

HEALTHY Times

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



June 4, 2010, 21st Annual Conference on Medical Care. Pictured L to R: Walter Bender, President, The Arc of New Jersey; John Guhl, Director, New Jersey Division of Medical Assistance and Health Services; Morning Keynote Speaker; Barbara Kornblau, JD, OTR/L, Dean of the School of Health Professions and Studies, University of Michigan-Flint; Beverly Roberts, Director, Mainstreaming Medical Care Program; Kenneth Ritchey, Assistant Commissioner, NJ Department of Human Services; Thomas Baffuto, Executive Director, The Arc of New Jersey.



Mark Nasjleti was the afternoon Keynote Speaker for the June 4th conference. A gentleman with Down syndrome, Mark has developed his own business, **Go Voice for Choice**, which provides presentations on making healthy lifestyle choices for people with developmental disabilities, their families and their caregivers.

Movement Disorders Associated with Developmental Disabilities

Roger Kurlan, MD

Problems with brain development can manifest themselves in a number of ways, one of which is disordered movements. One of the most common forms of disordered movement includes the presence of extra, often peculiar movements that generally fall into the categories of habits, mannerisms, stereotypies, compulsions and tics.

Habits are repetitive coordinated movements commonly seen in individuals without developmental disabilities during times of boredom or fatigue. Some habits, such as thumb sucking, occur during the course of normal development and may persist unusually long in children with developmental disabilities, while others, such as nose picking, can be socially inappropriate and may cause problems with socialization.

Mannerisms are peculiar or unusual characteristic ways of performing a normal activity, such as an odd way of walking or talking. Mannerisms are characteristic of patients with schizophrenia.

Stereotypies are coordinated, rhythmic, repetitive, patterned movements, postures or vocalizations that are repeated virtually the same way over and over again. These can be simple actions like body rocking, head nodding or moaning, or more complex actions like walking in circles, standing/sitting, or repeating certain words or phrases. Some stereotypies, like picking, scratching,

Movement Disorders, continued on page 8

The Balancing Act: Uncovering the Most Effective Treatments to Decrease Severe Behaviors and Increase Life Skills

Caroline Eggerding, MD

Every family of a child with an intellectual disability or autism tells a unique story. Many successfully meet day-to-day challenges with local resources and support. However, 10-15% of those with intellectual disabilities and autism develop challenging behaviors, such as self-injury, aggressive outbursts and tantrums that can damage surroundings, significantly impact the individual's quality of life, and take an enormous toll on family functioning. When community and school interventions are not successful, a more intensive multidisciplinary program is needed. Some families find their way to Bancroft's Lindens Neurobehavioral Stabilization Program, a short-term residential behavioral health program. There, challenging behaviors that threaten safety and well-being are addressed using a comprehensive team approach and applied behavioral analysis (ABA) techniques.

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Maintaining Healthy Skin

Sally Deeney, RN, BSN, CWOCN

People who have disabilities may develop skin breakdowns that can become chronic and serious. Individuals who use wheelchairs, wear leg braces, and have other medical conditions such as diabetes and impaired circulation are at greater risk to develop skin ulcers and infections. It is important for self-advocates and caregivers to have a good understanding of the dynamics of maintaining healthy skin.

The skin is an amazing, and often overlooked organ. It is the largest organ in the body and provides many important functions. Healthy skin can be maintained by understanding basic principles of structure and function. Skin breakdown can be avoided or corrected by understanding the reasons associated with skin breakdown as well as understanding the basic tenants of wound healing.

The skin is made up of an outer and inner layer. The outer layer is called the epidermis. This layer is relatively uniform in thickness with the exception of the palms and soles of the feet. This avascular layer regenerates approximately every four to six weeks with skin cells beginning in the base layer and moving outward to ultimately slough off. The inner layer is called the dermis. This layer contains blood vessels as well as hair follicles and sweat glands. The dermis also contains the protein fibers collagen and elastin to provide the skin with strength and elasticity. Just below the skin is the adipose or fatty layer. This provides the body energy reserve as well as cushioning.

