

HEALTHY TIMES

A medical newsletter for health care professionals and caregivers of individuals with intellectual and other developmental disabilities



L. to R. DHS Asst. Commissioner Kenneth Ritchey, DMAHS Director John Guhl, DHS Commissioner Jennifer Velez, The Arc of NJ President Bruce Bird, Executive Director Thomas Baffuto, Mainstreaming Director Beverly Roberts and Morning Keynote speaker Andrew Eddy, MD.



L. to R. Thomas Baffuto, Beverly Roberts and Afternoon Keynote speaker Jeffrey Levine, MD

19th Annual Conference Welcomes a Variety of Developmental Disabilities Professionals

Diverse audience gains state-of-the-art knowledge
In medical, dental and mental health care trends and services
Diane Flynn

The Arc of New Jersey's Mainstreaming Medical Care Program's **19th Annual Conference on Medical Care for Persons with Developmental Disabilities** has come to represent a benchmark for providing relevant and topical information about health care for individuals with intellectual and developmental disabilities in New Jersey. On Friday, May 30th, at the Westin Hotel in Princeton, an audience of more than 400 doctors, dentists, nurses, direct support and administrative professionals, New Jersey Department of Human Services (DHS) personnel and HMO staff attended the highly anticipated event. Mainstreaming Medical Care Director Beverly Roberts spoke briefly during the opening remarks portion of the conference and then allowed her months of intensive preparation to unfold throughout the day into a consistent and unified program. Jennifer Velez, Commissioner of the New Jersey Department of Human Services, opened the Plenary Session, followed by Kenneth Ritchey, Assistant Commissioner in charge of the Division of Developmental Disabilities and John Guhl, Director of the Division of Medical Assistance and Health Services. Each provided an in-depth look at what is happening at the State level as well as changes on the horizon. Next, Keynote Speaker Andrew Eddy, MD, Vice President of Medical Affairs at the Southeastern Ohio Regional Medical Center and former Medical Director for the Ohio Department of Mental Retardation

and Developmental Disabilities provided a unique glimpse into some of the successful programming implemented at that Department.

A second Keynote speaker took the podium after lunch, providing an extremely engaging presentation about promoting healthy lifestyles. Jeffrey Levine, MD, Associate Professor and Director of Women's Health Programs at the UMDNJ-Robert Wood Johnson Medical School and participant on the NBC reality television show, *The Biggest Loser*, talked about his own transformative journey to a healthier lifestyle and how we, in our myriad roles as caregivers, can promote healthy lifestyles to our patients, consumers and family members.

A broad selection of twelve workshop topics, from which each registrant selected two, rounded out the day, and attendees had the opportunity to visit and speak with twenty-three Exhibitors lining the hallways. Preliminary feedback from those in attendance has been extremely positive. ❖

Many thanks to our Conference Platinum Contributors!

AmeriChoice
AMERIGROUP Community Care
Horizon NJ Health

The Systemic Effects of Oral Disease for Persons with Developmental Disabilities

*Evan Spivack, DDS**

*From his presentation on May 30, 2008 at The Arc of New Jersey's 19th Annual Conference on Medical Care for Persons with Developmental Disabilities.

Dentists have always given careful consideration to the effects of cardiac, neurological and other systemic diseases on the treatment offered to their patients. Over twenty years ago, research began to indicate that the reverse was also true, that oral health could have a significant impact on

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Team Tools to Optimize Behavioral Health Outcomes

*Carol Persons, MD and Dina McFalls, MS**

**From their presentation on May 30, 2008 at The Arc of New Jersey's 19th Annual Conference on Medical Care for Persons with Developmental Disabilities*

Diagnosis of mental illness in patients with intellectual disabilities can be problematic for a variety of reasons. Generally speaking, the key to an accurate psychiatric diagnosis is a verbal account of symptoms by the patient, making diagnosis for individuals with intellectual disabilities particularly challenging, since they may have limited communication ability and are often not able to accurately self-report. In addition, manifestation of physical or mental symptoms can be misinterpreted by caregivers as behavioral, affecting their accurate tracking, documentation and reporting to an appropriate health care professional. Moreover, today's managed care environment frequently results in increased patient caseloads without a concomitant increase in time allocated for each patient, severely limiting a physician's ability to develop a true picture of a patient's presenting symptoms.

