HEALTHY Times

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

Dr. Ana Gomes received the Healthcare Professional of the Year Award from The Arc of New Jersey, October 28, 2010.
See page 3 for Article on Dr. Gomes' award

Dementia in Aging Adults with Developmental Disabilities

Seth M. Keller, MD

A number of years ago I never put much stock into thinking about my own physical condition as an older person, but now that I'm about to turn 50 years old, it has begun to creep into my thoughts. I have been caring for adults with and without developmental disabilities (DD) for a good number of years, and certainly I have seen the various problems that aging can have upon our bodies and mind. It became obvious that the baby boomer generation is living longer and that healthcare and social practices must keep up with these trends. Adults with DD who are aging do now and will continue to strain the system of care especially because of current inadequacies in training and governmental support. Dementia is one of the accepted consequences of aging that will occur, and we must be prepared to know how to help with this challenging, life altering circumstance.

Life expectancy of individuals with DD has significantly increased over the past fifty years, and this has led to an increased risk of aging-associated disability in mental and neurological functions. As with the general population, dementia is a growing source of morbidity and mortality, and is known to be associated with unique caregiver issues, considerable burden and rising care costs. The mean age at death for persons with DD rose from 19 years during

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Community Based Programming for Children with Severe Behaviors: The Challenge of Keeping These Children in New Jersey

Russell J. Kormann, Ph.D.

When discussing the development of programming for children and adults with autism and other developmental disabilities who also present with serious behavioral and/or psychological challenges, ideology and practical reality often collide. The Olmstead decision in community services, and the initiation and reauthorization of the Individuals with Disabilities Education Act and the No Child Left Behind Act in educational circles, were not only landmark decisions, but also created significant challenges for service providers across the country. Individuals with developmental disabilities who present with medical, psychiatric and/or behavioral challenges are now returning to our in-district classrooms and communities at an ever-increasing rate. The federal government has made the message clear: "Provide services for all individuals with special needs that are natural setting based and least restrictive in nature, and do it quickly." The community has heard the message and responded with an unprecedented emphasis on community integrated housing and inclusive educational programming. Critical questions, however, remain unanswered: What clinical services are needed to best ensure that students and residents with developmental disabilities and behavioral challenges are supported in the most effective way possible? How can we best assist in the return of students who have historically been served by out of state residential treatment facilities to their natural homes and local school districts while providing them with the clinical services that their behavioral profiles require?

Specialized Treatment for Children with Special Needs

Children that present with a combination of developmental disabilities and severe behavioral and/or psychiatric disorders have been labeled as dually diagnosed and make up a significant portion of the DD population. When considered with medically frail individuals, this population represents a group that requires more intensive, specialized residential care (i.e. developmental centers), academic

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The Arc
of New Jersey

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www.mainstreamingmedicalcare.org

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We welcome comments and suggestions for future articles, and readers are encouraged to re-print or excerpt articles; please credit *Healthy Times* and **The Arc of New Jersey**, and forward copies to:

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CPR and DNR Decision Making

In a recent article in the quarterly newsletter, *Age in Action* from the Virginia Department for the Aging, Viki Kind, MA gives an excellent summary of the considerations involved in end-of-life decision making. While the article is not specific to individuals with developmental disabilities, it encompasses many important factors to consider when making end-of-life decisions for a loved one. As individuals with developmental disabilities age, these end-of-life decisions will often need to be made. A brief summary of the considerations mentioned in the article:

- CPR or cardio pulmonary resuscitation used to be simple to understand. In the past, it was a physical procedure used primarily on patients who were having a heart attack and who might benefit from an attempt to restart the heart.

- Over time, life saving procedures have become more complex, and can involve, in addition to CPR, medication, electrically shocking the heart with paddles and/or use of a ventilator. Every year, researchers adapt life saving procedures to try to save more lives, not just those having a heart attack. As the process has become more complex, the communication of the patient's wishes needs to be more specific.