The skin serves several important functions. It provides protection from external factors such as chemicals, bacteria, viruses, and more. It also prevents the body from losing excessive fluids or electrolytes. The skin helps the entire body to regulate temperature by dilating or constricting the blood vessels to either cool off or retain heat. The skin also regulates temperature by excreting sweat which serves to cool the skin. Finally, the skin provides body image through expression, communication, and personal identity.

There are several factors that can affect the skin. Age is a factor that cannot be controlled. The natural aging process results in a number of changes including a loss of collagen and elastin, increased epidermal turnover time, as well as a decrease in sweat glands, sebum production, and hair follicles. Sun exposure is a factor that can be modified. Excessive sun exposure leads to accelerated skin aging; dry, tough and wrinkled skin. Excessive exposure can also lead to cancerous changes, thus sunscreens should be used and avoid sun exposure during the peak hours of 10 AM to 4PM. Adequate hydration is another important factor to affect skin. Good oral fluid intake and adequate moisturizer application will promote healthy skin. Good nutrition is also essential. A diet balanced in protein, carbohydrates, fats, vitamins and minerals will maintain healthy skin. Healthy skin promotion can also be accomplished by the following; avoid smoking, use of gentle soaps and cleansers, and managing stress.

Reasons for Skin Breakdown

Skin breakdown can occur for many reasons. Upon initially experiencing an injury, the body should progress through specific phases of healing. This begins with hemostasis, wherein blood to the injured areas will clot. The next phase involves inflammatory factors that clean up any damaged or unhealthy tissue. Healthy tissue is then able to fill in the wound during the proliferative phase. Once the wound is filled in or covered the final stage is scar tissue formation, or the maturation phase. When a person is in good health, and no other factors prevent healing, a wound should go through these phases of healing in an orderly and timely manner.

Wounds that do not complete the healing process, or "get stuck" result in a chronic wound. A wound that has not improved in 4 weeks, or is not completely healed in eight weeks should be considered a chronic wound. Chronic wounds should be evaluated to determine what underlying problem or etiology is preventing or prolonging the healing process. Some of the most common etiologies associated with chronic wounds include: pressure, blood flow or circulation issues, diabetes or neuropathy, and infections. Identifying these underlying etiologies and correcting them is the first step in assisting a wound to ultimately heal.

Skin, continued. on page 3

Common Etiologies

Pressure ulcers may develop when the skin is compressed between a bony prominence and an external surface for a prolonged period of time. Other factors that can contribute to pressure related ulcers are friction and shear. Friction is a result of an abrasion on the epidermis and/or dermis; often seen as a result of sliding along a surface such as a mattress. Shear is a combination of both friction and gravity wherein the forces of gravity push down and resistance is seen between the body and the external surface. Excessive moisture also contributes to skin breakdown, and incontinence needs to be proactively managed. These forces can result in damage ranging from a reddened epidermis to a wound extending all the way to bone or other supporting structures. Corrective action must be taken to relieve pressure through position changes, off loading mattresses and seat cushions.

Wounds can also develop and/or have delayed healing as a result of inadequate circulation. Inadequate arterial circulation results in a decreased or absent amount of oxygen-rich blood being carried to the limbs. When this occurs, there are not enough nutrients to maintain healthy tissue or heal a wound. Poor venous circulation can also contribute to wounds. The veins function to bring oxygen-poor blood back to the heart. When the veins fail to do this adequately, excess fluid pools in the limbs and leads to swelling and wound formation. Similar swelling can also be seen as a result of compromised lymphatic flow, and wounds can also develop. Once identified, issues of circulation can be managed through surgical intervention or, in the case of venous or lymphatic inadequacy, through compression and elevation.

Neuropathic wounds are another type of wound and most commonly associated with diabetes. The loss of sensation associated with neuropathy can directly lead to wounds; a classic example of this is walking with shoes that are ill-fitting and not being able to feel that a blister and ultimately a wound is being formed as a result. Because the ability to feel is no longer present, those with neuropathy need to rely on visual inspection in order to check for skin breakdown. Any areas of pressure or tissue damage need to be correctly offloaded.

