Seizure Disorders and Older Adults with Developmental Disabilities
Seth M. Keller, MD

Adults with Developmental Disabilities (DD) are able to live significantly longer due to an overall improvement in healthcare. The DD population faces many uncertain health challenges during the aging process. Seizures remain a very common and complicated medical issue with added variables that are not seen in the younger DD population.

In the 1930s, life expectancy for individuals with DD was 18.5 years. Today, life expectancy for individuals with DD is 66.2 years. Life expectancy for individuals with mild DD approaches that of the general population. Life expectancy for individuals with DD depends to a large degree upon the level of involvement. The more severe the impairment the more likely they are to have a reduced (shortened) life expectancy. Improvements in early infant health care, with recognition of and extra attention to the DD child, have lead to longer life-spans and overall healthier individuals.

The typical aging process in those with DD may be accelerated due to a number of factors. Adults with Down Syndrome have a significantly increased rate of Alzheimer's Disease by the time most reach 50 years old. Sensory impairment, gait and joint dysfunction, as well as frequent falls, are all very common in the aging DD population. There is also a lack of awareness and attention towards preventive health issues in the older

Seizure Disorders, cont. on page 3

New Jersey Division of Developmental Disabilities and The Arc of New Jersey Issue Important Advisory Concerning H1N1 (“swine”) Flu Virus

Anyone who is caring for, or cares about, someone with a developmental disability should be aware that certain underlying medical conditions often found in people with these disabilities can make them susceptible to more severe complications from the flu virus than individuals without these conditions. Cont. on page 4

Honoring What is Hidden in Plain Sight: Helping Persons with Developmental Disabilities Deal with Grief and Loss Issues
William C. Gaventa, M.Div. and Jamie Roos

In Good Grief, a classic small book on grief and loss, author Granger Westburg notes that “grief delayed is grief denied, and grief denied is grief delayed”. For too long, the grief and loss experienced by individuals with developmental disabilities has been both denied and delayed. It is denied when there is an underlying assumption that these individuals do not experience grief in many of the same ways as others or that the issue cannot be addressed with them because “they won’t know how to handle it”. And it is delayed because we don’t know what to do to support individuals with developmental disabilities in the grief process, and therefore either delay informing them about the loss of a family member or friend, or don’t facilitate their participation in the normal rites and rituals of mourning that are a part of cultural and religious traditions.

Loss is not just about issues at the end of life, or about grief over the death of a family member or friend. Loss occurs any time a caring relationship is severed - when people move from a home or community in which they have lived for years, when favorite staff leave, and when hopes and dreams get blocked for one reason or another. Although it may not always get talked about, loss is everywhere in the ID/DD system of services and supports, just as it is in “normal life”, perhaps even more so because of the frequently revolving nature of caregiver and other

Grief and Loss, cont. on page 6
Vision: Its Importance for Persons with Intellectual and Developmental Disabilities

Paul Berman, O.D., F.A.A.O.

As founder and Senior Global Clinical Advisor of Special Olympics Lions Clubs International Opening Eyes (SOLCIOE), I have learned a lot about the visual needs of persons with intellectual and other developmental disabilities. Working with Special Olympics athletes around the globe, it has been determined that 37% of those examined needed new or different glasses, 66% had not had their eyes examined in the last three years, and that 18% had eye health issues, one-third of which required immediate medical attention. And surprisingly, there appears to be little difference in these disturbing statistics between the developed and the developing world.

This universal phenomenon of apparent neglect with regard to the vision health of individuals with developmental disabilities is attributable to several causes. When a person with an intellectual disability is not able to do something, the underlying reason is often assumed to be the disability itself, with the result that the possibility of a contributing sensory issue (i.e., a hearing or vision issue) is not even considered. In addition, individuals with intellectual disabilities frequently encounter difficulties in advocating on their own behalf when it comes to health care. For instance, adult consumers in the United States usually receive their health care coverage from Medicare and Medicaid, whose low provider reimbursement rates make patients covered by these plans “undesirable”. And finally, surveys show a severe lack of formal training in the majority of medical, dental, podiatry and optometry schools with regard to the examination, care and treatment of people with developmental disabilities, leaving emerging health care professionals without sufficient clinical exposure to feel comfortable treating this population.