- The scope of a physician's Do Not Resuscitate Order varies from state to state and, in some cases, hospital to hospital. The regulations of NJ's Division of Developmental Disabilities seek to clarify some distinctions by separating Do Not Resuscitate orders from decisions to Withhold or Withdraw Life Sustaining Medical Treatment. The regulations define a Do Not Resuscitate Order as "a physician's written order not to attempt cardiopulmonary resuscitation in a hospital or out-of-hospital situation in the event the individual suffers cardiac or respiratory arrest." Further interventions related to Decision Making for the Terminally ill are defined in regulation as "Life Sustaining Medical Treatment (LSMT), the use of any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery, or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function and thereby increase the expected life span of the individual."

- In practice, CPR is effective on healthy patients only 17% of the time (Peberdy, et al. 2003) and for patients with health problems, the effectiveness is near zero. *In addition, the procedure can have serious complications, including broken ribs, a collapsed lung, damage to the windpipe, and even brain death.*

- Decision-makers need to be educated more fully about current CPR and other end-of-life procedures so that they can more effectively make a compassionate decision about whether their loved one would want to have CPR or other interventions performed.

- It is important to have these conversations early, well before the critical decision needs to be made. Communication is vital. If a health care directive or DNR (do not resuscitate) order is in a loved one's medical records, the family needs to make sure that both they and the physician are aware of how that facility will interpret the instructions and the likely consequences. Vigilance is necessary to make sure that the instructions are clearly marked in the patient's chart and that everyone in charge of the individual's care is aware of the directive and its *case-specific* instructions.

Questions related to New Jersey residents with developmental disabilities who have a legal guardian, can be directed to Jessica Anastasi, Chief of NJ's Bureau of Guardianship Services at Jessica.Anastasi@dhs.state.nj.us.

An electronic copy of the full article can be obtained by contacting Helen Rivera at hrivera@arcnj.org.

Dr. Ana Gomes Named Healthcare Professional of the Year

The Arc of New Jersey's Healthcare Professional of the Year Award was presented on October 28, 2010 to Dr. Ana Gomes, an outstanding physician serving people with developmental disabilities in Warren County.

Dr. Gomes is a family practice physician and owner of Kaleidoscope Medical Associates in Philipsburg, NJ. In addition to her own practice, Dr. Gomes is also the medical director at two local nursing homes and a volunteer medical director and practicing physician at Life Choices, Inc., a pregnancy help center in Philipsburg.

Dr. Gomes has been actively involved in the care of persons with developmental disabilities for many years. Her own experiences in childhood help her to appreciate the gift of life at every stage and she treats each patient as an individual worthy of dignity and respect.

In 2009, Dr. Gomes was awarded The Arc of Warren's Professional Services Award for the excellent care she provides for patients with developmental disabilities. The Arc of Warren describes Dr. Gomes as "one of the few medical professionals who treat our consumers without worrying about Medicaid paying the bill, takes care of all the paperwork, and has been known to go out of her way to make our consumers less fearful about procedures they undergo in her office. She takes her time with them, as well as with staff and family members, to answer every question."

Peter* has multiple developmental disabilities and is a patient in Dr. Gomes' office. We spoke to his mother about Dr. Gomes. Peter's mother told us that what is so wonderful about Dr. Gomes is her "common sense" approach to healthcare. Because she is a family physician, she treats not just Peter, but the whole family. If Peter is ill with the flu, the whole family will be treated. Peter's mom describes Dr. Gomes as gentle and respectful to people with disabilities. "She speaks to them like a person and I really appreciate that."

It is clear that Dr. Gomes is a dedicated professional, committed to gentle and compassionate care for persons with developmental disabilities. Congratulations to Dr. Gomes for being The Arc of New Jersey's Healthcare Professional of the Year!

**not his real name*

Guide to Hospice and Palliative Care

United Hospital Fund's Next Step in Care has published a ***Family Caregiver's Guide to Hospice and Palliative Care.*** This guide answers a number of important questions when making end-of-life decisions, including whether to transition to hospice or to continue with only palliative care. It also provides the nice side-by-side comparison of Hospice vs. Palliative care, reproduced below. To view the guide, visit: **http://www.nextstepincare.org/uploads/File/Guides/Hospice/hospice.pdf**