Beyond these direct, "human" barriers to appropriate mental health assessment, psychiatrists treating individuals with intellectual disabilities have long struggled to define the symptoms of mental illness as they manifest in this particular population, including target symptoms of specific mental health diagnoses. For instance, while the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), a classification tool that provides universal standards for defining the verbally reported symptoms of those in the general population, has been widely available for many years, it was not until 2006 that the Diagnostic Manual for Intellectual Disabilities (DM-ID), a clinical guide for the assessment of mental health symptoms in individuals with intellectual disabilities, was published by the National Association for the Dually Diagnosed (NADD).

Recognizing these inherent obstacles to appropriate mental health assessment and treatment for individuals with intellectual disabilities, Philadelphia Coordinated Health Care (PCHC) has, over time, developed
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Trinitas Hospital's Crisis Response Service Successfully Meeting a Critical Need

Lucille Esralew, PhD

June 18, 2008 marked the one-year anniversary of the inception of the New Jersey Division of Developmental Disabilities' (DDD) unique statewide crisis response service, which is administered and delivered by Trinitas Hospital's **Statewide Clinical Consultation and Training** (SCCAT) program. To date, SCCAT clinicians have provided clinical crisis response to over 800 consumers, their families and staff, working to stabilize the presenting mental health and/or behavioral crisis and ensure continuity of the community-based residential and program placements.

SCCAT delivers short-term clinical mobile outreach, technical assistance and supports to consumers and their families/caregivers, and maintains four locations in New Jersey: Parsippany, Cranford, Wall and Voorhees. Fourteen Masters-level clinicians have regular contact with consumers in a variety of venues, including their own homes, day programs, residences and hospital units. Families, developmental disability and mental health agency staff, DDD case managers and consumers themselves can access services through the *24/7 emergency number, 888-393-3007*. SCCAT clinicians provide on-site assessments to identify needed supports and work with consumers, families and staff until problem situations become manageable and relevant longer-term services can be coordinated.

Case Examples

A community-based psychiatrist called us about *Marianne*, a 39-year-old woman with Down Syndrome and no previous psychiatric history who suddenly began exhibiting psychotic symptoms. At the time of the call Marianne was living in New Jersey with her sister, although she was not linked to New Jersey's DDD services because she had previously been living out-of-state with her mother. The family suggested that she may have experienced trauma that adversely affected her daily functioning to the point that she could not sustain her lifestyle, and that might be a contributing factor to the current mental health crisis.
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**Trinitas Hospital's Crisis Response Unit,
continued from page 2**

A SCCAT clinician began to visit Marianne to provide on-site support, while her psychiatrist worked with the family to adjust her medication. The SCCAT clinician met with the family (including her young niece and nephew) to provide information regarding Marianne's psychiatric illness and the management of symptoms on a daily basis, and continues to provide weekly follow-along to ensure that Marianne and her family are able to manage Marianne's mental health issues within the home environment. The clinician offers suggestions regarding positive daily routine and encourages the family to involve Marianne in select local recreation programs in order to access peer contact and leisure activities, as tolerated.

Marianne gradually began experiencing fewer days in which she heard voices, and now reports that she is less distressed and is participating in family outings. SCCAT continues to work with Marianne's psychiatrist, providing Marianne with brief counseling to increase her capability to cope with recent stressors.

.....
James is a 37-year-old non-verbal autistic male residing in a group home with a history of co-occurring psychiatric and behavioral problems. SCCAT received a call about James when he was brought to the local emergency room following a severe episode of self-injury and immediately dispatched a clinician to meet with him at the emergency room. The SCCAT clinician worked with the local screener to determine the best response to James's recent increase in self-injury and other aggressive behaviors, followed James on the local psychiatric unit and arranged for a phone consultation between SCCAT's Medical Director and James's attending psychiatrist, with SCCAT eventually participating in the discharge planning. James's medication was adjusted while he was on the hospital unit, and the SCCAT clinician followed James back into the community to promote his re-integration into the group home and day program routine. In addition, the SCCAT clinician provided training to staff and family regarding positive communication, functional communication, and potential environmental triggers that might be avoided.

.....
Stephanie is a 21-year-old female linked to DDD Community Services and living in her own home with her parents. She has graduated school, does not have a job or a day program and has become increasingly aggressive, targeting her younger siblings in particular, and increasingly difficult to redirect. A SCCAT clinician conducted an assessment of Stephanie at her home and coordinated a consultation and medication review with a local psychiatrist (Stephanie's medication had previously been prescribed by the family physician).

The SCCAT clinician provided educational material to Stephanie's family, including suggestions with regard to positive routine and effective communication, and also accompanied Stephanie on her first visit to a local partial care program. The SCCAT clinician recommended a referral to the Division of Vocational Rehabilitation (DVR) for assessment for vocational training or job placement, and worked closely with all members of the family, including Stephanie's siblings, to increase their understanding of Stephanie's support needs and to improve family interaction.

