life, and parents won't always be present to care for their kids. A valuable solution is a Supplemental Needs or Special Needs Trust (SNT), which can be established with the help of an attorney. The SNT allows families safely to put away money for their children without affecting the money the child receives from the government because the trust is set up in another person's name with the individual with the disability named as the beneficiary. For more detailed information on a Special Needs Trust, see the following website:  
<http://www.altonweb.com/cs/downsyndrome/index.htm?page=feetrust.html>

**Hands-On Banking-**Developed by Wells Fargo as a free public service, this innovative, entertaining program is available in Spanish and English and contains no commercial content. The curriculum is designed for self-paced, individual learning for kids, teens and adults. It may also be used in the classroom and with community groups. The lessons are narrated, animated, colorful, and fun! For more information go to <http://www.handsonbanking.org> or <http://www.elfuturoentusmanos.org>

**Financial Literacy**-Research shows that low educational attainment, employment expectations and confusing governmental programs with conflicting eligibility criteria have resulted in many young people with disabilities not making successful transitions from school to postsecondary education, employment and independent living. "Financial Literacy Information for Young People with Disabilities" discusses various state and federal initiatives for individuals with disabilities and their families to become more economically self-sufficient. The Brief includes descriptions of financial literacy programs and additional resources. For more information go to <http://www.ncwd-youth.info/resources & Publications/information Briefs/issue16.html>

## **ACADEMICS & LEARNING**

**Helping Your Gradeschooler With Homework**-Homework is your child's responsibility, so you should stay out of the way, right? Not necessarily. With a little support from you, homework can be a positive experience for your child.

[http://www.kidshealth.org/parent/positive/learning/help\\_gradeschooler\\_homework.html](http://www.kidshealth.org/parent/positive/learning/help_gradeschooler_homework.html).

**Toolkit on Teaching and Assisting Students with Disabilities**-The U.S. Department of Education strives to expand educational opportunities and to improve instruction for all students. The Office of Special Education and Rehabilitative Services (OSERS), the Office of Elementary and Secondary Education (OESE), and the Institute for Education Sciences (IES) are collaborating and linking their programs together to support states' efforts to improve instruction and assessment of all students with disabilities. To support this initiative, the Department has developed a *Tool Kit on Teaching and Assessing Students with Disabilities (Tool Kit)*, which offers a compilation of current information that will move states forward in improving results for all students with disabilities. The Tool Kit will be added to over time to include more information designed to support states' efforts and to communicate the results of research on teaching, learning, and assessments. To view the toolkit, visit: <http://www.osepideasthatwork.org/toolkit/index.asp>

**The Johns Hopkins University Center for Data-Driven Reform has launched a free online Web site, Best Evidence Encyclopedia (BEE).** The new site gives educators and researchers unbiased researched-based information about such topics as mathematics, comprehensive school reform, education service providers, technology in reading and math, and reading for English Language Learners. The site can be found at <http://www.bestevidence.org/>

## **MENTAL HEALTH, SOCIAL-EMOTIONAL DEVELOPMENT, BULLYING**

**Bullying and Your Child**-Kids who are bullied often experience low self-esteem, and those doing the bullying may go on to engage in more serious antisocial behaviors. What is bullying and what can you do about it? <http://www.kidshealth.org/parent/emotions/behavior/bullies.html>. The law is clear about a school district's obligation to prevent harassment of students and take action when it occurs, and now parents and advocacy groups are delivering a loud message to school officials and other policymakers that children should not have to endure ugly bullying at school as an inevitable rite of passage. Go to <http://www.nsba.org/site/docs/39100/39055.pdf> for more information.