Principles of Wound Management

Once a wound has formed, there are several components to address in order to heal the wound and prevent further breakdown. The first factor to consider is the etiology. Once this is determined, it is then possible to alleviate that underlying problem (e.g., restore circulation or eliminate pressure). Next determine if the wound has any infection present by checking for surrounding redness, increasing pain, fever, cultures, etc, and treat accordingly. Infection can be present in the wound bed only and thus treated with products designed to kill bacteria locally, or it can be present in the entire body and be treated systemically with antibiotics. *Nutritional status also needs to be evaluated and treated if needed.* Protein is an essential part of skin and additional amounts may be needed to heal a wound. Some other nutritional elements important in skin formation are vitamins A and C, as well as zinc. These and others should be considered on an individual basis and supplemented accordingly.

Dressing the wound can be a confusing dilemma with a wide variety of wound care products available on the market. There are basic "rules" that should be considered to help select an appropriate dressing. Wounds heal best in a relatively moist

environment. Current products are designed to provide this. If a wound is draining heavily there are products that will absorb the excess and still maintain that moist environment. If a wound is dry, then a product should be used that will add moisture to the wound bed in order to promote healthy cell growth. All open cavity or "dead space" needs to be filled in. This means if a wound presents as a large crater, then dressing material should be packed into all dead space with each dressing change. Determining when to change the dressing will be driven by how much drainage is present and the type of product that is being used.

Conclusion

The skin is an important organ in the human body. Understanding how the skin works, and ways to promote good skin health will allow for maintaining healthy skin. If breakdown does occur, remember the basic information in order to promote wound healing. Determine the underlying problem that has caused or delayed wound healing and eliminate it. Identify and treat any infection or nutritional deficiencies that may exist. Finally select dressing products that will fill all open cavities and provide for moist wound healing. *Speak with your health care provider about the advisability of consulting with a wound care specialist if a chronic skin breakdown develops.*

Sally Deeney, RN is a Nursing Coordinator for the Wound Healing Center at Morristown Hospital.

Diabetics are More Susceptible to Heat Complications

According to a study published recently in The Journal of Applied Research, a complication of diabetes, both Type 1 and Type 2, is the body's impaired ability to adjust to rises in temperature, which can cause dangerous increases in body temperature during the summer.

The underlying problem, nerve damage, occurs in 60 to 70 percent of Americans with diabetes and can affect nearly every organ in the body, including sweat glands. When nerve damage keeps the sweat glands from working properly, the body fails to cool down as the air temperature increases.

In addition, research from the Mayo Clinic has shown that (1) diabetic patients have higher rates of hospitalizations, dehydration and death in the heat, and (2) a majority of individuals with diabetes are unaware of the greater risk and of the need for special precautions.

Diabetes is a critical health care issue for many populations, including those with intellectual and developmental disabilities. It is extremely important that caregivers of persons with I/DD who have diabetes ensure proper hydration of their family member or consumer and monitor the individual's temperature to make sure they stay cool, particularly during the hot summer months.

The Impact of National Health Reform on Individuals with Developmental Disabilities in New Jersey*

**The following is a condensed version of A Preliminary Overview of the Impact of National Health Care Reform on Individuals with Developmental Disabilities in New Jersey, prepared by The Arc of New Jersey; the full report is available at www.arcnj.org.*

In March 2010, the Patient Protection and Affordable Care Act (PPACA) and the Health Care and Education Affordability Reconciliation Act (HCEARA) were signed into federal law. Together, these health reform laws will have direct and indirect benefits for individuals with intellectual and other developmental disabilities nationwide.

