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The Arc Talks...

www.arcnc.org

January 2006

Action Plan on Developmental Therapy Definition

The division of Mental Health/Developmental Disabilities/Substance Abuse has announced that the Developmental Therapy Definition intended to replace the Community Based Service (CBS) Medicaid service has been turned down by the Federal Government. This means that for individuals currently receiving CBS there will be no Medicaid State Plan alternative service when NC's new rehabilitation option Medicaid plan is approved. Members should be cautioned that this does not necessarily mean that those individuals receiving CBS will lose service. The State has indicated they are working on options that will allow for those individuals to continue receiving service through other funding streams. (The Arc has been involved in numerous discussions with state officials about potential options.)

It is estimated that nearly 6,000 people with developmental disabilities receive this Medicaid service in NC. CBS is critical for these individuals and our position is that every person currently in service must continue to receive service at least comparable to what they receive now. Additionally the state must have a plan to serve those people who would have been able to receive the developmental therapies service if it had been approved.

We intend to work with state agency personnel to develop a plan to serve these individuals. We have also been clear that we will begin to work on an advocacy strategy with the administration and the General Assembly.

The Arc, along with other agencies, is pre-

paring for a grassroots advocacy campaign designed to send a strong message to legislators and the administration of the critical nature of this issue. Beginning in early January, we will issue alerts to members through our E-Alert system with specific legislative and administration targets. These alerts will include a focused message for those individuals as well as personal stories about how CBS has served people with developmental disabilities.

Our goal is to assure that the administration and the legislature commit to a seamless solution to this problem.

Members of The Arc who are affected by this issue should sign up for the E-Alert network by clicking on our web page at www.arcnc.org and sign up for Action Alerts. Others who are not members or who are not personally affected should also sign up if they are willing to e-mail and call public officials.

Additionally, members who can, should plan to attend the January 26th Legislative Oversight Committee on Mental Health/Developmental Disabilities/Substance Abuse at the Legislative Building at 9:00 a.m. This meeting will have a heavy concentration on developmental disabilities and the Developmental Therapy issue will be a major part of the agenda. A large turnout will send a strong message.

The first alert on this issue will be e-mailed on January 5th, so please sign up as soon as possible. For questions, please feel free to contact The Arc of North Carolina office at 800-662-8706 or e-mail Dave Richard, drrichard@arcnc.org or Ellen Russell, erussell@arcnc.org.

INSIDE THIS ISSUE:

NGA	2
The Arc US	3
Resources	4
IDEA Proposed Regulations	5
DHHS Medicaid Memo	6
Partners in Justice Conf.	8

National Guardianship Association

The National Guardianship Association (NGA) has announced that Jean Farmer Butterfield and Barbara Cooper-Robinson of The Arc of North Carolina, Inc., in Raleigh attended the 18th Annual Conference of the National Guardianship Association (NGA) held in Cleveland, Ohio, November 6-9, 2005.

Some of the highlights of the 2005 NGA Conference included:

Jennifer Moye, Ph.D., Director of the Geriatric Mental Health Clinic of VA Boston and Assistant Professor at Harvard Medical School, gave the opening keynote address on "Psychological Assessment as it Relates to Competency." Dr. Moye discussed psychological models and assessment tools for decision-making capacity, including Medicare decision-making, financial management and independent living.

2005 NGA Judges Panel featured judges from across the United States including the **Honorable Irvin Condon** from Charleston, SC; the **Honorable Patrick Ferchill** from Fort Worth, TX; the Honorable John Maher from Kingston, NH; and the **Honorable Jack R. Puffenberger** from Toledo, OH. The judges discussed current hot button guardianship issues and explained how they ruled on guardianship matters within their courts.

Mary Alice Jackson, Esq., and Martin Smith, M.D., presented "Guardianship Challenges at the End of Life." The session examined the medical, legal and ethical issues faced by guardians and strategies for making life-ending decisions, which are medically, legally and ethically appropriate.

About the National Guardianship Association (NGA)

Founded in 1988, NGA is comprised of more than 700 individuals in public and private, for-profit and not-for-profit agencies and organizations as well as individuals concerned with guardianship issues. NGA provides its members with education and training, networking opportunities, and the opportunity to set a national agenda to ensure standards of excellence. The National Guardianship Foundation (NGF) administers a guardianship certification examination, which is the only national credentialing process for guardians in the nation.