	Palliative Care	**Hospice Care**
Goals	To assess and treat the patient's pain and other physical, psychosocial, and spiritual problems.	To keep the patient comfortable, as free as possible from pain and symptoms, and allow him or her to maintain a good quality of life for the time remaining. Hospice accepts death as an inevitable outcome for a patient with a terminal (end-stage) illness. In hospice, both the patient and family are the focus of care.
Patients	Palliative care accepts patients who have complicated or advanced medical disease. There is no time limit in terms of life expectancy --patients may or may not be dying. Patients can get treatments intended to cure. They also can participate in research studies.	Hospice only accepts patients who are near the "end of life" (meaning they have a terminal illness) and are likely to die within 6 months if the disease runs its normal course.
Where care occurs	Palliative care is usually given in hospitals. Sometimes it takes place at nursing homes or assisted living facilities. Palliative care at home is possible but not readily available.	Most hospice care happens at home, although it can also be given in other settings as well, such as the hospital, nursing home, or assisted living facility.
Who provides the care	Palliative care is a medical subspecialty. This means that doctors and nurses who practice palliative care have extra training about ways to manage symptoms. They work with a team of other professionals.	Hospice care is a team approach, led by doctors and nurses with special training. Specialists may provide spiritual, psychosocial and other care. Hospice care may require a lot of time and effort from the family.
Paying for services	There is no special insurance benefit for palliative care. The patient's health insurance generally covers palliative care services.	Hospice is a Medicare (federally funded) program. Many state Medicaid plans and private health insurance plans pay for hospice. A patient who chooses the Medicare hospice benefit agrees to give up treatments meant to cure disease. This is in return for other types of support and supplies.

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(special education/self contained instruction) or combined (residential schools serving behaviorally involved students) programs. One of the most well respected treatment facilities serving students with severe clinical profiles is the Neurobehavioral Unit (NBU) at the Kennedy Krieger Institute (KKI) in Baltimore, Maryland. The KKI website describes the Neurobehavioral Unit in part as:

> *A unique program that specializes in the treatment of severe and highly treatment resistant problems, provides intensive behavioral assessment and treatment services not available elsewhere, offers integrated and targeted application of behavioral and pharmacological interventions, and espouses a data-based approach. Criteria for admission are that behavior is of such a severity and/or intensity that the individual is a danger to him or herself and is at risk for long-term residential placement.*

The KKI program is designed to provide the extensive programmatic and environmental structure that treating individuals with severe behaviors require. Grounded in Applied Behavior Analysis, programs such as KKI seek to provide a treatment environment and a trained professional staff that can tolerate the display of severe behaviors and withstand their inevitable escalation. Concurrently, these programs seek to present patients with alternative and more adaptive behavioral skills through the development of new programmatic contingencies. These programs, however, are often complex and are built on the results of multi-factor, functional behavioral assessments and performance data that is often collected multiple times per hour. The combination of antecedent and consequence driven behavioral programming carried out by well trained staff members make facilities like The Kennedy Krieger Institute effective in managing severe behaviors.

Maintaining this type of treatment environment as separate from the “typical” community has always been multi-functional if not controversial: Centralization of expertise and “protection” of the community from disruptive or dangerous behaviors represented the philosophies which drove treatment. Such programs however, exact an extraordinary physical and emotional toll on the staff members charged with its implementation. The provision of constant clinical intervention coupled with the ability to tolerate the effects of behavioral escalations make treatment fidelity and staff burnout and turnover key challenges of such specialized programs.

Transition of Services to Community Settings

The goal of those invested in the academic, behavioral and social well being of behaviorally vulnerable children is to find ways of supporting them in their natural environments (family homes, local school districts, etc.) These individuals are not easy to serve. As motivated as everyone is to have children currently being served out of state to return, a professionally competent clinical and educational system must be in place prior to a child’s transition back home. Similarly, the goal of any residential treatment team is to fade out some portions of what is often a very complex and time consuming clinical treatment program so that it can better fit the natural environment lifestyles that most families or community residential staff members lead. Developing an ongoing training and intervention mechanism for the direct support “personnel” (i.e. classroom teachers and aides; parents) who are now faced with the frequent occurrences of challenging behaviors from these returning students is critical. Such support must address the specific needs of the child, the parents/staff, the environment and the system in which the behaviors are displayed. These variables must be reflected in any intervention approach as they represent the “natural setting” in which the child lives. These needs can best be met by an on-site behavioral consultation model that focuses on the natural setting and earmarks the parent/academic staff as the designated consumer of training and the initial vehicle for change.