**Wetting Problems May Be Linked to Behavioral Issues**—Dealing with urinary incontinence at school can be emotionally challenging for kids and may be linked to an increased risk of psychological problems, researchers say. [http://www.kidshealth.org/research/wetting\\_behavior.html](http://www.kidshealth.org/research/wetting_behavior.html)

**National Anti-Stigma Campaign:** What a Difference a Friend Makes is designed to decrease the negative attitudes that surround mental illness and encourage young adults (ages 18-25) to support their friends who are living with mental illness. The Web site was launched by the Ad Council and the Substance Abuse and Mental Health Services Administration in partnership with other federal agencies, state mental health agencies, leading researchers on stigma, and a broad coalition of stakeholders. Content is based on research demonstrating that the prevalence of serious mental illness among young adults (ages 18-25) is almost double that of the general population, and that this age group shows the lowest rate of help-seeking behaviors. The site includes tools to help in the recovery process, information about different kinds of mental illnesses, true stories about support and recovery, and an interactive video about how friends can make a difference. A search tool is provided to help locate mental health services by state and territory. The Web site also contains public service announcements for television and radio that illustrate how friendship may be the key to recovery. The resources are intended for use by health professionals and others working to minimize future disability by broadening social acceptance and ensuring that young adults with mental illness receive the early support and services they need. The Web site is available at <http://www.whatadifference.samhsa.gov>.

**Perceptions of Depression, ADHD, and Stigma Among Youth 8-18:** Approximately one in ten American children and youth experience a behavioral, emotional, or mental health disorder that could be identified and treated. Stigma associated with mental illness can dissuade young people and their families from seeking help. Staff at the Research and Training Center on Family Support and Children's Mental Health at Portland State University collaborated with a group of young adult advisors and the research firm, Harris Interactive, to produce two surveys focusing on perceptions of mental health difficulties and on the stigma associated with these difficulties among children and youth aged 8-18. A nationally representative sample of more than 1,300 U.S. children and teenagers responded to one survey, which was conducted online by Harris Interactive this June. An additional survey, conducted by Harris Interactive in August, gathered similar information from more than 3,600 adults. The press release can be found at <http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=1095>

**Mental Health Update: Mental Illness Myths and Facts**—Mental illnesses are very common. They are also widely misunderstood. People with mental illnesses are frequently stigmatized by others who think it's an uncommon condition. The truth is, mental illness can happen to anybody. This information has recently been updated, and is now available - [http://www.whatadifference.samhsa.gov/learn.asp?nav=nav01\\_1&content=1\\_1\\_mythsfacts](http://www.whatadifference.samhsa.gov/learn.asp?nav=nav01_1&content=1_1_mythsfacts) . Please visit the Mental Health - <http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=151> section of DisabilityInfo.gov for a more comprehensive list of resources on this subject.

## **COMMUNITY & SCHOOL INCLUSION; SELF-DETERMINATION**

**Coalition for Community Integration:** The mission of this Coalition is to assure that people with disabilities have a right to long term services and supports in their own homes and communities, that they can stay out of and leave institutional and congregate settings if they wish to, and they can exercise their rights to be as independent as they want to be. For more information go to [http://www.ciprg.com/ul/bsitf/CCI\\_brochure.doc](http://www.ciprg.com/ul/bsitf/CCI_brochure.doc)

**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/>

**State of the States in Developmental Disabilities-**How well are we moving towards the goal of ending, as the Supreme Court stated in Olmstead, unnecessary institutionalization in the DD community? Braddock's 2005 State of the States in Developmental Disabilities (for FY 2004) - <http://www.cu.edu/ColemanInstitute/stateofthestates/> provides an opportunity to measure where we are and to compare states.

**Consumer-Controlled Budgets-**In a nation founded on the promise of securing "the blessing of liberty" for all, people with disabilities have found themselves often forced to exchange their personal freedoms for the services and support they need. Unwilling to accept that the need for support is incompatible with personal freedom, growing legions of individuals with disabilities, their families, advocates, public officials, and service providers have developed and promoted new ways of increasing the control that people with disabilities have over their own lives and futures. This publication from the Institute on Community Integration and Research and Training Center on Community Living can be found at <http://ici.umn.edu/products/impact/171/default.html>

## **FAMILY SUPPORT & STRENGTHENING; TIPS FOR EFFECTIVE PARENTING**

**"You're so smart. Why don't you just do it?"** Does the title sound familiar? How many times parents have we thought this about our child, and maybe even said this to our child? Probably more times than we care to admit! Think of the child who can state that he should hand in his homework but chronically fails to do so, or the child who goes to her room with every intention of getting dressed for school, only to still be in her pajamas 20 minutes later! This article will attempt to explain why "just doing it" is more complicated than it may seem and how we can help children learn to "do it." <http://bridges4kidsnewsdigest.c.topica.com/maaftoiabvuhJcjcSyFbafpLKt/>