For more information about NGA or for story ideas and interviews, contact Ann Krauss, NGA Communications Director at akrauss@kellencompany.com.





Monday Memo

HOW ARE WE DOING? – In an effort to better serve our chapters, The Arc of the United States is offering a convenient mechanism to assess the national office’s activities and services. Please complete the assessment by submitting a short on-line survey. If you are not able to access the form via the link provided, you can visit the Chapters Only section of our web site at www.thearc.org for more information. If you have any questions or concerns, please contact Kate Minkiewicz at minkiewicz@thearc.org. Thank you in advance for taking a moment to complete the survey and sharing your valuable feedback with us.

FUNDRAISING ALERT - TIPPING
A financially sound organization receives funding from a variety of sources, for instance from individual donors, foundations, corporations, and governments. An organization may be "tipped" out of tax exempt status when most of its support comes from a few sources.

Through the annual filing of Form 990, the IRS requires that a charitable organization demonstrate that at least one-third of its support come from the general public (including support from government units) over the course of a four-year period. If an organization fails to meet this requirement, its public charitable organization status will be tipped into private foundation status.

There are many consequences of tipping. An organization that is tipped into private foundation status will be subject to an ex-

cise tax on net investment income. Eligibility for private foundation grants will be impacted, and restrictions on some tax deductible gifts will apply. Certain programs operated by a charitable organization will require advance approval from the IRS.

The IRS rules related to tipping are complicated, and there are exceptions to the rules so charitable organizations are encouraged to consult the IRS, an accountant or a tax attorney before accepting a large contribution. The Arc's Resource Development Office recommends a periodic review of IRS Publication 527, Tax Exempt Status of Your Organization.

RESOURCES
The Arc of the United States' development office is available to assist chapters with fundraising issues and seeks to develop collaborative fundraising programs for state and local chapters. You can contact **The Arc's Development office** by email donorsupport@thearc.org or call (800) 433-5255.

At the local level, many nonprofit associations offer a wide variety of fundraising courses and provide networking opportunities. Check with **The Association for Fundraising Professionals (AFP)** to find local resources (www.afpnet.org).

The Chronicle of Philanthropy is a twice-monthly subscription newspaper that covers a wide variety of issues relating to fundraising and nonprofit management. www.philanthropy.com

“In an effort to better serve our chapters, The Arc of the United States is offering a convenient mechanism to assess the national office’s activities and services.”

Resources/Information

The Council on Quality Leadership Meeting

After a long delay we have been able to schedule the Council to come to a meeting with our chapters on **January 11th in Raleigh**. We want to extend this invitation to all of our chapters. If you are currently provide services or are considering doing so in the future this meeting will be very important. It is our hope that we as Chapters of The Arc in NC can work with the Council to provide accreditation and to do so at a rate that is affordable to our members.

Details as to time and place are still to be worked out but please hold the date! More detailed information will follow the first week of January. Please call if you have questions.

Dave

Dave Richard
Executive Director
The Arc of NC
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*The ASANC
has changed
the 2006
convention
date and
location due
to the closing
of the
previously
booked hotel.*

Association of Self-Advocates of NC, Inc.

2006 Convention Change of Date to March 24-26, 2006
(previously March 17-19, 2006)

Change of Location to The North Raleigh Hilton
(previously Adams Mark Hotel, Charlotte)

Please Mark Your Calendar! We Apologize for Any Inconvenience Watch for Registration Materials in Early January.

Reserve Early – Open to First 740 Registrants

One-Stop Benefits Website

The Department of Labor announced the launch of a website designed to serve as a one-stop resource for all government benefits. With benefits programs from participating Federal agencies and State organizations, **GovBenefits** is the most comprehensive online resource for government-to-citizen assistance programs available. The website lists benefits by state, category, and features a detailed resource page.

<http://www.govbenefits.gov/govbenefits/index.jhtml>

INFORMATION BULLETIN - From the National Down Syndrome Society - December 28, 2005

Proposed Requirements and Selection Criteria Published For IDEA Multi-Year IEP and Paperwork Reduction Pilots

In the Federal Register for December 19th, the U.S. Department of Education published notices of proposed requirements and selection criteria for the Multi-Year IEP and Paperwork Reduction Pilots permitted under IDEA 2004. It is important to note that these are not regulations.