Challenges to a Community Service Support Model

There are several obstacles, however, that must be overcome when attempting to implement a treatment model that utilizes parents/direct service professionals as the agents of change. The stress associated with providing services to individuals with developmental disabilities and behavioral challenges in both community residences and classroom environments is well documented. Low pay, long hours, inadequate training in behavior management, and the potential for personal injury are all obstacles that the educational and disability community must overcome in its attempt to provide effective and consistent behavioral support to children with dual diagnoses. A support model that views parents/staff members as “the behavioral experts” who are a required component to any effective treatment approach and that promotes skill and confidence through the development of management skills is necessary in order to serve these vulnerable citizens in the most inclusive academic and educational settings possible.

Community and academic inclusion implies not only a presence, but an active participation in naturally occurring environments (residential or academic) for individuals regardless of developmental, psychiatric or behavioral challenges. It becomes critical that we in the service delivery system have the ability to create programs for these children that not only maintain their safety and well being, but also offer active programming that meets the criterion of “best practice.” Without such programming, students with dual diagnoses returning to New Jersey from out of state residential treatment programs will have little chance of living a full and satisfying life.

Case Example

Andy is an eight year old boy diagnosed with Pervasive Developmental Disorder to (PDD) whose behavior both at home and school had become so severe that he had been admitted to the Kennedy Krieger Institute’s Neurobehavioral Unit. Andy presented with physical aggression (i.e. striking and biting others) severe tantrums and elopement. His behavioral episodes often resulted in the application of personal control techniques (PCTs) in the form of physical restraints. Prior to his admission at KKI, Andy’s parents and school staff were using PCTs to address his behavior an average of 150 times per week. He resided at KKI for 8 months during which time he was treated with a combination of medication and intense behavioral programming. The program was operated by 4-5 clinical staff members 16 hours per day and resulted in significant behavioral reduction. Andy’s parents were trained in the treatment as part of

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KKI's home transition program and Project Natural Setting Therapeutic Management (NSTM) at Rutgers University was contacted to assist Andy's parents upon his return home. Prior to his discharge, however, NSTM staff consulted with Krieger clinicians to modify Andy's residential treatment program to meet the needs and skill levels of Andy's parents. This process was no small task as the programmatic intensity and efficiency of a KKI program is nearly impossible to replicate in a natural family's home. After multiple meetings with KKI staff and Andy's parents, an appropriate transition process and amended behavioral support program was agreed upon. Andy returned with the initial support of KKI's transition team and Project NSTM provided Andy's parents with weekly behavioral consultation to implement, maintain and monitor his home based program. Out of this consultation and planning process, behavioral system utilizing social stories, role play, behavioral parent coaching and an in-home level system was developed and implemented. Andy's behavioral gains at KKI were maintained and continued to grow:

Frequency of PCTs Utilized Per Week Post KKI Discharge:

Week 1:	32
Week 10:	16
Week 20:	2.5
Week 32:	0

It is clear that Andy's successful transition back to New Jersey from an intensive out of state residential treatment program was made possible by the preparation, collaboration and preparation of Andy's treatment team. This team included the sending staff, Andy's parents and the receiving clinical staff to ensure that the very difficult process of "behavioral re-entry" was given the time and resources that his behavioral profile demanded.

Conclusion

It is important that we as a community want to keep our children with dual diagnoses who are currently being served in out of state residential treatment programs home. To that end, it is neither prudent nor ethical to bring these children home to programs that are not fully equipped to address the challenging behavioral, psychiatric and medical needs that they possess. The provision of high quality, evidence based treatment is hard to accomplish in a community based system that is manned by parents, teachers, residential staff and paraprofessionals who possess a varying amount of skill, training, and experience with severe behaviors and the stress that they bring, but it is possible. We must expend as much time and energy as is required to ensure that these vulnerable students receive the care and clinical expertise that they deserve so that they can indeed, stay home. If we do this, then the goal of community and educational inclusion for children with complex behavioral and psychiatric challenges can be realized. It is our duty to make sure that this happens.

Russell J. Kormann, Ph.D. is the Project Director of Natural Setting Therapeutic Management, Rutgers The State University of New Jersey.