**Parenting Information Handouts** - Dozens of handouts containing information on General Parenting Information, Specific Concerns/Problems, Discipline/Intervention Strategies, Injury Prevention, Parental Involvement in Education, and Children's Development. <http://bridges4kidsnewsdigest.c.topica.com/maaftoiabvuhKcjcSyFbafpLKt/>

## FAMILY PROFESSIONAL COLLABORATION

**Family Voices is pleased to announce that two new reports are now available: Families in Program and Policy FiPPs MCH Report and Families in Program and Policy FiPPs CSHCN Report.** These reports summarize interviews conducted by parent leaders with state Title V MCH and CSHCN Directors/Staff, regarding participation of families in their program and policy activities. Such activities include advisory committees, addressing state performance measures, special initiatives, the Block Grant process, in-service trainings, and families employed as program staff. These reports provide extensive quantitative and qualitative information on the progress of family leader participation in Title V. Hardcopies of these reports (\$3.00/ea) may be ordered through the [Family Voices Online Catalog](#) or by calling the Family Voices National Office at (505) 872-4774. Copies may also be downloaded at <http://www.familyvoices.org/projects/fipps.php>.

## CHILD WELFARE AND FOSTER CARE

**Comparing Instruments for Family Assessment in Child Welfare Services** Source: Children's Bureau Express - December 14, 2006 Valid and reliable instruments can help caseworkers with family assessment by structuring the collection of information and ensuring that relevant categories of information are included. A recent study evaluated 85 family assessment instruments to identify those that are comprehensive, valid and reliable, and practical for use in child welfare settings. For more information go to [http://cbexpress.acf.hhs.gov/articles.cfm?issue\\_id=2006-11&article\\_id=1242](http://cbexpress.acf.hhs.gov/articles.cfm?issue_id=2006-11&article_id=1242)

**Foster Children Exempt from DRA Verification Requirements**-A provision included in the Tax Relief and Health Care Act of 2006 (H.R. 6111) exempts foster children and children receiving adoption assistance from new citizenship verification requirements established under Medicaid. These requirements were included in regulations issued by the Centers on Medical Services (CMS) as a result of the Deficit Reduction Act, passed last February

## SPECIFIC DISABILITIES AND HEALTH CONCERNS

**Down Syndrome**-Last year, studies published in *Pediatrics* and *American Journal of Obstetrics and Gynecology* revealed that often parents are given outdated, depressing information related to Down syndrome. One of the many recommendations coming out of the studies was that when physicians explain Down syndrome to parents, sensitive, accurate and consistent messages must be conveyed. To help physicians, The National Down Syndrome Congress ([www.ndsccenter.org](http://www.ndsccenter.org)) has created a new brochure that provides accurate medical information presented in a positive manner. To obtain a complimentary copy of this brochure, please contact Sue Joe at [sue@ndsccenter.org](mailto:sue@ndsccenter.org), or 800/232-6372. The NDSC also has other free materials on topics such as dual diagnoses, educational best practices, advocacy and independent living.

**Osgood-Schlatter Disease**-Osgood-Schlatter disease (OSD) is far less frightful than its name. Though it's one of the most common causes of knee pain in adolescents, it's really not a disease at all, but rather an overuse injury. <http://www.kidshealth.org/parent/general/aches/osgood.html>

**Kids Got a Cold?** With kids getting up to eight colds a year, this contagious viral infection is the most common infectious disease in the United States and the top reason kids visit the doctor and miss school. <http://www.kidshealth.org/parent/infections/common/cold.html>

**Promising New Treatment Could Blow Lice Away-**Any parent whose child has had a head full of lice knows how frustrating the process of getting rid of the resilient insects can be. But thanks to some groundbreaking new research, lice may have finally met their match. <http://www.kidshealth.org/research/lousebuster.html>

**Depressed?** Depression is very common and affects as many as 1 in 8 people in their teen years. For more information about how depression is diagnosed and treated, check out this article for teens. [http://www.kidshealth.org/teen/your\\_mind/feeling\\_sad/depression.html](http://www.kidshealth.org/teen/your_mind/feeling_sad/depression.html)