The multi-year IEP pilot allows up to 15 states to seek approval for proposals to offer parents the option of a multi-year IEP, not to exceed 3 years. IDEA states that this pilot was developed to offer the opportunity for long-term planning.

The paperwork reduction pilot allows up to 15 states to seek waivers of certain IDEA statutory and regulatory requirements for a period not to exceed 4 years. IDEA 2004 states that the purpose of this pilot is to reduce excessive paperwork and non-instructional time burdens that do not assist in improving educational and functional results for students with disabilities. The statute also states that procedural safeguards, civil rights requirements, and the right to a free appropriate public education (FAPE) may not be waived or affected.

A careful review of the details of the proposed requirements and selection criteria for these pilots is essential in order to protect the educational rights of children with disabilities. It will be critically important to ensure that long-term planning does not limit the input of parents or the ability to plan for and measure student progress. It is also essential for States to have meaningful stakeholder input and agreement on the type of paperwork and activities that the States label as excessive and non-instructional. The short-term objective requirement for certain students with disabilities was eliminated in the IDEA reauthorization in the name of paperwork reduction. This decision raises concerns about where paperwork reduction might lead, in spite of the fact that procedural safeguards, civil rights requirements, and the right to FAPE are supposed to be kept in place.

The public has until March 6, 2006 to submit comments on the notices of proposed requirements and selection criteria for the pilots. NDSS will be sending you more information about the details contained in these notices as it develops its comments and recommendations.

The proposed regulations for the Multi-Year IEP can be found at:

<http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/E5-7506.htm>

The proposed regulations for the Paperwork Reduction pilot can be found at:

<http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/E5-7507.htm>

To receive your copy of this weekly e-mail report contact: mmwdc@ndss.org.

Disclaimer: MMWDC publishes information about issues and events that we believe to be important and likely to be of interest to advocates and others interested in inclusion of persons with disabilities in all parts of society. However, MMWDC and The Arc of the United States or The National Down Syndrome Society do not necessarily endorse all events, sponsoring organizations and reports which appear.



**North Carolina Department of Health and Human Services
Division of Mental Health, Developmental Disabilities and Substance Abuse Services**

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Michael F. Easley, Governor
Carmen Hooker Odom, Secretary

Michael Moseley, Director

January 3, 2006

MEMORANDUM

To: Legislative Oversight Committee Members
Commission for MH/DD/SAS
Consumer/Family Advisory Committee Chairs
State Consumer Family Advisory Committee Chairs
Advocacy Organizations and Groups
North Carolina Association of County Commissioners
County Managers
County Board Chairs
North Carolina Council of Community Programs
State Facility Directors
Area Program Directors
Area Program Board Chairs
DHHS Division Directors
Provider Organizations
MH/DD/SAS Professional Organizations and Groups
MH/DD/SAS Stakeholder Organizations and Groups
Other MH/DD/SAS Stakeholders

From: Mike Moseley

**Re: Communication Bulletin #052 – Federal Approval
of Enhanced Benefits**

It is my great pleasure to notify you that the federal Centers for Medicare and Medicaid Services (CMS) has approved the Medicaid State Plan Amendment (SPA) which the Department of Health and Human Services submitted to provide for new and enhanced services for individuals with mental illness and substance use disorders. It is our intent to implement these new services no later than March 31, 2006. As promised in Communication Bulletin #46, dated August 3, 2005, we will consult with key stakeholders and announce a definite date for implementation in the next week.

The approval of the new service definitions is a critical milestone in our efforts to transform the public mental health, developmental disabilities, and substance abuse services system. Along with the new Community Alternatives Program waiver for individuals with MR/DD (CAP-MR/DD) that was implemented September 1, 2005, these new definitions provide the clinical foundation for transforming the community service array and providing more effective services to consumers. Many of the new definitions represent evidence-based best practices or provide a platform through which evidence-based, emerging and promising practices can be delivered. With the implementation of these new definitions North Carolina will, for the first time, have services available for adult substance abusers at every level of care outlined in the American Society of Addiction Medicine (ASAM) Patient Placement Criteria. The new service array is also designed to improve consumers' access to services and increase consumers' choice of provider since all providers of these services will directly enroll in the Medicaid program.