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the 1930's to 66 years in 1993, an increase of almost 250%. There were an estimated 641,161 adults with DD age 60 and older in the US in 2000. It is projected that this group will nearly double in size to 1.2 million by 2030 when the last of the baby boom generation reaches age 60 (1). The screening, evaluation, treatment, and disposition of those adults suffering from dementia remain the key care practices which remain today poorly defined and practiced.

Research has demonstrated that most adults with Down syndrome (DS) over the age of 40 develop abnormal changes within their brains, such as plaques and tangles. These changes may lead to disruption and damage of memory pathways and neurons and eventually causing symptoms and signs of Alzheimer 's disease, the most common cause of dementia (2). Whereas it was once thought that individuals with DS would universally develop dementia as they age, it is now known that the population of adults with DS have increased risk, but brain changes do not invariably result in dementia in all adults. Adults with DD without DS are also at risk for developing dementia, but the rates and presentations of dementia are less certain. The expected age, onset of symptoms and rates of progression of dementia in those with developmental disabilities may not mirror what is seen in those without DD, and this difference may lead to delay in diagnosis as well as complications in management. Signs of dementia can include progressive memory loss, changes in behavior, poor attention and perception as well as the development of speech and language dysfunction. Activities of Daily Living (ADL's) progressively deteriorate, which directly impacts upon the individual's quality of life. Late stage dementia requires 24/7 care as well as the common occurrences of lung and bladder infections, falls and fractures, and seizures. Emergency room visits and hospitalizations result. The issues of death and dying with dignity become even more paramount.

The current screening tests for dementia that are used in the general population, such as the Mini Mental Status Exam (MMSE), are not appropriate and sensitive for most adults with DD. The MMSE, to be accurate, requires that an individual is typically highly verbal, educated, and can stay focused. Most instruments used to screen individuals for dementia cannot be easily applied to adults with developmental disabilities. The few tests that have been developed for this particular population are geared to individuals with Down syndrome; we do not know if they can be as useful in the cognitive screening of adults with other developmental disorders.

What is needed is the development of a practical test that is brief, able to track and follow ADL's, and can be performed by reliable support staff such as nurses, Direct Support Professionals (DSPs), or family members. This type of screening is currently being tested and used in a number of communities and states across the country. Once there is documentation that cognitive decline is actually occurring, it is then up to the staff and health care system to try to

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determine the cause and hopefully provide measures of intervention. Once dementia is suspected, the cause for this decline is then sought. Alzheimer's dementia can never be proven with certainty because there are currently no specific tests that can prove that an individual has it while the person is alive. The only definitive tests are post-mortem. Alzheimer's is often diagnosed when other causes are excluded and the individual shows many of the characteristic signs of this condition. Blood tests, EEG's, and imaging of the brain are often used as diagnostic tools to help with the diagnosis. Tests such as PET scans, and spinal fluid analysis are not practical and accepted as standardized to confirm the diagnosis. The next most important goal for the care team is to try to intervene and help support the individual with the symptoms associated with dementia as well as to prepare for the progressive changes that often come along during the course of the illness. There are 3 areas of care that need to be addressed: social, behavioral, and medical.

It is important for the individual and to those helping to support him/her to understand that cognitive decline will have a rather dramatic impact upon daily functioning. A very small decline may in some individuals have a very large impact upon their independence. The support team must proactively look for these signs. Healthy eating and exercise may help slow down the progression of decline, as well as aggressive blood pressure control. Staff needs to encourage that these practices are followed. Staff needs to be trained on how to act and communicate with someone who has dementia.

There are 3 options for the living situation as one declines. The person can "Age in Place" in which the necessary supports are arranged for the person in the home or living environment. The second approach is "In Place Progression", in which an agency develops a dementia specialty program to serve a number of people with similar needs with a range of residential accommodations and care in a specialized care setting. In the third approach, known as "Referral Out", the person is referred to a generic extended care or nursing facility (3).

Environmental modifications often need to be made to the living space of the person who has dementia. Installation of safety measures for wandering and falls, including alarms and added lighting, should be considered. Internal designs that optimize the use of open spaces and areas that are free of clutter and which provide ease of vision could be implemented. Remember, that individuals may not be aware of common hazards and safety issues.