**What's ADHD?** Some kids have ADHD. This disorder makes it hard for a kid to pay attention. Find out more in this article for kids. [http://www.kidshealth.org/kid/health\\_problems/learning\\_problem/adhdkid.html](http://www.kidshealth.org/kid/health_problems/learning_problem/adhdkid.html) **About**

**Autism:**

<http://news.bbc.co.uk/2/hi/health/6241733.stm> - cartoons to assist children with Autism

[http://www.teacch.com/info\\_primer.html](http://www.teacch.com/info_primer.html) - 20 questions and answers on Autism.

<http://www.autism-society.org/site/PageServer> - the latest news in Autism

<http://www.autism-pdd.net/> - Signs and Symptoms of Autism and

PDD [http://www.kidspeace.org/healingMagazine/NEWHealing/healing\\_ss06\\_7.htm](http://www.kidspeace.org/healingMagazine/NEWHealing/healing_ss06_7.htm) - 10 Things Your Child with Autism wish you knew

<http://www.med.yale.edu/chldstdy/autism/asdiagnosis.html> - Asperger Syndrome Guidelines for Assessment and Diagnosis

**On December 19, 2006, President Bush signed the Combating Autism Act of 2006 (S. 843).**

This Act authorizes expanded activities related to autism research, prevention, and treatment through FY 2011. There are more than 1.5 million cases of autism in the United States. To see the full White House press release go to

<http://www.whitehouse.gov/news/releases/2006/12/20061219-3.html>. More information about the law is available at <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:SN00843:@@L&summ2=m&>

**State Approaches to Serving Students with Autism Spectrum Disorders** Source: Project Forum -

December 31, 2006 This In-Brief Policy Analysis clarifies terminology and reports findings gathered from a survey of state special education staff. Findings are reported in the following areas: state-level staff time and responsibilities; specific services for Part C eligible children; specific services for students with Asperger Syndrome; types of professional development activities offered; taskforce roles; how states measure outcomes; barriers to providing services to this population; and more. The most mentioned barrier to serving this growing population was the lack of educational professionals with ASD expertise. It is available at

<http://www.projectforum.org/docs/StateApproachestoServingStudentswithAutismSpectrumDisorders.pdf>

**Asthma:** From *WebMD*: [Childhood Asthma Rise Remains a Puzzle](#), 12/12/06 - According to a new CDC report, "The State of Childhood Asthma, 1980-2005," nearly one in 10 American children now has asthma, a sharp rise that still has scientists searching for a cause. At the same time, racial disparities show evidence of worsening. While 8% of white children are estimated to have asthma, 19% of Puerto Rican children and 13% of black children have the disease.

**The new edition of Knowledge Path: Asthma in Children and Adolescents** is an electronic guide to a selection of current, high-quality resources about asthma in children and adolescents; asthma management; and the impact of asthma on homes, schools, and communities. The knowledge path, produced by the MCH Library, presents general resources and information on special topics, including asthma information for families, asthma information in school, and asthma and environmental triggers. Tools for staying abreast of new developments in pediatric asthma research are also identified. The knowledge path is intended for use by health professionals, program administrators, policymakers, educators, community activists, and families who are interested in obtaining timely information on this topic. The knowledge path is available at [http://www.mchlibrary.info/KnowledgePaths/kp\\_asthma.html](http://www.mchlibrary.info/KnowledgePaths/kp_asthma.html).

**Information on Genetic Disorders-**Physicians and families can now turn to [Genetics Home Reference](#), a new online resource from the National Institutes of Health to explain and understand over 500 topics on genetic conditions and related genes. The site features an illustrated tutorial that explains the basics of genetics and includes a glossary of genetics terms. The lay-friendly site is particularly helpful to parents whose newborns have been detected with a genetic condition, and are looking for easy-to-read information on specific conditions.

**Genetics Influence Risk of Retinopathy of Prematurity-**Even with prevention efforts and treatment, retinopathy of prematurity accounts for 3% to 11% of blindness in kids. Despite the prevalence and seriousness of this visual problem, doctors can't always determine why some preemies develop it and others don't.