Members of the SCCAT team collaborate regularly with other agencies by providing services that effectively merge the efforts of all providers involved, ensuring that each consumer receives the necessary supports.

SCCAT accepts calls from any referral source on behalf of adults with intellectual and other developmental disabilities who are in mental health or behavioral crisis. SCCAT clinicians are mobile and will go to any location where an individual is experiencing a problem. Supported by dual funding from the Divisions of Developmental Disabilities and Mental Health Services, there is no charge for SCCAT's services. For more information you can visit them on the web at www.sccatnj.org. ❖

Lucille Esralew, PhD, is Program Director of Statewide Clinical Consultation and Training (SCCAT), a program of Trinitas Hospital. She can be reached at 1-888-393-3007 or 908-497-9636, ext 203.

**Mark Your Calendars and
Celebrate Dual Diagnosis Month!**

What: SCCAT 9th Annual Conference
When: October 30, 2008
Where: The Pines Manor, Edison, New Jersey

Helping a Grandchild with a Disability

Herbert D. Hinkle, Esq. and Valerie A. Powers Smith, Esq.

A grandparent's support is invaluable to a family caring for a child with a disability. As the financial and legal issues facing the family change over time, grandparents can bolster a long-term plan for the grandchild's care that will have long-lasting positive affects on an entire family.

Good planning by the whole family can alleviate unease arising from such costs or concerns as medical expenses or therapy not covered by insurance or government programs. While reducing worries about the child's future and the lifelong responsibility for the child's supervision, a grandparent's assistance can also diminish any emotional impact on other grandchildren in the family.

Monetary gifts to a grandchild with disabilities can create problems if not properly managed. Normally at age 18, a person with a significant disability becomes eligible both for a monthly cash benefit - or Supplemental Security Income (SSI) - as well as Medicaid health insurance and funding for adult services. However, any resources or investments in excess of \$2,000 render the grandchild ineligible for benefits covering the costs of sought-after supervised living arrangements and adult day programs.

A grandchild's future is made secure by making modest monetary gifts directly to the parents, and any larger ones to a grandchild's singular Special Needs Trust (SNT) of future gifts and bequests that, when properly drafted, will not be counted as a resource terminating eligibility for SSI and Medicaid.

In addition to having the ability hold real estate where the grandchild may eventually live, an SNT can purchase services not attainable through government or private programs, or therapy and healthcare, education and training, vacations, and recreation to protect and enhance the grandchild's lifestyle. Funds can also reimburse family members for expenses incurred while monitoring the grandchild's health.

As an alternative, when paid out, the benefits of a life insurance policy, purchased for one or both parents, and held by the SNT, will alleviate the

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Helping a Grandchild, continued from page 3

burden of setting aside assets for the child with a disability while even saving estate taxes in some cases. The best choice here would be a joint survivorship life insurance policy on the lives of both parents as it costs less and will prove more useful over time.

Does a Will leave an inheritance to a grandchild with a disability? A Will that names the grandchild specifically instead of the grandchild's SNT can cause serious problems. It is also important to be aware that should the grandparents' own children predecease them, the grandchildren often are the next beneficiaries under the will or on retirement and 529 accounts or life insurance.

Within a wide range of circumstances in each family exists many good choices for providing long-term care and support to a grandchild with a disability. The involvement of grandparents can make a difference in the family's overall quality of life as they collectively navigate the needs of the grandchild. ❖

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Herbert D. Hinkle, his partners, Ira M. Fingles and S. Paul Prior, and their colleagues, Valerie A. Powers Smith, Hillary Freeman and Amy Duff maintain a statewide law practice with offices in Lawrenceville, Marlton and Florham Park, New Jersey; and Bala Cynwyd and Plymouth Meeting, Pennsylvania. They lecture and write frequently on topics of law, aging, disability, health care, estate planning, special needs trust, guardianship and special education, and are available to speak to groups in New Jersey and Pennsylvania at no charge. They can be reached at 609-896-4200 or 215-860-2100.

Team Tools, continued from page 2

oped and implemented the use of specific tools to assist families and direct care teams with organizing and presenting the psychiatric status of the individuals they support.