IMPROVED ACCESS TO HEALTH COVERAGE

Private insurance companies will be prohibited from:

- Excluding or rejecting consumers based on pre-existing conditions (effective 09/23/2010 for children ages birth through 18; effective 01/01/2014 for everyone else).
- Charging higher premiums based on pre-existing conditions (effective 09/23/2010).
- Dropping a beneficiary who becomes ill (effective 09/23/2010).
- Placing any lifetime limits on coverage (effective 09/23/2010), and any annual limits on coverage (effective 09/23/2010 for new plans and existing employer plans; effective 01/01/2014 for all others).
- Considering disability and health status when setting premiums; specifically, insurance eligibility rules based on health status (including medical conditions, mental illness and disability) are barred for both individual and group plans (effective 01/01/2014).

Private insurance companies will be required to:

- Guarantee issue and renewal of policies; specifically, insurance companies must accept every employer and individual who applies (effective 01/01/2014).
- Provide coverage to a beneficiary's dependent child up to the age of 26, regardless of the dependent's place of residence or marital status (effective 09/23/2010). *In some cases New Jersey law already extends coverage to a beneficiary's dependent child until age 30, although a higher premium can be charged for that dependent.

Health Insurance Marketplace Exchange

- A state-based health insurance marketplace Exchange is intended to increase choice and foster competition by enabling consumers to compare coverage and premiums (effective 01/01/2014). States may choose to run their own Exchange (New Jersey has not yet announced whether it will or not).
- The federal Department of Health and Human Services (DHHS) will oversee multi-state plans and will subsidize premiums for individuals with incomes up to 400% of the Federal Poverty Level (effective 2014).
- In order for private insurers to participate in these exchanges, minimum benefit standards and limitations on cost sharing must be met; and of particular note, coverage for rehabilitative and habilitative services and devices will be required.

- Effective late June 2010 (through January 1, 2014) there will be a temporary High Risk Insurance Pool geared toward individuals with pre-existing conditions who were uninsured for six months prior to applying for coverage in the pool. This high risk pool is a stop-gap measure until the new marketplace Exchange is up and running. While New Jersey is not one of the 34 states that currently run their own high risk pools, Governor Christie has committed that New Jersey will run its own high risk pool.

Medicaid Expansion

- Medicaid eligibility will increase to 138% of the Federal Poverty Level (effective 2014), and Medicaid reimbursement for physicians and pediatricians will increase in 2013 and 2014.
- The creation of a Federal Coordinated Health Care Office will address care coordination for dual eligibles (those receiving both Medicaid and Medicare).
- A new HCBS (Home and Community Based Services) spousal impoverishment protection (effective 01/01/2014, for five years) that will permit spouses of individuals receiving Medicaid home and community based services to keep half of the couple's assets with a maximum (approximately \$2,700 a month in income and about \$22,000 to \$110,000 in assets).

IMPROVED ACCESS TO LONG TERM SERVICES / SUPPORTS

The Community Living Assistance Services and Supports (CLASS) Program

- The CLASS Program will make long-term care insurance available to all working Americans, who will be automatically enrolled with the choice to opt out.
- Beneficiaries will pay a monthly premium, either individually or through their employer, that is expected to be approximately \$120 per month with exceptions for full-time students and those living below the Federal Poverty Level (who will have a \$5.00 per month premium).
- After five years, beneficiaries with functional limitations (need for assistance with activities of daily living) will have the option of receiving a cash benefit of around \$50 a day to offset long-term care costs.

The Community First Choice (CFC) Option

- The CFC Option is a new state Medicaid option (effective 10/01/2011) that will require participating states to provide self-directed services statewide in the most integrated setting appropriate to the individual.

The Home & Community Based Services (HCBS) State Plan Option

- Amendments to the current Medicaid Home and Community Based Services (HCBS) Option (not the Waiver) went into effect on April 1, 2010, although New Jersey does not currently utilize the HCBS State Plan Option.
- States can expand income eligibility to 300% of SSI and target specific populations for five years.
- Limitations on type/scope of services available under the HCBS Option have been removed and states can now offer an or all of the same services allowed under the HCBS Waiver.
- States cannot cap the number of eligible people, maintain waiting lists or limit services to certain geographic areas.