Communication Bulletin #052
January 3, 2006
Page 2

The new service definitions have been through a very lengthy review process and have been the subject of intense negotiations with CMS. We know that the lengthy approval process has been stressful for Local Management Entities, providers and the consumers we all seek to serve. We are very pleased to be able to begin the New Year with this very positive news.

cc: Secretary Carmen Hooker Odom
Dr. Allen Dobson
Allyn Guffey
Dan Stewart
DMH/DD/SAS Executive Leadership Team
DMH/DD/SAS Staff
Rob Lamme
Rich Slipsky
Wayne Williams
Kaye Holder
Carol Duncan Clayton
Patrice Roesler
Coalition 2001 Chair

The Arc of NC Needs Your Help!

This is the official announcement that the new State Medicaid Plan Amendments have been approved by CMS. This plan amendment is where the new service definitions are included. As reported, Developmental Therapy, a service for people with developmental disabilities, was not included.

We are still finalizing our action plan for advocacy on the CBS/Developmental Therapies issue. You will receive an update by Friday January 6th. We anticipate having much more detailed information on exactly what CMS approved, the division of MHDDSA thinking on how to deal with the Developmental Therapy issue, and a more comprehensive version of our advocacy strategy.

Please sign up for The Arc of NC's Action Alert Network so you can participate in our advocacy efforts. Go to www.arcnc.org to sign up.



Partners in Justice BUILDING BRIDGES *and changing lives*

The Durham Hilton February 10, 2006

A conference for Judges, Attorneys, Magistrates, Law Enforcement Officers, Community Corrections Officers, Correctional Officers and Human Service Workers

Seating is Limited so Register Now!! You don't want to be left out

This one day, groundbreaking event will feature keynote addresses by national experts, followed by small group discussions led by North Carolina experts from the professions involved in the criminal justice system on identifying and accommodating cognitive disabilities.

Ethics Continuing Legal Education credits will be offered, as well as Continuing Education Units for other disciplines.

http://www.arcnc.org/pij/pij_conf.html

Keynote Speakers

Robert Perske

Robert Perske tracks, works with and writes about people with intellectual disabilities who confessed to murders they did not commit, over 100 of them. He founded The Friends of Richard Lapointe described in the Emmy winning 60 Minutes presentation, "Did He Do It?" Perske wrote the case vignettes for the 1976 Report to President Nixon, Mental Retardation: Century of Decision, and authored the 1978 Report to President Carter, Mental Retardation: The Leading Edge – Service Programs that Work.

Robert and his illustrator wife, Martha, received The Healing Community Arts and Letters Award for their work in developmental disabilities at the United Nations in 1987. In 1999, The National Historic Preservation Trust on Mental Retardation honored Robert and Martha as two of the 35 persons who made major contributions in the field of mental retardation in the 20th Century.

Perske was the first non-lawyer to receive the American Bar Association's Paul Hearne Award for Service to Persons with Intellectual Disabilities, Washington, DC, in 2002.



**Dennis Debbaudt**

Dennis Debbaudt is the proud father of Brad, a young man who has autism. In the 1980's, Dennis wrote for the Detroit News and worked with network television current affairs programs in the U.S., Canada and United Kingdom. A professional investigator and journalist for 28 years, Dennis turned his attention to autism spectrum disorders in 1987 after his son was diagnosed with this condition.

Debbaudt has authored numerous articles and books including *Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders* for

Jessica Kingsley Publishers, London UK (2002) and *Contact with Individuals with Autism: Effective Resolutions* with Darla Rothman, Ph.D. for the FBI Law Enforcement Bulletin (2001).

In 1999, Dennis was instrumental in the development of the state of Maryland's Police and Correctional Training Commissions curriculum *Why Law Enforcement Needs to Recognize Autism* and consulted to ABC News 20/20 for a segment about false confession and autism. His new *Autism & Law Enforcement Roll Call Briefing Video* released in 2004 and reviewed in the March, 2005 FBI Law Enforcement Bulletin, is in use by the Department of Homeland Security, police departments and training units throughout the U.S. Dennis is a member of the American Society for Law Enforcement Training and has produced autism related safety and risk training curricula and tools since 1995.

The Building Bridges Changing Lives Conference [schedule](#) as well as [hotel information](#) and [registration information](#) is available on-line.

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The Arc Talks... is a monthly publication designed for local chapters of The Arc of North Carolina. If you have received this publication and are not a member of The Arc in North Carolina, please consider joining. To find the chapter in your area call The Arc of NC at 1-800-662-8706 or visit the website at www.arcnc.org

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