Although the use of planning and documentation tools has long been the norm in our system, available tools have focused largely on the severity and complexity of behaviors (Adaptive Behavior Scale, Reiss Scale, etc.) or the function of behaviors (functional assessment). Indeed, it seems that when it comes to documenting mental illness and its treatment, we have concentrated on behavior plans, rather than developing tools that separate out behaviors from target symptoms of a given mental illness. Since proper management of psychiatric symptoms is crucial for optimizing behavioral health outcomes, the tools that PCHC developed are intended to promote accurate reporting, documentation and diagnosis, foster team communication and provide easy access to current functional status for treating physicians.

The primary tool is referred to as **Behavioral Health: Team Review of Psychotropic Medication** (also called "Team Review Form" or "90-Day Form"). This three-part form was initially developed to satisfy court requirements related to the Pennhurst class of individuals in Philadelphia in 1995 and enables team members to document treatment progress, including any mitigating factors. The first page is completed by residential staff or the family based upon current status and current diagnosis as documented by the treating physician. The second page is completed by the behavioral specialist and documents the current behavior support

plan, the current status of target symptoms of mental illness, and any aggravating medical or environmental issues. Pages one and two are completed prior to the visit to the treating physician, who then completes page three.

The second tool is a **database** in which information is compiled about the accuracy, completeness and clarity of treatment objectives as documented in the Team Review Form. This tool is designed primarily for use by residential agencies to enable them to assess the overall quality of the supports provided to individuals with a dual diagnosis (it is also the format used by the PCHC psychiatrist to review the Team Review Forms for the Pennhurst Class members, whose teams still submit forms every ninety days for each person who takes psychotropic medication).

Analysis of data collected over the past four years indicates steady improvement in 1) correspondence between target symptoms and accurate diagnosis and 2) correspondence between diagnosis and appropriate treatment. It becomes clear, therefore, that the vigilance offered via use of the Team Review Form, combined with the comprehensive review capability provided by utilization of the aggregate data can influence outcomes for individuals in a positive direction, if only because, de facto, teams must increase their focus on provided supports.

PCHC's "team tools" have been refined and tested over a fifteen-year period with individuals, families and teams in the southeast region of Pennsylvania. It is the strong feeling of PCHC staff that use of these tools can shine light on pertinent areas of psychiatric treatment and improve behavioral health outcomes for individuals with a dual diagnosis. The Team Review Form and the quality assurance database provide two useful tools for individuals, families and teams seeking optimum mental health and are available by contacting Diane Flynn, Administrative Assistant, Mainstreaming Care Program at 732-246-2525, ext 28, or by email at dflynn@arcnj.org. ❖

Carol Persons, MD is a psychiatrist with, and Dina McFalls, MS is Director of Philadelphia Coordinated Health Care (PCHC) in Pennsylvania. Visit them on the web at www.pchc.org.

Early Intervention System Point of Entry Regionalized

New Statewide Toll-Free Referral Number

1-888-NJEI-INFO (888-653-4463)

Effective July 1, 2008 the New Jersey Early Intervention System (NJEIS) has regionalized the system point of entry (SPOE) for referral of children birth to age three with developmental delays and disabilities. This toll-free number *replaces* the direct referral for early intervention through twenty-one (21) county numbers. Families and primary referral sources will now call **1-888-653-4463** to refer a child to the NJEIS. For children birth to age 21 with special health care needs, referrals continue to be made through the 21 county Special Child Health Case Management Units (SCHS-CMUs). The SCHS-CMU referral numbers can be found at:

<http://www.nj.gov/health/ahs/sch/sccase.shtml>

The Early Intervention System (EIS), under the Department of Health and Senior Services, implements New Jersey's statewide system of services for infants and toddlers birth to age three with developmental delays or disabilities, and their families.

Important Information on Medicaid Managed Care, Care Management and Exemptions

Beverly Roberts

New Jersey's Medicaid program continues the process of informing SSI beneficiaries that they must select a Medicaid HMO or request an exemption; if either a beneficiary or his/her caregiver does neither of these things prior to the deadline date, he/she will be randomly assigned to an HMO (*auto-assignment*). For purposes of its outreach to Medicaid beneficiaries, New Jersey's counties were divided into five groups, called tiers, all of which have completed auto-assignment except for Tier 5, consisting of Hudson, Hunterdon, Somerset and Union Counties. Letters are expected to be mailed to beneficiaries in Tier 5 this summer, with an auto-assignment effective date of January 1, 2009.

New Jersey's Exemption Policy

(for SSI beneficiaries who do not want to be in a Medicaid HMO)

The new Medicaid policy on exemptions from Medicaid managed care is "hassle-free". Any child or adult with a disability who receives Supplemental Security Income (SSI) and who wants to have an exemption from Medicaid managed care *will automatically receive it* by calling the **Health Benefits Coordinator** (HBC) program at **1-800-701-0710**.