State Balancing Incentives Program

- States can choose to participate in a new State Balancing Incentives Program, which will temporarily (10/01/2011 through 9/30/2015) increase the federal Medicaid matching rate for participating states that undertake structural reforms to increase diversion from institutions and expand the number of people receiving home and community based services. To be eligible for participation, states must implement a single point of entry system, a standardized assessment instrument for determining eligibility, a system for monitoring capacity, a data collection infrastructure and case management services.

Money Follows the Person Rebalancing Demonstration Extension

- In 2007, New Jersey received a five-year, \$30.3 million grant to transition 590 individuals (329 of those are individuals with developmental disabilities) from institutional care to home and community based services. The Rebalancing Demonstration provides for enhanced federal medical assistance percentage (FMAP) for 12 months for each person transitioned from an institution to the community during the Demonstration period (extended through 2016).

DISABILITY-SPECIFIC PROVISIONS

Closing gaps in health care delivery to people with disabilities

- The federal Department of Health and Human Services (DHHS) will be required to collect, analyze and monitor data for trends in health disparities in people with disabilities (as well as other populations) and make reports available.
- By the end of March 2012, minimum accessibility criteria must be established for medical diagnostic equipment used in (or in conjunction with) physician's offices, clinics, emergency rooms, hospitals and other medical settings, ensuring that equipment is accessible to and usable by individuals with accessibility needs.

REMINDER! NJ individuals with developmental disabilities who are Medicaid beneficiaries have a choice about whether they receive health care from a Medicaid HMO or from the fee-for-service (regular Medicaid) system. Before making any changes, it is necessary to check with the individual's health providers to learn whether they will be available if the individual's method for accessing health care is changed. Changes made within the Medicaid system – including switching to another HMO, or enrolling in/disenrolling from the Medicaid managed care system – are effective on the first day of the month. The “cut-off” date to make a switch is usually two weeks before the end of the month. For example, if a request for an HMO change was made during the first two weeks of August, the effective date for the change would be Sept. 1st. But a request for an HMO change made during the last two weeks of August would not be effective until Oct. 1st. The phone number to use when requesting any of the aforementioned changes is **1-800-701-0710**.

If individuals with developmental disabilities have difficulty accessing medically necessary providers and services within the Medicaid managed care system, please contact Helen Rivera at **hrivera@arcnj.org** or **732-246-2525, x35** with the *specific* details of the problems encountered.

- A new National Health Care Workforce Commission will be created to coordinate and communicate with the Departments of Health and Human Services, Labor, Veterans Affairs, Homeland Security and Education; determine whether the demand for health care workers is being met; identify barriers to improved coordination at the Federal, State and local levels; encourage innovations to address changing needs, technologies and the environment; and analyze the health care workforce needs of special populations, including individuals with disabilities, and making recommendations for policies to meet those needs.

New grant programs targeting individuals with disabilities

- Community Transformation Grants will be available to state and local government agencies, and community based organizations and nonprofits to implement, evaluate and disseminate evidence-based community programs to prevent the development of secondary disabilities and reduce chronic disease rates.
- Grants will be available to (1) enhance training for primary care providers and to support and develop training for dentists, including specific training in the care of vulnerable populations, (2) provide training opportunities for direct care workers, and (3) develop training and certification programs for personal or home care aides with core training competencies including training specific to individuals with developmental disabilities.

ADDITIONAL RESOURCES

The White House:
www.whitehouse.gov/healthreform

US Department of Health and Human Services:
www.healthreform.gov

Kaiser Family Foundation:
<http://healthreform.kff.org>

Medicaid Prior Authorization Now Required for Medically Necessary Diapers

Medicaid has set up a new process for Medicaid beneficiaries who are incontinent and need diapers. Medicaid now requires a prior authorization process, with a mail-in (not a fax) of the request. **The Medicaid prior authorization expires after 6 months**, at which time the consumer must have a new prescription from the doctor and receive approval from Medicaid again. Ideally, there should be a 3-day turnaround from when the Medicaid office receives the paperwork. It is recommended, however, that caregivers initiate the request for diapers early, to avoid running out of this essential supply.