Challenging behaviors often become quite problematic as the individual declines. Cognitive decline may also lead to an increase in impulsive responding. The support staff, with the assistance of health professionals, can help to reduce the strain that these various behaviors can put upon the individual as well as the staff and family. Pharmacological and non-pharmacological approaches are frequently employed. Careful attention also has to be paid to the possibility of medication side effects, such as drowsiness, and falls.

Several prescription medications are on the market specifically for Alzheimer's disease. These medications may slow the progression of decline as well as improve some cognitive function. However, none of these medications are cures, and in fact the benefits are often marginal at best. Individuals with DS and dementia have been studied to see if some of these treatments are effective. The results are mixed. Since there are currently no specific tracking or monitoring efforts in place, the decision on their effects is quite arbitrary. Since everyone with dementia progresses, how do you really know if these drugs are working or not? These are the questions that I ask myself as a neurologist when I decide to prescribe these "memory "medications.

We are all getting older, sad to say, but true. The loved ones whom we care for are in the same boat as we are. They, however, may be faced with a more rapid decline as well as a larger immediate impact upon their quality of life. Dementia may not be simple to diagnose, treat, or prevent its progression, but people with dementia can be supported. Dementia is a problem that will not go away, and will only become more prevalent as more individuals with developmental disabilities are aging. It is, therefore, recommended that every agency begin to review their current policies and training methods on how to care for those with dementia.

1. Heller, T., & Factor, A. (2004). Older adults with developmental disabilities and their aging family caregivers. Chicago: RRTC on Aging with Developmental Disabilities, University of Illinois at Chicago

2. Dalton A.J. & Crapper-McLachlan D.R. (1986) Clinical expression of Alzheimer's disease in Down's syndrome. Psychiatric Clinics of North America 9, 659-70.

3. Janicki, M.P., Supporting People with Dementia in Community Settings. Community Supports for Aging Adults with Lifelong Disabilities, (2000) Janicki and Ansello, editors, 387-413

Seth Keller, MD is a neurologist with a private practice in Burlington County, NJ. He is President of the American Academy of Developmental Medicine and Dentistry, a national nonprofit organization dedicated to advancing education, training and policy for adults with developmental disabilities.

Editor's note: The Arc of New Jersey's 22nd Annual Conference on Medical Care for Persons with Developmental Disabilities, to be held on Friday, June 3, 2011, will focus on older adults with developmental disabilities, with several sessions focusing on screening and services for people with dementia.

Non Emergency Medical Transportation Available for NJ Medicaid/Family Care Beneficiaries

There has been a change in how Medicaid transportation is provided for NJ Family Care and Medicaid recipients. The Medicaid contract for transportation has been awarded to LogistiCare, a medical transportation company, operating throughout the State of New Jersey. Free transportation to non-emergency, medical, dental, and behavioral health appointments is available for people who are on Medicaid/NJ Family Care and have no other way to get a ride. Rides are available for people who can walk without another person's help, for people who need assistance walking or are in a wheelchair, and for people who need a stretcher (not an emergency). This type of transportation should not be used in an emergency. **If a consumer has an emergency, call 911**. General guidelines for arranging transportation are:

- All rides must be for a medical reason, such as an appointment with a physician or nurse practitioner, dentist, behavioral health clinician, or dialysis.
- The transportation must be requested by **12:00 noon**, at least 2 business days before it is needed.
- The number to call, statewide, is **1-866-527-9933.** The hours for reserving transportation are **8:00 a.m. to 4:00 p.m., Mon. to Fri.**
- Please have the following ready when calling for a ride:
  - The consumer's full name
  - The consumer's NJ FamilyCare/Medicaid ID number
  - The consumer's pick-up address and zip code
  - The name, phone number and address of the health care provider
  - Appointment time and date
  - Special transportation needs (if applicable)
- If a ride is needed to a regularly scheduled appointment (such as dialysis), tell a LogistiCare customer service person what the schedule of visits will be. They will call the medical office and ask them to send them a form that says regular rides are needed.
- Once the transportation has been arranged, the consumer should be ready and waiting at least **15 minutes** before the scheduled pick-up time. If your ride is more than 15 minutes late from the pick-up time, you should call the LogistiCare "Where's My Ride?" line at **1-866-527-9934**.