SOLCIOE was founded eighteen years ago, in large part to counteract the inherent negative effects of these kinds of issues. During that time, with the support of Special Olympics and Lions Clubs International, more than 750 events have been conducted, and eighteen thousand professional volunteers, optometrists, ophthalmologists and opticians have donated their time to provide vision screenings to 148,522 athletes in 70 countries and 46 states in the United States.

In an effort to help fill the educational void, a Global Curriculum has been compiled by vision care experts from all over the world, is available in both a four-hour student (resident) DVD format and a two-hour professional Continuing Education (CE) module, and was cited as an exemplary resource by Julie Gerberging, MD, MPH, former Director of the United States Centers for Disease Control and Prevention (CDC).

And finally, SOLCIOE is in the process of creating a Willing Provider website that will enable persons with intellectual disabilities to locate health care professionals who have identified themselves as having a good comfort level and/or experience working with this population.

At a typical SOLCIOE event, volunteer eye care providers can examine hundreds of persons with intellectual disabilities (we do this annually at the Special Olympics New Jersey Summer Games at The College of New Jersey). It is a unique and invaluable opportunity for eye care professionals to improve their clinical skills and, perhaps more importantly, to gain a deeper understanding of and respect for people with intellectual and developmental disabilities.

The following case examples illustrate the tremendous impact that SOLCIOE’s efforts have produced.

Nancy, a 28-year-old woman, tended to be very dependent on her mother and was seemingly unable to take care of her own personal hygiene needs. Following her vision screening, she was given her first pair of glasses. Her mother reported that upon receiving them she was able to go to the ladies room by herself for the first time. During the Special Olympics track and field event, Nancy actually stopped running because for the first time she was able to see her mom observing her.

John, a 22-year-old Special Olympics athlete from Canada, was extremely nearsighted. We asked him what sport he competed in. When he responded "track and field", I asked, "How can you see?" With a big smile, he replied, "That’s easy; I just follow the blur in front of me!" Somehow, John managed to always get a Silver Medal. At that event, John received a pair of glasses, and it was truly an emotional moment when John came back to give us a thank-you hug wearing his Gold Medal.

(We are able to provide glasses to athletes like Nancy and John through the generosity of Safilo,

Vision, cont. on page 3
Seizure Disorders, cont. from page 1

individual with DD. Many of these factors can lead to an increased frequency of seizures in the aging population. Seizures are one of the most common medical complications seen in those with DD. Seizures frequently occur in the younger DD population due to acquired birth injuries as well as to genetic causes. Seizures secondary begin to occur in the aging brain often due to trauma, cerebrovascular disease and neurodegeneration. There is a much higher rate of Partial seizures in the aging group as compared to Primary Generalized in the younger population.

Syncope and behavioral difficulties are common in the aging DD population. Often the physical manifestations of these conditions can be confused with an epileptic seizure. The diagnosis of the “true” disorder is challenging due to a number of factors. Elderly and poorly verbal adults with DD may not be able to describe their symptoms, and witness accounts of the event by by-bystander may not be reliable. Cooperation and relaxation during MR imaging and EEG is most often impossible unless sedation and even conscious sedation is made available. These additional measures, however, may add unwarranted risks.

Once a seizure diagnosis is confirmed, pharmacologic measures are employed to control these events and thereby reduce and prevent any associated injuries from a seizure. Anti-Epileptic Drug (AED) usage can be challenging due to possible adverse events more commonly seen in aging adults. There may be a higher susceptibility to cognitive side effects, fatigue, ataxia and falls, as well as drug-drug interactions. Bone marrow suppression and hyponatremia can also be seen more commonly in the aged population.