If caregivers are having a problem getting the medically necessary diapers and they need emergency intervention, they should reach out to the Medicaid Assistance Customer Center (MACC) that serves their county, and speak to the Director. You may contact Helen Rivera at **hrivera@arcnj.org** or **732-246-2525, x35** for a current list of the MACC offices, which includes the Director's name and phone number. That list is also available at www.arcnj.org.

Meet Annie*

By 9 years of age, Annie had been admitted to a psychiatric hospital. She had been diagnosed with fetal alcohol syndrome, pervasive developmental disorder, intermittent explosive disorder and attention deficit disorder with an intellectual disability, and her medication list included Clozaril, Cogentin, Buspar and other prescription drugs. Her behavior was regularly self-injuring, her tantrums were frequent and she was unable to communicate effectively. Annie's home was not safe as a result of her behaviors, and her adoptive parents feared that Annie would never lead a happy or productive life.

In the past, New Jersey children and adolescents with intellectual disabilities and severe emotional/behavioral challenges were often sent to out-of-state residential facilities. In Annie's case, however, her parents were led to the Lindens Program, a residential neurobehavioral stabilization program in Haddonfield, New Jersey. Lindens is run by Bancroft, a private, nonprofit organization providing programs and supports for children and adults with intellectual and developmental disabilities, autism and acquired brain injuries. The program specializes in treating children with intellectual and developmental disabilities whose behaviors have progressed to the point that they cannot participate in typical family life, school and community recreational and socialization opportunities.

The Lindens Program became Annie's new home, and the task of helping Annie required a team effort that included the Lindens staff and Annie's family. The goals for Annie's admission included decreasing her self-injurious behavior, aggressions, disruptions and tantrums. The family and the Lindens team also agreed to work on improving the quality of her speech and her use of expressive language and social interactions. Upon Annie's admission, the reasons for Annie's challenging behaviors were identified through functional analysis and the team learned that Annie's tantrums and difficult behaviors occurred when she sought highly preferred objects and activities. The behavioral team further explored Annie's preferred objects and activities in order to identify motivating experiences for her. The team proceeded with a comprehensive treatment plan focused on positive supports. The plan included ignoring her difficult behaviors, blocking dangerous behaviors (without reinforcing them) and rewarding positive behaviors. The team also prompted her through tasks, rewarded appropriate verbal requests and used a timer to help her "wait."

A structured schedule helped support Annie during treatment. Appropriate behavior was reinforced; the team worked to improve communication and adaptive skills; and Annie was progressively weaned from her prescription medications. By the end of her stay, the team reported a decrease in Annie's severe behavior by more than 50%, and her language skills improved significantly, with intelligibility improving from 48% to 71%. Annie was discharged to a community group home setting six months after she arrived at the Lindens program and was on no medications at the time of discharge. She continued to thrive at the group home and is now back with her family and attending a community school program.

Treatment at the Lindens

The Lindens Program is centered on applied behavioral analysis, or ABA, and program participants are supported by a team of professionals that includes behavior analysts, psychiatrists, neurologists, speech and language pathologists, nurses, social workers and other clinical experts. Throughout a child's stay, the team reviews nutritional and general health to identify concerns that may contribute to disabling behavior patterns. A speech and language pathologist addresses communication deficits that frequently contribute to challenging behaviors and works with the family and other team members to identify the best interventions to improve language skills. A neuropsychology screen and psychiatry evaluation define any associated mental health diagnosis and help determine appropriate medications that could enhance the overall treatment plan. Teachers are available to provide on-site learning opportunities and transition the child as soon as possible to a more typical classroom. And social workers consider family supports and cultural needs, and assist in planning for life beyond the Lindens.

As treatment progresses, training on daily living and functional skills is provided to further prepare participants for a less restrictive setting. Training includes appropriate social behavior, communication, personal care, cooking and academic and vocational skills.

Bancroft's Lindens Neurobehavioral Stabilization Program works to decrease the intensity and occurrence of severe behaviors and increase the life skills in children and adolescents with intellectual and developmental disabilities. The Lindens Program utilizes a comprehensive, multi-disciplinary team approach in order to accomplish these goals and, hopefully, restore participants' ability to live in a less restrictive community setting.