[http://www.kidshealth.org/research/genetics\\_retinopathy.html](http://www.kidshealth.org/research/genetics_retinopathy.html)

**Information on Cerebral Palsy-**

<http://specialchildren.about.com/od/cerebralpalsy/bb/cpresources.htm?nl=1>

**Information on Congenital Heart Disease-**

<http://specialchildren.about.com/od/congenitalheartdefect1/bb/chdresources.htm?nl=1>

**Information on Cystic Fibrosis-**

<http://specialchildren.about.com/od/cysticfibrosis/bb/cfresources.htm?nl=1>

**Information on Diabetes-**

<http://specialchildren.about.com/od/juvenilediabetes/bb/jdresources.htm?nl=1>

**Information on Food Allergies-**

<http://specialchildren.about.com/od/foodallergies/bb/foodallresource.htm?nl=1>

**Information on Fragile X-**

<http://specialchildren.about.com/od/fragilex/bb/fxresources.htm?nl=1>

**Information on Dwarfism-**

<http://specialchildren.about.com/od/dwarfism/bb/LPresources.htm?nl=1>

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

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

<http://www.partnershipforparents.org/guide/item/38> - receiving bad news from your child's doctor.

<http://www.partnershipforparents.org/guide/item/37> - talking to your child's doctor

[http://additudemag.com/additude.asp?DEPT\\_NO=302&ARTICLE\\_NO=40](http://additudemag.com/additude.asp?DEPT_NO=302&ARTICLE_NO=40) - advocating for your child's educational needs

[http://www.childrenshospitals.net/AM/Template.cfm?Section=Child\\_Advocacy1&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=8&ContentID=20660](http://www.childrenshospitals.net/AM/Template.cfm?Section=Child_Advocacy1&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=8&ContentID=20660) - NACHRI supports the advocacy leadership of children's hospitals and promotes their involvement in public education, community health and the advancement of child health policy and legislation. To assist our members, NACHRI also works closely with national organizations to raise awareness of children's health issues and to promote knowledge and resource exchange within the children's hospital community.

<http://www.ldperspectives.com/freeinfo.6.asp> - 10 ways to advocate for your child with a learning disability

<http://www.irsc.org:8080/irsc/irscmain.nsf/outweb?readform&site=http://ask.hrsa.gov> - You can order, free of charge, publications and materials developed by HRSA Bureaus and Offices. The Web site also features information on resources that may interest you, including organizations, news sources, and current HRSA initiatives.

**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://protectedtomorrows.com/community/articles/162.php> - putting money aside without jeopardizing your child's resources

[http://www.cancer.org/docroot/MLT/content/MLT\\_1x\\_Medical\\_Insurance\\_and\\_Financial\\_Assistance\\_for\\_the\\_Cancer\\_Patient.asp](http://www.cancer.org/docroot/MLT/content/MLT_1x_Medical_Insurance_and_Financial_Assistance_for_the_Cancer_Patient.asp) - Medical Insurance and Financial Assistance for the Cancer Patient; the information is applicable to different diagnosis.

<http://www.wheelsforhumanity.org>

Collects used wheelchairs. Partners with other relief and development agencies to restore and distribute them to disadvantaged people with disabilities around the world.

[http://www.chesapeakeadd.com/pdf/about/speed\\_ins\\_pynt.pdf](http://www.chesapeakeadd.com/pdf/about/speed_ins_pynt.pdf) - How to speed up insurance payments

<http://www.patientcenters.com/autism/news/insurance.html> - Health Insurance when you have a child on the Autism spectrum

<http://depts.washington.edu/uwautism/pdf/NYT-AutismInsuranceTreatment.pdf> - battling insurers over autism treatments

**3. 504 & ADA 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://www.diabetes.org/advocacy-and-legalresources/discrimination/school/schoollaw.jsp> - what children are eligible for 504 Plans

<http://www1.usu.edu/mprrc/infoserv/pubs/HealthcareBookletKids2005.pdf> - serving children with special health care needs - a parent's guide

<http://www.usdoj.gov/crt/ada/pcatoolkit/abouttoolkit.htm> - ADA Best Practices Tool Kit for State and Local Governments. The Tool Kit is designed to teach state and local government officials how to identify and fix problems that prevent people with disabilities from gaining equal access to state and local government programs, services, and activities. It will also teach state and local officials how to conduct accessibility surveys of their buildings and facilities to identify and remove architectural barriers to access.