There is also a significant change in physiology and metabolism as we age. Hepatic and renal function slow, but these processes are tremendously impaired even further due to the addition of pharmacologic interventions. The complicated co-morbid health states and the often over-usage of polypharmacy can lead to an abundance of toxicity and unpredictable clinical responses to therapy. Protein and albumin levels are often lower as we age, which can lead to higher free levels of AEDs and therefore increase the chances of drug toxicity. Bone loss is also a common consequence of chronic AED usage. Fracture rates are high in the DD population. The appropriate monitoring, prevention, and treatment of osteoporosis in adults with DD has not been consistently studied.

Refractory Epilepsy is a very common health problem. Seizures are considered to be medically refractory after trials of at least 2-3 appropriate AEDs have failed to gain seizure freedom and control. Adults with DD may be up to 30-50% medically refractory. The appropriate choice of a specific AED, either as Monotherapy or in combination, is vital. Consideration of long-acting compounds and conversion to Monotherapy may improve seizure control and lessen toxicity. Avoidance of sedating AEDs, such as benzodiazepines, Barbiturates, and Dilantin, should be considered. The newer AEDs have not been proven to be more efficacious than the Classic/Older AEDs, although usage of the newer AEDs may be preferred due to less hepatic and renal monitoring and fewer drug to drug interactions. The newer AEDs don't have required and accepted therapeutic drug levels.

Although generic substitution of medications is a common cost-saving practice, the generic substitution of AEDs is controversial. The FDA mandates that Brand and generic drugs must have equivalence; this is called “bioequivalence”. Generic AEDs may lead to small variations in absorption and concentration which may affect efficacy and toxicity. The American Academy of Neurology (AAN) opposes legislation that would impede physicians’ ability to determine which AED to prescribe.

Seizures in adults without DD are common. The causes and types of seizures are different from those seen in children. There are a number of physiologic changes that occur in our body as we age which significantly impact drug efficacy, absorption, and metabolism. The aging adult with DD and seizures will have many of the same issues as the non-DD adult; however, diagnosis and treatment problems are often greatly magnified and complicated. The caregiver needs to have a heightened sensitivity to co-morbid health states, polypharmacy, and possible adverse events which may directly impact negatively upon the individual's ADLs and QOL. ###

Seth M. Keller, MD is a neurologist with Neurology Consultants of Burlington County, New Jersey.

Social Security's Online Services Win Accolades

The Social Security Administration's online services have earned the highest overall score in the most recent e-Government Satisfaction Index. The Index, which is administered by ForeSee Results in conjunction with the University of Michigan’s American Customer Satisfaction Index (ACSI), also gave three of SSA's applications the highest scores in government. In a separate survey, Nextgov, a website devoted to technology and the federal government, listed www.socialsecurity.gov as one of the top five federal websites in its review of best online practices.
Parents of daughters with severe developmental disabilities are sometimes faced with the issue of how to protect their daughter from unwanted pregnancies. While there are a variety of contraceptive methods, many are not feasible due to the severity of the disability. In such cases, parents find themselves considering sterilization. The 1981 landmark case of I/MO Grady, which involved a 19-year-old woman with severe mental retardation and Down's Syndrome, addressed this very issue setting standards to protect against abuses in the sterilization of mentally impaired persons.

In Grady, the Supreme Court of New Jersey determined that it is within the court's judgment, rather than the parents' to determine the need for sterilization. In that regard, the court must be satisfied that sterilization is in the best interest of the incompetent person. To that end, the Supreme Court set forth the following standards that must be met before the Superior Court of New Jersey, Chancery Division may exercise this power:

1) All procedural safeguards must be satisfied, including the appointment of an independent guardian ad litem to act as counsel for the incompetent individual during the court proceedings, with full opportunity to present proofs and cross-examine witnesses at the hearing, and to represent zealously the interest of his/her ward in other appropriate ways.

2) The court must receive independent medical and psychological evaluations by qualified professionals.