An exemption from Medicaid managed care may be requested in the following circumstances:

- 1) Individuals who receive SSI benefits and are currently in the regular Medicaid system: When they receive a letter from NJ Medicaid saying that they must choose an HMO, they have the option of requesting an exemption and remaining in the regular Medicaid system.
- 2) Individuals who receive SSI benefits and are currently in a Medicaid HMO: They have the option of requesting an exemption and returning to the regular Medicaid system.

There are many children and adults with disabilities who have been unable to access quality medical and dental care from the Medicaid fee-for-service system. For many of these individuals, Medicaid HMOs have provided increased access to needed health care services. At times, however, families and agency staff have been able to locate excellent health care services from primary care physicians and specialists who are not available within the same Medicaid HMO. These consumers often benefit from having an exemption from the Medicaid HMO system so that the continuity of care is not disrupted.

New Jersey's Medicaid HMO Care Management Services

Everyone with a developmental disability who receives SSI benefits and is enrolled in one of New Jersey's Medicaid HMOs *should automatically receive care management services*. Care management services are available at no charge to every HMO enrollee, but are not available to people in the regular Medicaid system. Care managers are nurses or social workers who have extensive experience assisting persons with disabilities navigate the Medicaid managed care system and providing a coordinated approach to health care. The amount of help that a particular child or adult will receive from the care manager depends upon the level of need. For example, a caregiver for an individual with a developmental disability who does not have extraordinary health care problems may contact the care manager for the following types of reasons: to

arrange for transportation to a doctor's appointment (at no charge); to locate a specialist; or to locate a dentist. It is likely that there would be much more intensive involvement from a care manager when a consumer has significant problems such as an uncontrolled seizure disorder, asthma, or health care problems that result in hospitalization.

In addition, children with disabilities who are enrolled in NJ FamilyCare are also eligible for Care Management Services, at no charge. However, the HMO may not realize that a non-SSI child with a disability needs these services, in which case a phone call to the HMO's Care Management Unit from the pediatrician or nurse (or the parent) may be necessary to request these helpful services. Requests for a Medicaid HMO to provide care management services can also be initiated by social workers, case managers, or teachers - anyone who recognizes that the child needs care management services.

Care Management Phone Numbers

For individuals who are already enrolled in a Medicaid HMO, the table below provides phone numbers to use to make a referral for care management or to request additional assistance for a participant who already has a care manager. ❖

AmeriChoice	Special Needs Hotline	1-877-704-8871, ext. 5260
	If member is a DDD client, contact Developmental Disabilities Health Alliance (DDHA) for Care Management	1-877-334-2462
AMERIGROUP Community Care	Janet Pizzelanti, VP of Health Care Management Services	732-452-6044
HealthNet	Case Management Program	1-888-228-2109
Horizon NJ Health	Care Coordination/ Special Needs Unit	1-800-682-9094, ext. 89385
University Health Plans (UHP)	Margaret Jagerburger, Manager of Care Management	732-476-1200

The Arc of New Jersey's Department of Education Advocacy

Stephanie Kramer, Director

The Arc of New Jersey's **Department of Education Advocacy** works with families and school districts to ensure that children with disabilities receive quality educational services tailored to their unique needs. The Department issues a quarterly newsletter entitled, *The Education Advocate*. The latest edition provides information on two new laws in New Jersey, one pertains to transition planning for high school students and the other one addresses graduation ceremonies. In addition, the newsletter provides great information on the Adult Service System and explains the various State agencies and the types of programs children can access after graduation. To view this and other issues of The Education Advocate, go to:

http://www.arcnj.org/html/education_advocate.html.

To be added to the listserv and receive The Education Advocate as soon as it is available, please contact Stephanie Kramer at skramer@arcnj.org or by phone at 732-246-2525, ext 20.

Oral Disease, continued from page 1

systemic health. As new evidence accumulates, the questions are turning toward a possible causal link between oral and systemic health. This research will have a major impact on persons with developmental and other disabilities, and on our society, which must bear the costs of care for those affected individuals.

Persons with developmental disabilities are at greater risk of developing cardiovascular, respiratory and gastrointestinal disorders (Connolly, 2001), and may suffer up to six times the mortality rate from preventable diseases as the general population (Alexander et al, 2008)—and the picture of oral health is no better. Periodontal disease and dental caries have higher incidence for persons with disabilities, the progression of these oral diseases is often quicker and the effects are more dramatic. A recent study of over nine million children with special health care needs found that more than ten percent of these children suffered from unmet dental needs.