**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?**

<http://www.kytril.com/patients/cp-talking-to-doc.asp> - tips on talking to your health care providers

<http://www.thebody.com/gmhc/issues/jan01/terminology.html> - understanding medical terms

<http://www.healthliteracy.com/article.asp?PageID=5179> - article aimed at assisting patients/parents ask questions to Doctors and health care professionals.

<http://www.bizjournals.com/resources/best-health-insurance.html> - what to look for when selecting a new insurance carrier

<http://www.mchlibrary.info/nonenglish.html> - The MCH Library's online catalog, MCHLine®, includes materials for consumers and professionals in numerous languages other than English, and the Organizations Database identifies additional sources for these materials.

<http://www.do2learn.com/disabilities/diagnosis/areasoverview.htm> - The professionals and testing involved in receiving a diagnosis.

**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 with special health needs?)**

<http://www.med.umich.edu/llibr/yourchild/specneed.htm> - tips on helping you and your child's siblings cope.

<http://www.amsa.org/pdf/culture.pdf> - cross-cultural issues in primary care

<http://www.partnershipforparents.org/guide/item/49/catid/6> - preparing for a crisis

**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.georgiasouthern.edu/~esbutler/articles/EPHRStudyRevisedVersionSept20.htm> - The Electronic Patient Record - A New Model: Who is Using It and Is It Worth Continuing Development

<http://specialchildren.about.com/od/medicalissues/qt/notebook.htm> - ways and reasons to create a health care notebook

(see: Parent to Parent of NYS Health Care Record Keeping Notebook

<http://www.parenttoparentnys.org/Family2Family/Record%20Keeping/notebook.htm> )

<http://www.pacer.org/mpc/pdf/mpc-44.pdf> - folder to keep all school records

<http://www.kidsource.com/kidsource/content/history.html#contents> - record keeping of family history in child's memory.

<http://www.schwablearning.org/articles.asp?r=861> - How to get your child's records and why it's important.

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://www.medicalhomeinfo.org/Publications/eNews/announce.html#a1> - the future of medical homes

<http://www.medicalhomeinfo.org/publications/Downloads/CPMedical%20Home%20article.pdf> - building a medical home for a child with a chronic illness.

<http://www.ada.gov/business.htm> - To meet the goals of the ADA, the law [established requirements for businesses](#) of all sizes. These requirements went into effect on January 26, 1992. Businesses that serve the public must [modify policies and practices](#).

<http://www.medicalhomeinfo.org/publications/Downloads/CPMedical%20Home%20article.pdf> - building a medical home

<http://www.medicalhomeinfo.org/publications/Downloads/MHArticleGELESKE.pdf> - article on building a medical home.

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

<http://www.partoparvt.org/6WaysAppendix.doc> - everything you need to know about SSI.

[http://www.cms.hhs.gov/MLNProducts/downloads/Relationship\\_Brochure.pdf](http://www.cms.hhs.gov/MLNProducts/downloads/Relationship_Brochure.pdf) - Brochure on the Medicaid Medicare relationship

<http://protectedtomorrows.com/community/articles/152.php> - brief overview of government benefits

<https://s044a90.ssa.gov/apps12/best/benefits/> - benefit eligibility screening tool for SSI

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?

[http://www.hogg.utexas.edu/PDF/mental\\_illness.pdf](http://www.hogg.utexas.edu/PDF/mental_illness.pdf) - a handbook for attorneys who represent client's with mental illness.

<http://www.ssa.gov/pubs/10026.html> - an electronic leaflet about benefits for children with special needs.

<http://www.thearcofil.org/secure/reveal/admin/uploads/documents/income%20tax%20facts.pdf> - tax return information for parents of children with special needs

**Ideas for this newsletter?** Please email them to Diana Autin, [Diana.autin@spannj.org](mailto:Diana.autin@spannj.org).