3) While the incompetent person need not be present at the proceedings, the trial judge should personally meet with the individual to obtain his/her own impressions of competency.

4) The court must find that the individual lacks the capacity to make a decision about sterilization and that the incapacity is not likely to change in the foreseeable future.

5) The court must be persuaded by clear and convincing proof that sterilization is in the incompetent person's best interests. To determine those interests, the court should at least consider the following factors: the possibility that the incompetent person (a) can become pregnant; (b) will experience trauma or psychological damage if she becomes pregnant or gives birth (the same should be considered from the sterilization operation); (c) the likelihood the individual will engage in sexual activity either voluntarily or involuntarily; (d) the inability of the person to understand reproduction or contraception and the likely permanence of that inability; (e) the feasibility and medical advisability of less drastic means of contraception now and in the future; (f) the advisability of sterilization at the time of the application rather than in the future; (g) the ability of the person to care for a child; (h) evidence that scientific or medical advances may occur within the foreseeable future which will make possible either the improvement of the individual's condition or alternative and less drastic sterilization procedures; and (i) a demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience. ##

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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.

Deciding When Contraception is Right for a Woman with Developmental Disabilities

Leone Murphy, RN, MSN

There are many successful methods of contraception that can be prescribed for women who have developmental disabilities and are sexually active or may be at risk for sexual abuse. Some of the methods available are birth control pills (BCP), the birth control patch, subdermal implants, hormone injections, such as Depo-Provera, and intrauterine devices (IUD). All of these methods require yearly gynecological exams and pap smears.

There are pros and cons to each method of contraception and these concerns need to be discussed with the woman and her guardian or caregiver in the case of those women who have severe intellectual disabilities. For example, birth control pills require that they be taken daily but have the benefit of a lighter menstrual period and more stable moods. The birth control patch is placed on the skin and remains in place for three weeks. It is then removed and a week later another patch is applied. Subdermal implants are placed under the skin in the doctor's office and can remain in place for up to five years. The hormone injections are given every three months and often result in the cessation of menstruation. IUDs are inserted through the cervix into the uterus during a gynecological exam and must be checked yearly but can remain in place for up to five or more years.

Even though contraception to prevent pregnancy is a major concern, it is important to remember that none of these methods protect the woman from sexually transmitted disease (STD) including H.I.V. It is important to discuss this serious concern with the health care provider and to consider options to protect the woman. Neglecting to consider the risk of STDs can be life-threatening. Counseling and education on sexual activity are important services that need to be provided to women with developmental disabilities. ###

Leone Murphy is the former Director of Health and Behavioral Services at The Arc of Monmouth Ambulatory Care Center, and current President of Comprehensive Healthcare Consultants Group, LLC.
Mainstreaming Medical Care Advisory Board Members Honored at The Arc of New Jersey’s 60th Anniversary Reception

On June 19, 2009, The Arc of New Jersey held its 60th Anniversary Reception at the Doubletree Hotel in Somerset. The elegant evening, which included a visit from Governor Jon Corzine as well as a number of other distinguished guests, was rounded out by the presentation of Partners in Advocacy Awards to people or organizations who had given of themselves to help The Arc fulfill its mission.

Aging Issues Explored as The Arc of New Jersey Presents 20th Annual Conference on Medical Care

On May 29th, 2009, the 20th Annual Conference on Medical Care for Persons with Developmental Disabilities was convened in Princeton. Over the years this annual event has evolved into one of the state’s premier educational venues with regard to the health care of individuals with developmental disabilities. New Jersey Department of Human Services Commissioner Jennifer Velez opened the program, with Assistant Commissioner Kenneth Ritchey and John Guhl, Director of the Division of Medical Assistance and Health Services, also providing remarks. Ann Clemency Kohler, Executive Director of the National Association of State Medicaid Directors in Washington, DC and former NJDHS Deputy Commissioner, gave the morning Keynote address and Fredric Feibusch, Director of Residential Services for YAI: National Institute for People with Disabilities, provided the afternoon Keynote Address. Promoting Healthy Aging was the theme this year, and more than 350 conference participants attended workshops with topics ranging from mental health to policy development to long-term care planning. A unique and valuable resource, the Health Care Professional’s Pledge, was distributed to all attendees. This tool was developed by members of Council 1 of the New Jersey Self-Advocacy Network as part of a sensitivity training for healthcare professionals, entitled I’m the Patient, and a Person! ###