Research has focused on periodontal disease as the oral condition most clearly linked to systemic health. Periodontal disease is an inflammatory reaction to a chronic bacterial infection leading to damage to the tooth's supporting bone and soft tissues. Although often unseen, the surface area of the diseased pocket epithelium is equivalent in size to the surface area of the palm of one or two hands. This represents a significant infection.

While Medicaid expenditures in 2005 exceeded \$300 billion, dental spending accounted for just over one percent of this total (CMS Medicaid Financial Management Report-FY 2005). Fortunately, new evidence may justify greater dental spending to help mitigate systemic diseases and their costs.

The Medical-Dental Relationship

Dr. C. Everett Koop, the former U.S. Surgeon General, perhaps said it best back in 2000, *"You're not healthy without good oral health"*. His comment is indicative of the mounting evidence linking oral health and several systemic conditions, including cardiovascular, neurological and respiratory diseases, diabetes, pre-term and low-birth weight pregnancies, rheumatoid diseases and even several types of cancer. In the largest study to date, and the first to demonstrate an oral health link to lung cancer, over five thousand cancer patients were studied (Hiraki et al, 2008). After taking confounding factors such as smoking and alcohol use into account, it was found that those with tooth loss were 54 percent more likely to develop lung cancer, 68% more likely to develop head and neck cancer, and 136 percent more likely to develop esophageal cancer.

Cardiovascular disease: The CDC reported total costs of \$393 billion (all payers) for the treatment of cardiac disease in 2002. Given this staggering figure, it is not surprising that prevention of cardiac disease and elucidation of cardiovascular pathophysiology has attracted significant research. Numerous detailed studies have concluded that there is a relationship between periodontal inflammation and the presence, development and progression of cardiovascular disease. A meta-analysis of the literature (Janket et al, 2006) concludes that periodontal disease appears to be associated with a 19% increase in risk of future cardiovascular disease, and when looking at risk of stroke alone, those with periodontal disease had a risk factor almost three times greater than the orally healthy population. Research has shown a statistically significant relationship

between the periodontal pathogens in plaque and coronary heart disease (Spahr et al, 2006), and while a causative relationship has yet to be firmly established, mechanisms explaining this interaction are being explored.

The plaque biofilm covering teeth is made up of hundreds of different types of bacteria, which release various pro-inflammatory substances that act to produce an inflammatory response. Through various interactions with blood cells and blood vessel walls, these biological factors contribute to the formation of the atherosclerotic plaques of heart disease.

Neurological disorders: Dementia is a leading and rapidly growing cause of disability and death. Alzheimer's disease is the most common form of dementia, affecting over four million people in the United States, with a prevalence of ten percent among those over age 65. Older adults with Down syndrome are almost universally afflicted with dementia, and with the increased life expectancy of those individuals, greater attention is being paid to the medical and societal impact of this disorder.

Recent studies have highlighted the connection between dementia and periodontal disease. A study of community-dwelling Korean adults (Kim et al, 2007) noted that having fewer teeth was significantly associated with dementia, an association that was even stronger for those without dentures. An abstract presented at a recent scientific conference (Stewart, 2007) followed 638 Swedish women since 1968, and demonstrated decreasing tooth number as a predictor of dementia. According to this study, "dental health is a prospective predictor of dementia which does not appear to be accounted for by cardiovascular comorbidity".

Mechanisms by which periodontal disease is related to dementia have been advanced and it is believed that a bacteremia is caused by the entry of oral pathogens into the bloodstream. This bacteremia leads to an elevation of serum cytokines which may play a role in microglia activation and atherosclerosis and potentially in the development of dementia. It has also been theorized that direct bacterial seeding of the brain, in combination with the genetically modulated release of interleukins, may lead to neuropathology.

Pre-term birth and low-birth weight pregnancies: Over four million babies were born in 2003 and of these, 12.3% were pre-term, and 7.9% were low-birth weight (Cuevas et al, 2005). Over five billion dollars is spent annually caring for these babies in their first year of life, many of whom will go on to survive with significant disabilities. This cost of care extends not only through the years, but to illnesses suffered by their caregivers as well. One study (Brehaut et al, 2004) of caregivers of children with cerebral palsy shows that they suffer from chronic illnesses at far greater rates than do general caregivers. Representative illnesses include back problems (35.5% versus 12.2% for general caregivers), migraine headaches (24.2% versus 11.2%), arthritis (17.3% versus 7.3%), asthma (15.8% versus 6.3%) and diabetes (3% versus 1.1%); 32.7% suffered from three or more conditions, as opposed to 10.1% of general caregivers.