To learn more about the Lindens Program, or other programs and services offered by Bancroft, please visit www.bancroft.org or call 800.774.5516.

Dr. Eggerding serves as Vice President of Clinical Services and Chief Medical Officer of Bancroft, and is the current Chairperson of the New Jersey Governor's Council for the Research and Treatment of Autism.

ONLINE SURVEY: FAMILY AND INDIVIDUAL NEEDS FOR DISABILITY SUPPORTS (FINDS)

The Arc of the United States is conducting an anonymous, confidential survey (until September 1, 2010) to capture the perceptions of individuals with intellectual and developmental disabilities and their families, on issues concerning disability support needs across the life spectrum. The link for the survey may be found at www.arcnj.org, or by going directly to:

<http://www.surveymonkey.com/s/TheArcFINDS2010>

We encourage all individuals with I/DD and their family members to participate in this survey.

Division of Child Behavioral Health Services: Need-Driven, Youth and Family Guided Services

Dr. Nadezhda Robinson

(Editor's Note: The services available to New Jersey's youth {case management, in-community and in-home therapeutic services, evidenced based practices, out-of-home treatment settings and non-traditional resource access} are available to all youth with mental health needs who are enrolled in the DCBHS system, including children and adolescents with developmental disabilities.)

Ten years ago, New Jersey state planners secured one of the first grants awarded by the federal Substance Abuse and Mental Health Services Administration (SAMHSA) to build a statewide system of child behavioral health services and care. By 2005, New Jersey's Division of Child Behavioral Health Services (DCBHS) had developed a statewide system of care with community based services available in every county for youth with emotional and behavioral health challenges and their families. The system is based on public-private partnerships where local service providers contract with DCBHS to provide services that are need-driven, strength-focused and guided by the youth and families themselves.

DCBHS is a sister division to the Division of Youth and Family Services (DYFS) and is housed within the New Jersey State Department of Children and Families (DCF), which is dedicated to the safety, health and well-being of youth and their families. This service system allows families to access mental health services without having to "open a case" with DYFS – a significant change from the past. Services are available to youth and families before young people become involved in the juvenile justice system or as an alternative to that system when appropriate. Youth and their families – whoever that may be: grandparents, kin, biological or adoptive parents, etc. – are served with the goal of keeping children in their homes, their own communities, engaged in school and out of legal trouble.

DCBHS offers a wide variety of mental health services to youth and their families. This includes varying intensities of case management, in-community and in-home therapeutic services, a variety of evidenced based practices, out-of-home treatment settings and non-traditional resource access. Case management is focused on

accessing and utilizing all resources available to youth and families: maximizing and coordinating all resources. These services available through DCBHS have demonstrated various positive outcomes for youth in improved behavior, emotional regulation, interpersonal relationship functioning, school functioning, and coping skill reliance.

DCBHS places a high priority on the promotion of evidence-based and evidence-informed children's mental health services in New Jersey. Overwhelming data and literature demonstrate many youth and families, historically viewed as not amenable to treatment, make sustainable positive changes when the right interventions are employed. DCBHS is focusing state resources on supporting these interventions.

DCBHS provides a central point of access via a contracted systems administrator, PerformCare, for all DCBHS services. PerformCare maintains a call center, staffed by independently licensed mental health clinicians, which ensures families have access to services and ongoing quality assurance. Families may call the 24-hour, seven days a week, toll-free Access Line at: **877-652-7624**.

A licensed clinician at PerformCare assists the family in identifying the mental health needs of the youth and his/her family's intensity of need. Youth may be eligible for an initial biopsychosocial and needs assessment, conducted in their home by a licensed professional clinician, to determine appropriate care. Youth already engaged with a mental health service provider will be encouraged to have their provider contact PerformCare to collaborate in planning. Youth with immediate and imminent risk needs will be connected with emergency services to address immediate safety and risk concerns. Youth with moderate to high or immediate intensity of need who do not need police or screening intervention will be connected with DCBHS's urgent response system, Mobile Response and Stabilization Services.