Further information about the program can be found at: **http://www.state.nj.us/humanservices/dmahs/home/logisticare_english.pdf**

If caregivers of consumers with developmental disabilities have difficulty accessing LogistiCare's transportation, please let us know by contacting Helen Rivera at The Arc of New Jersey, hrivera@arcnj.org, 732-246-2525, ext. 35.

Celiac Disease in Persons with Developmental Disabilities

There are two new reports out on Celiac disease (CD), one of which specifically studied CD in persons with developmental disabilities. The first report, published in the *Journal of Developmental Disabilities*, reviewed what is known about CD and its consequences in the general population and in people with developmental disabilities.

The second report, published in the *Annals of Medicine*, noted that CD occurs more often as adults age and suggested that the disease may have environmental influences. In a sample of 3,511 patients without developmental disabilities, followed from 1974 to 1989, cases of CD doubled, according to proteins measured in blood samples. This provides evidence that the condition doesn't start in childhood, as doctors once thought it did, researchers said.

Celiac disease is a medical disorder that results from a sensitivity to gluten, a protein that is found in many grains. CD is under-recognized and under-diagnosed in the general population and in those with developmental disabilities. While there is presently is no cure, treatment with a gluten-free diet can effectively control or reverse symptoms in a high percentage of patients. Consequences of untreated Celiac disease can include symptoms referred to as "digestive" as well as others that are behavioral, neurological or neuropsychological. There is also evidence of an association between Celiac disease and early cognitive decline or dementia in the general population.

Please see our website (www.arcnj.org) for further information on these two studies.

RESOURCES

A new booklet, **Supporting Feeding & Oral Development in Young Children: Guidelines for Parents**, distributed by ***Down Syndrome Ireland*** is now available online at: **http://www.downsyndrome.ie/docs/feeding_oral_development.pdf**

This booklet is an excellent resource and is intended to be used as a reference for the first 2 or 3 years of life.
It addresses feeding issues for young children with Down syndrome, congenital heart disease and/or feeding difficulties.

The National Association of State Directors of Developmental Disabilities Services newsletter, *Community Services Reporter* has published a commentary on end of life decision making for individuals with developmental disabilities by Leigh Ann Creaney Kingsbury, MPA, a gerontologist and CEO of InLeadS, Inc. Consulting and Training. The commentary, "What Edward Taught Us About Healthcare Decision-Making Before and at End of Life: Why We All Must Listen," is available at: **http://www.elpnet.net/documents/WhyWeMustDoAdvanceCarePlanning.NASDDDS.9.09.revisedfinal.pdf**

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SAVE THE DATE!

FRIDAY, JUNE 3, 2011

22nd Annual Conference on Medical Care for Persons with Developmental Disabilities

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

British Medical Journal Reports that Autism Study's Fraudulent Data Led to Worldwide Fear of MMR Vaccine

A recent report in the British Medical Journal noted that the data used by Dr. Andrew Wakefield in his 1998 research, describing a link between the measles-mumps-rubella (MMR) vaccine and autism, "wasn't just poor science, it was outright fraud." Wakefield continues to defend his study; however, ten of the co-authors on the study have repudiated it. Last year it was officially retracted by The Lancet, and Dr. Wakefield and his senior research advisor have had their medical licenses revoked for unethical treatment of patients.

Many subsequent studies on a possible link between and MMR vaccine and autism have found no credible evidence of a link. It is important for all children, including children with autism and other developmental disabilities, to get the recommended vaccines. The benefit of a widespread public vaccination program has shown to be highly effective in eliminating many childhood diseases, including measles, mumps and rubella. According to the Centers for Disease Control, a vaccine, like any medicine, is capable of causing serious problems, such as severe allergic reactions. The risk of the MMR vaccine causing serious harm, or death, however, is extremely small. Getting the MMR vaccine is much safer than getting any of these three diseases and most people who get the MMR vaccine do not have any problems with it. Parents should not be afraid to vaccinate their children based on this one study, which has now been shown to be fraudulent.

An electronic copy of the full British Medical Journal article is available on our website, or by emailing Helen Rivera at hrivera@arcnj.org.

We strive to keep an updated mailing list for our publications. If your address has changed or will be changing, or if you are receiving this publication in error, please forward an email update to Helen Rivera at **hrivera@arcnj.org**, or call Helen at **732-246-2525, x35**. ***Thank you!***