It has been suggested that circulating cytokines resulting from periodontal inflammation lead to early labor, and may also restrict placental blood flow, thus leading to intrauterine growth restriction. A study of over one thousand pregnant women (Offenbacher et al, 2006) showed that women with good oral health delivered pre-term 11.2% of the time, while those

with periodontal disease had a 28.6% incidence of pre-term birth. When looking at women delivering very pre-term, those with good oral health had an incidence of 1.8%, as opposed to 6.4% of those with periodontal disease. Other studies have linked periodontitis to a sevenfold increase in premature birth (Moutsopoulos et al, 2006).

Diabetes mellitus: Periodontal disease and diabetes mellitus have been recognized for over twenty years as diseases that markedly impact each other. Poorly controlled diabetes may lead to the worsening of oral health, and untreated periodontitis has been shown to increase the risk of poor glycemic control (Brown et al, 1989). A later study (Thorstensson et al, 1996) reported that 82 percent of diabetics with severe periodontitis experienced onset of one or more major cardiovascular, cerebrovascular or peripheral vascular events during the study period of up to eleven years, compared with only 21 percent of diabetic patients without periodontitis. Later studies have confirmed that periodontal treatment can improve glycemic control (Albandar et al, 1996; Brown et al, 2002).

The total costs for caring for persons with diabetes was \$132 billion in 2002, with direct costs in excess of \$90 billion (CDC data). The bacteremia resulting from periodontal disease leads to elevated levels of IL-1 beta and TNF-alpha which, respectively, contribute to the development of type I and type II diabetes. Improvement in oral health to improve glycemic control has the potential to dramatically decrease these costs and the expenses associated with secondary diseases.

Respiratory diseases: Aspiration and its complications are major causes of morbidity and mortality for persons with developmental disabilities and others with limited mobility and/or immune compromise. The aspiration of periodontal pathogens into the airway may lead directly to the development of respiratory disease, whereas there is good evidence that improved oral health and frequent professional oral health care reduces the progression or occurrence of respiratory disease (Azarpazhooh et al, 2006).

There may also be a link between periodontal disease and chronic obstructive pulmonary diseases. A recent study evaluating data from NHANES-III (Scannapieco et al, 2001) looked at a population of 13,792 individuals and found that those with moderate loss of periodontal attachment were at greater risk for Chronic Obstructive Pulmonary Disease, and that increased attachment loss was linked to diminishing lung function in those individuals.

The costs surrounding treatment of those with respiratory disease are high and rising. Average total charges for the care of a patient with aspiration pneumonitis have risen from \$24,000 in 1993 to nearly double that figure just ten years later (CMS data). In considering the ancillary costs involved in the care of those with chronic respiratory diseases, this issue takes on added urgency.

Treating Periodontal Disease

There are three primary treatment approaches involved in the treatment of periodontal disease. Oral hygiene instruction, aimed at educating the patient and caregiver, is a key component in an ongoing professional dental relationship despite the fact that in and of itself such instruction is of limited value in improving oral health. Multiple studies have shown that scaling and root planing are effective, but it requires regular maintenance to secure treatment gains (Badersten et al, 1984; Nordland et al,

1987; Levine, Wilson, 1992). The third treatment approach is the use of pharmacotherapeutics, most notably chlorhexidine and doxycycline, as adjuncts to scaling and root planing, with numerous studies having confirmed their value in the overall oral health care plan. Studies have shown trends in the reduction of markers of inflammation such as IL-6 and c-reactive protein as early as one month following periodontal treatment (Elter et al, 2006).

It is well-documented that oral disease, while prevalent in the general population, is increased in incidence and severity for persons with special needs. A growing body of research is being reported in the medical and dental literature establishing a link between periodontal disease and several medical conditions, and future results are likely to show direct causality of systemic diseases due to periodontal pathology. We have clearly progressed past the point where oral health care can be looked at independent of the rest of medical care. Treatment of active oral disease, and the prevention of disease development and progression, should be seen and funded as a cornerstone of healthcare policy. The impact of such policy would result not only in improved health for individuals, but in decreased healthcare costs for our society. ❖

Dr. Evan Spivack is Director of the Special Care Treatment Center at the New Jersey Dental School-UMDNJ. This program provides comprehensive dental care for persons with developmental and other disabilities and works to educate dentists and future dental professionals in the care of these populations, and can be reached at 973-972-0098.