State Announces Change in Process for Medicaid Beneficiaries Requesting Medical Transportation

As of July 1, 2009, there is a change in the process for requesting medical transportation. Although consumers will continue to be provided with transportation for all qualified medical appointments, there is a change for some people regarding whom to contact to receive medical transportation services. The New Jersey Division of Medical Assistance and Health Services (DMAHS) has hired LogistiCare Solutions to arrange and manage non-emergency medical transportation for some clients. LogistiCare will manage non-emergency ambulance (if you are unable to sit up and you require a stretcher) and Mobility Assistance Vehicle (MAV) transportation (if you require assistance walking or require a wheelchair) statewide for consumers who do not participate in an HMO; and lower level transportation (cabs, bus passes/tickets, etc.) for all eligible clients in Essex and Hudson Counties (see tables below).

If you encounter a problem with the new Medicaid transportation procedures, please contact the Medicaid Office of Customer Service at 609-631-4641. Be prepared to provide specific details, including: the name and Medicaid number of the client who has a transportation problem; the client’s county and home address; the address of the office where the medical treatment is provided; and the specifics of the transportation problem.

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<tr>
<th>CLIENT IN AN HMO</th>
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<th>Process as of 07/01/2009</th>
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<tr>
<td>Mobility Assistance Van (MAV)</td>
<td>Contact HMO</td>
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</tr>
<tr>
<td>Livery (Essex or Hudson Counties)</td>
<td>Outreach Transportation Provider Directly</td>
<td>Contact LogistiCare at 1-866-527-9933</td>
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<td>Livery (Other 19 Counties)</td>
<td>Contact local County Welfare Agency</td>
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Many thanks to Our Platinum Contributors!

AmeriChoice
AmeriGroup Community Care
Horizon NJ Health
relationships in the lives of individuals with ID/DD. And when it is not talked about, i.e. conceptually and/or emotionally shared and understood, these individuals may end up acting it out, just as the rest of us do, in any number of inappropriate ways, including anger, depression, guilt, etc. Clearly it is of utmost importance that guidance is available to help persons with developmental disabilities deal with grief and loss issues, and that caregivers and staff are prepared to be there and listen to a person’s concerns, allowing them to grieve in their own way and time and to know they are supported in doing so.

Thankfully, in the last decade, there has been increased attention paid to addressing the grief and loss experienced by people with developmental disabilities (see End-of-Life Resources on page 7). Jeffrey Kauffmann, in the Philadelphia area, writes eloquently about the behavioral expressions of grief and the importance of intentional agency policies and structures to support people in times of grief. He also suggests the use of “loss inventories,” working with individuals and their families to learn how loss is addressed in their family, their culture and their religion, and letting them know the agency will address those issues when loss inevitably occurs. There are a number of agencies in New Jersey that have successfully incorporated intentional work and resources:

- Celebration of Life services have been performed at The Arc of Somerset County by chaplain-consultant Jamie Roos. These services provide consumers with a structured opportunity to express their grief and to remember the good times shared with their friend or loved one who has died.

- Working with The Arc of Hunterdon County’s grief and loss support group, which has been in place for a number of years, Melody Steinman, a Boggs Center pastoral care trainee, developed a resource manual for group home staff that revolves around a fictional story about the natural death of a person living in a group home (see Resources).

- A number of agencies, like the New Jersey Association for the Deaf-Blind, have experienced the loss of a favorite person whom they served, only to recognize that while friends and close workers were supported, the whole agency had been impacted and therefore needed to develop creative ways to respond as an agency.