The number of youth and families receiving services through DCBHS continues to grow. The reported figure of DCBHS enrolled youth for State Fiscal Year 2009 was 41,614. Additional information about DCBHS is available on the web at: <http://www.nj.gov/dcf/behavioral/>.

Dr. Robinson is the Director, Division of Child Behavioral Health Services, New Jersey Department of Children and Families.

RESOURCES



Now Available! The **Family Emergency Quick Reference Guide**, a brochure that provides very helpful and concise information for families to know if their loved one is experiencing a mental health crisis. This brochure is a companion to the free, 33-page Family Crisis Handbook which was widely disseminated several months ago. The brochure and handbook were written by Donna Icovino, Family Advocate and Co-Chair of the NJ Department of Human Services Dual Diagnosis Task Force, and Lucille Esralew, Ph.D., Program Director, Statewide Clinical Consultation and Training (SCCAT), Trinitas Regional Medical Center. These materials are also available on our website: www.arcnj.org; click on "Information;" then "Issues and Resources;" then "Dual Diagnosis (mental illness/developmental disability)."

The Elizabeth M. Boggs Center on Developmental Disabilities has published **Being a Healthy Adult: How to Advocate for Your Health and Health Care**, a guide to assist young adults with disabilities in becoming strong advocates on behalf of their own health. The guide, which is free of charge and available in both English and Spanish, includes activities, worksheets, and tips for communicating effectively with health care providers. For information or to receive a hard copy, contact Kathy Roberson at **732-235-9317** or kathy.roberson@umdnj.edu. The booklet is also available to download and print at the Boggs Center's website: http://rwjms.umdj.edu/boggscenter/products/Product_Health.html

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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*

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hitting or poking, can be self-injurious. Approximately one-quarter of people with cognitive disabilities living in institutions have stereotypies. Stereotypies are also commonly seen in persons with autism and autism spectrum disorders and the congenitally blind and deaf. Some believe that stereotypies occur due to inappropriate brain processing of external stimuli, while others conjecture they are a form of self-stimulation or perhaps a way of counteracting overstimulation. Stereotypies seem to be linked to abnormal dopamine neurotransmission in the brain, and when they are self-injurious or disabling, antipsychotic medications (which block dopamine receptors) can be used.

Compulsions are repetitive, seemingly purposeful behaviors that are often performed (1) in response to an obsession (such as frequent hand washing in response to a fear of germs), (2) according to certain rules (i.e., performed in a certain order or a specific number of times), or (3) to ward off harm to self or others. Individuals usually attempt to ignore, resist or suppress the compulsions. Disabling obsessions and compulsions are referred to as Obsessive-Compulsive Disorder (OCD) and have been linked to abnormal serotonin neurotransmission in the brain. Available treatments include cognitive-behavioral therapy, serotonin-reuptake inhibitor medications and, for severe cases, deep brain stimulation surgery.

Tics are involuntary jerks and twitches (motor tics), noises or sounds (vocal tics). When there are multiple motor and vocal tics and they are chronic, the diagnosis of Tourette's syndrome (TS) is often made (there is a close but complex relationship between TS and developmental disabilities). Tics commonly occur in people with cognitive disabilities, autism, Asperger's syndrome and developmental stuttering, and are linked to excessive dopamine neurotransmission in the brain. When disabling, tics can be suppressed by guanfacine and antipsychotic medications.

Many children and adults with developmental disabilities are treated with medications that can induce movement disorders. The most common class is antipsychotic drugs, which are often prescribed to treat agitation and aggressive behavior. These medications can cause restlessness (akathisia), symptoms like slowness, stiffness and tremor that can resemble Parkinson's disease (parkinsonism), and involuntary movements of various types such as lip and tongue movements (tardive dyskinesia). Such problems can often be ameliorated by decreasing the dosage or switching to other types of drugs (the newer "atypical" antipsychotics seem less likely to cause these side effects).

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