Volunteers Sought for Women's Health Study

The Arc of New Jersey is working with a group of researchers from Columbia University Medical Center and the NYS Institute for Basic Research in Developmental Disabilities on a study of women's health among women with Down syndrome. With funding from the National Institutes of Health, Dr. Nicole Schupf, Associate Professor of Clinical Epidemiology at Columbia University Medical Center and Head of the Laboratory of Epidemiology at the NYS Institute for Basic Research, is leading the research, which has the full support and cooperation of The Arc of New Jersey and approval from the New Jersey Division of Developmental Disabilities. The study will investigate how hormones and the changes that accompany menopause are related to health and cognitive changes in women with Down syndrome.

Dr. Schupf and her team are seeking volunteers who are **women between the ages of 30 and 45 years with Down syndrome**. Information about medical history, health and functional abilities will be collected approximately every 18 months over a three-year period. This work will take place at the day program or residence, and will be scheduled at the volunteer's convenience. The research procedures involve simple tests of abilities likely to be affected by aging or memory loss.

We hope this study will yield new understanding of the relationships between women's hormones and disease risks, and then point the way to improving the health of women with Down syndrome. If you are interested in learning more about this study or in having your daughter or relative participate, **please contact Diane Flynn at The Arc of New Jersey at 732-246-2525, ext 28, or via email at dflynn@arcnj.org.**

New Jersey's FY2009 Budget Signed into Law

Jessica Ganz

On June 30, 2008, Governor Jon Corzine signed into law the **Fiscal Year 2009 Appropriations Act**. Fortunately, despite the threat of cuts, services for individuals with intellectual and other developmental disabilities and their families were preserved, with one exception—the DDD-funded Community Professional Supports and Training (CPST) program was eliminated. Although the Division has provided assurances that those who had been receiving CPST services will be able to receive speech therapy, physical therapy, occupational therapy, and behavioral supports from the state Medicaid program, The Arc of New Jersey will be closely monitoring this situation, and urges anyone with a developmental disability who has difficulty accessing the medically necessary services that were previously available through the CPST program to contact Beverly Roberts, Director of The Arc of New Jersey's Mainstreaming Medical Care Program at broberts@arcnj.org or by phone at 732-246-2525, ext 34.

The Arc of New Jersey fought hard to ensure that the FY2009 budget included funding to address the critical need for community-based residential services for persons with developmental disabilities, as the waiting list of individuals who require such services has soared to more than 8,000. In the end, thanks to a budget resolution sponsored by Senator Loretta Weinberg (NJ-37), the New Jersey Department of Human Services will have \$12.5 million in FY2009 to reduce this waiting list, build capacity in the community and provide a ray of hope to families who have been waiting for years. The Arc of New Jersey is pleased with this appropriation, and pleased that, given the opportunity to become more informed about the severity of this issue, the legislature was willing to step up and take action that was long-overdue.

In another budget victory, this was the seventh consecutive proposed budget that **included** co-pays for Medicaid beneficiaries, and it was the seventh consecutive time they were **defeated**. A member of The Coalition for a Moral Budget, The Arc of New Jersey was instrumental in the ongoing advocacy efforts to defeat this proposed revenue generator, and also in compiling a comprehensive white paper outlining the research about the long-term ill-effects of co-pays.

Unfortunately, despite efforts by the Cost of Providing Care Coalition, of which The Arc of New Jersey is a member, the FY2009 budget did not include a cost of providing care increase for community provider contracts. The Coalition had advocated intensively for a 3.6% increase, with a barrage of nearly 20,000 emails reaching legislators' electronic mailboxes by the eleventh hour urging inclusion, but to no avail. This is, however, a most urgent fight, and we are well-poised to continue it. We believe the shift will come when legislators have become re-educated to the point where cost of providing care increases are viewed as *mandatory growth* rather than simply "Christmas tree items".

In addition to these identified priorities, the wrap-around coverage for dual-eligibles (those receiving both Medicare and Medicaid) has been continued for FY2009.

While The Arc of New Jersey recognizes the considerable fiscal restraints on the Legislature this year, it is difficult to feel any real satisfaction with New Jersey's FY2009 budget—and certainly we will not be complacent with regard to identifying next year's priority issues and preparing to advocate for them with vigor and resolve. ❖

Jessica Ganz is Director, Governmental Affairs, The Arc of New Jersey

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Mainstreaming Medical Care is a special program of The Arc of New Jersey
Advocating for quality health care for individuals with intellectual and developmental disabilities