- The loss of an Allies group home resident in Ocean County led to the formation of another grief and loss group. Joanne Van Sant, a Clinical Pastoral Education student at Allies and The Boggs Center, assisted the group in planning a Service of Remembrance for that person and for other friends and loved ones recently lost.

- Rosemarie Newberry, a part-time chaplain at New Lisbon Developmental Center, has helped develop individualized memorial and funeral services for residents there, and is also helping staff to recognize the loss inherent in a move from an institutional setting to the community, even amidst the excitement and anticipation of such a move.

- Agencies in other states have developed collaborative grief and loss teams that are prepared to respond to situations of grief and loss as they arise.

Grief and loss can be dealt with in many creative ways, as long as the attention and intention are there as well as courage among caregivers and staff to act together. It necessitates planning ahead and developing relationships with those who are used to dealing with grief and loss, such as those in religious communities and hospice networks. By reaching out to those with experience and expertise in the field, staff and caregivers better equip themselves to be able to assist each consumer through the process of grieving.

Two Case Examples

"Jennifer" is a 32-year-old woman with Down syndrome who had been dealing with the death of Susan, one of her housemates. Usually very talkative and able to express her emotions to staff, Jennifer became withdrawn and did not want to talk about how she was feeling. It was suggested to the staff that perhaps Jennifer needed a different outlet for expressing her grief. Jennifer was asked if she wanted to color some pictures and she gladly sat down and started coloring. She drew a picture of a heart and then she drew two people inside of the heart; Jennifer said that she would always have a place in her heart for Susan. Jennifer eventually talked with staff about how she was feeling, but the breakthrough occurred when Jennifer was allowed to draw a picture and express her grief in her own way.

"Joe" is a 40-year-old man with Cerebral Palsy who is non-verbal. Joe's dad had died a few years ago and Joe was still missing him, expressing his grief by communicating with friends about what he was feeling. Joe wanted to do something special that would be a remembrance of his dad. It was suggested that a "Celebration of Life" service could be held. At the service there would be time for reflection, prayer and thanksgiving for Joe’s dad. The day of the service, Joe was so happy that his friends had come to offer their support. At the end of the service, Joe wrote a note to his dad and then the note was attached to a balloon. When the balloon was released Joe had a huge smile on his face; he commented on how much he still misses his dad but that by sending the balloon and note to his dad he still felt connected to him.

Conclusion

Supporting individuals with ID/DD in the grieving process requires planning ahead, because waiting until the crisis of a death has occurred and then scrambling to find supports ultimately means, as Granger Westburg says, "grief delayed". Grief and loss are there, in plain sight, and the first step in moving through them to healing is recognizing them. It is not an issue of "understanding", for none of us has perfect answers. It is a matter of caring, of walking with one another through the "valleys of the shadows of death" and knowing that we are not alone.

Resources

Although there is currently no directory available of bereavement or other counselors in New Jersey with expertise in supporting people with intellectual disabilities, there are growing numbers of clergy and chaplains like those mentioned above who can serve as a resource. Hospice chaplains and bereavement counselors are available, but disability service providers need to initiate relationships early and plan ahead, so that these professionals have opportunities to learn more about intellectual disabilities. A new listserv is available for persons in New Jersey interested and involved in aging and end of life issues with people with intellectual and developmental disabilities, and there are plans for collaborative initiatives between DD providers and hospice network (to add your name to this listserv, please contact Bill Gaventa at The Arc at The Boggs Center). Additional Resources on page 7.

William Gaventa, M.Div., Director, Community and Congregational Supports, The Elizabeth M. Boggs Center, Pediatrics-RWJMS/UMDNJ (bill.gaventa@umdnj.edu, 732-235-9304)

Jamie Roos, Chaplain, The Arc of Somerset County and Advocate, Lifetime Support Inc.(jroos@arcunion.org, 973-315-0029)
End of Life Resources
Compiled by William Gaventa, M.Div.

- Jones, Amelia & Tuffrey-Wijne, Irene. Positive Approaches to Palliative Care. Workbook from the UK published by BILD (British Institute on Learning Disabilities); www.bild.org.uk
- Thinking Ahead: My Life At The End, a Coalition for Compassionate Care project made possible through a Wellness Grant from the California Department of Developmental Services (2008). The Thinking Ahead workbook and DVD were designed specifically for and by people with developmental disabilities and are available free of charge at www.finalchoices.org.
- Last Passages is a joint project of the Volunteers of America, the University at Albany, NYSARC, Inc. and Marist College, whose purpose is to share information and promising practices to enhance end-of-life care for persons with developmental disabilities. For information, go to www.albany.edu/aging/lastpassages.
- The American Association on Intellectual and Developmental Disabilities (AAIDD) has a national action group that is working on end-of-life issues and is planning a series of teleconferences, a book and web-related resources. Contact AAIDD at 1-800-424-3688.

Other Helpful Resources:

Living with DEMENTIA is an outstanding resource developed by Down’s Syndrome Scotland. From its prologue: ‘This book is a collection of potential issues that you may come across in the home, with suggested solutions. The possible reasons for these changes are explained to give an insight into how dementia is experienced by people with Down’s syndrome.’

E-mail: info@dsscotland.org.uk
Internet: www.dsscotland.org.uk (or contact Diane Flynn at dflynn@arcnj.org for an electronic version)

No Wrong Door New Jersey is a collaboration of The Arc of New Jersey, the Mental Health Association in New Jersey, the New Jersey Coalition Against Sexual Assault, and the New Jersey Coalition for Battered Women. Initiated in late 2007 and funded by a $750,000 grant from the U.S. Department of Justice Office on Violence Against Women, this ongoing project seeks to address the issue of violence against women with intellectual/developmental disabilities and/or mental illness and to create a seamless entry and service system for those who are victims. For further information, please contact either:

Juan Santiago, Director, Developmentally Disabled Offenders Program
732-246-2525, ext. 31, jsantiago@arcnj.org or
Ann Wilson, Director, NJ Coalition for Prevention of Developmental Disabilities
732-246-2525, ext. 23, awilson@arcnj.org
**Horizon Foundation Provides Funding for Cancer Project at The Arc of New Jersey**

Diane Flynn

The Arc of New Jersey has received a grant from The Horizon Foundation of New Jersey to develop and distribute educational materials regarding prevention and screening for breast, prostate and colorectal cancer in individuals with developmental disabilities. Although screenings for early detection of breast, prostate and colon cancer are widely available, they are currently under-utilized by individuals with developmental disabilities due to lack of education, information and access. Since effective treatments exist for these cancers when diagnosed early, it is imperative that consumers, caregivers and health care professionals become educated about the need for these screenings to be routinely performed.

The Arc of New Jersey's Cancer Project is developing a series of booklets that will provide information to individuals with developmental disabilities and their caregivers about the importance of completing a comprehensive family health history and getting routine screenings for breast, prostate and colon cancer, and about lifestyle changes that can reduce the risk for these cancers. The booklets are expected to be available by end of summer, 2009 and will be free of charge.

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**Help Us Keep Our Mailing List Up-To-Date:**

CHECK YOUR ADDRESS!

If it is incorrect, incomplete or will be changing soon, or if you prefer that we remove you from our mailing list, please contact Diane Flynn by phone at 732-246-2525, ext. 28, or by email at dflynn@arcnj.org.

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**DON'T FORGET THE ARC OF NJ'S DIABETES MATERIALS!**

The Arc of New Jersey still has free materials available regarding the prevention and management of Type 2 Diabetes in persons with developmental disabilities. There are Caregiver and Self-Advocate versions of a 20-page guide booklet, as well as a limited supply of VHS films. Please call or email Diane Flynn for information or to order: 732-246-2525, ext. 28, dflynn@arcnj.org.

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**The Horizon Foundation for New Jersey**

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