

Andrew M. Cuomo  
Governor



Courtney Burke  
Commissioner

NYS Office For People With Developmental Disabilities

# Putting People First



## Aging In Community

Helping people with developmental disabilities age with dignity through fostering relationships, having good health, and living in the home of their choice



This booklet was first published in November 2008. Its inspiration and creation are due in large part to the Nursing Home Diversion and Discharge Subcommittee of the Commissioner's Task Force on Aging. Special thanks go to subcommittee members for their hard work, DDSO Directors and staff from across New York State for their tremendous backing. And to Dr. David Booth, former Director of the Staten Island DDSO, who chaired the subcommittee.

At OPWDD, our mission is, "We help people with developmental disabilities live richer lives." At no time is this mission more compromised than when a person must move to a nursing home prematurely or unnecessarily.

"DISABLED OR NOT, WE'RE ALL AGING. WE WILL ALL FACE THE SAME CHALLENGES, NEED THE SAME SUPPORTS, AND COMPETE FOR THE SAME SERVICES."

The fastest growing age group served by OPWDD is those over 50 years of age. We know that we will face more and more challenges related to aging as time moves on. Disabled or not, we're all aging. We all face the same challenges, need the same supports, and compete for the same services. Thus, the work you do to keep people at home has broader effects too.

Subcommittee members spoke with service coordinators, PASRR Coordinators, residential managers and others and asked them to write of their experiences in diverting people from nursing homes or keeping their stays short. The responses were overwhelming, and the intent of this booklet is to share the lessons learned from the telling. The stories are organized into ten themes, and published with lessons learned that further illustrate the themes.

Photographs remind us of our commitment to put people first and foremost. However, please note that the pictures in this document do not correspond to the stories told.

We are inspired by the commitment to success. We hope the lessons from these stories will be taught and applied towards further realization of richer lives for people with developmental disabilities.

*Martha Schunk, OPWDD Coordinator of Aging Services*



# Putting People First

## 10 THEMES FOR NURSING HOME DIVERSION & DISCHARGE

- PUT YOURSELF IN THE OTHER PERSON'S SHOES.  
*Advocate, Advocate, Advocate.*
- "LISTEN" TO PEOPLE.  
*Implement innovative strategies that address special needs as people age.*
- RELATIONSHIPS ARE KEY.  
*Promote personal connections, and maintain them even as people's needs change.*
- DON'T ACCEPT THE UNACCEPTABLE.  
*When services in a nursing home aren't appropriate for the person, think about alternative options.*
- KEEP THE CONNECTIONS.  
*If alternate services are needed, take steps to maintain the person's community.*
- WHAT CAN BE DIFFERENT?  
*Consider cross system supports and enhancements to a home, be it with staff, training or living environment modifications to support people in their home of choice.*
- KNOW YOUR RESOURCES.  
*Look for programs that specialize in unique services.*
- MAKE IT WORK.  
*If a time limited stay in a nursing home is necessary, plan the supports to maximize success.*
- HAVE HIGH EXPECTATIONS.  
*Be open to surprising recoveries.*
- TREAT PEOPLE LIKE FAMILY.  
*Be there to support end of life.*



PUT YOURSELF IN THE OTHER PERSON'S SHOES.

ADVOCATE, ADVOCATE, ADVOCATE!!

Last summer, as the PASRR Coordinator for the Long Island DDSO, I received a referral for Joey, who was 26 years old. While in college, he was involved in a bar fight and sustained a Traumatic Brain Injury. Over the course of six years, Joey was in at least five different nursing facilities on Long Island for treatment of his brain injury. His family moved Joey as they became dismayed with the lack of progress or therapy offered. But what was most disturbing to his family, Joey was living with older people who were not his peers.

Although Joey is on a waiting list for a group home with an agency in Long Island that provides services to those with brain injuries, the family did not want Joey to just wait and not grow to his potential. Out of desperation, they sought out a facility in Massachusetts. I met with the family, discussed their frustration and suggested another option that was not as far away. I suggested they visit a skilled nursing facility in Ulster County that specializes in services for people with traumatic brain injury as a comparison to the out-of-state facility. The family followed through and was very impressed with the New York State facility, and sought treatment there.

I attended the intake meeting with Joey and his family, to also familiarize myself with their services as we have other individuals living here. Joey has now lived here for four months. I have since kept in contact with his family, who tell me that Joey has made progress in his self care skills, in his ability to walk, and in his expressive skills. One significant change is that he is now happy and has friends his age and while he waits for a vacancy back home, he is learning and growing.

One thing remains constant... we must continue to advocate for the people we serve. As the PASRR Coordinator, advocating continues to be the pulse of my responsibility and has made a difference for many people.

*Shared by Patricia Weber, Long Island DDSO*

WHILE IN THE 1ST PART OF THE 20TH CENTURY, MANY PERSONS WITH DEVELOPMENTAL DISABILITIES WERE NOT EXPECTED TO REACH ADULTHOOD. THEIR LIFE EXPECTANCY IS NOW APPROXIMATING THAT OF THE GENERAL POPULATION (WITH THE EXCEPTION OF PERSONS WITH SEVERE DISABILITIES).

LESSONS LEARNED FROM JOEY'S STORY

- Be a good listener to actually hear what the individual/family wants.
- Be realistic. Be persistent. Be an independent thinker.
- Know how to compromise.
- Be ready to educate others.
- Sometimes you must be a cheerleader....let's try such and such....don't make up your mind without checking it out; I'll go with you... Know your local resources but if you don't, ASK.
- Be ready to offer choices.
- Finally, if one door closes, it's not the end....try another....maybe another path will be more successful.



## MORE ADVOCACY!!

John was one of the first individuals that I received a PASRR request on. He was a 52 year old man who lived in an IRA. Over the years he had lost some of his skills and recently had a g-tube insertion. He was moved to a nursing home to convalesce and the agency was requesting his permanent placement in the facility.

I visited John at the facility to determine how he would be best served. I was greeted by the Director of Nursing, who was unfamiliar with the PASRR process. She tried to justify John's continued stay, first because he was non-ambulatory, then because he had a feeding tube. My response was, "Where's the skilled nursing need?" She realized that I was right. We talked about what an OMRDD certified home could offer. Then I met John. He immediately told me he missed his home and asked when he could return.

After my visit, I let the agency know that John did not need a nursing home. The agency expressed concern about their ability to handle his feedings. I helped identify sources of training for their staff. I approved a short-term stay for John in the nursing home while staff were trained. John returned home after 40 days; he was ecstatic and the house staff were happy to see him too.

*Shared by Richard Gordon, Hudson Valley DDSO*

BE THE EYES, EARS  
AND MOUTH FOR THE  
PERSON WHEN YOU  
NEED TO BE. PLAN  
AHEAD TO IMPROVE  
THE OVERALL  
QUALITY OF CARE.  
FOCUS ON  
ACHIEVING PEOPLE'S  
HEALTH AND SOCIAL  
OUTCOMES.

## DIVERSION CONSIDERATIONS FOR PASRR COORDINATORS

- Ask for a description of the circumstances; then ask why the person can't return home? Ask whether the agency can create a residential alternative within its system of services? For a family, what supports can be put in place to help? Continue to maintain contact with the individual/family/advocates to discuss the situation and options.
- If the person doesn't need placement in a nursing facility but there is no immediate alternative and the person goes to convalesce, confirm that alternate referrals are sent out. If referrals have not been sent, mobilize those that can assist. Make personal contacts to scope out the options.
- Be proactive; initiate referrals to have people placed on waiting lists for community residential opportunities. Regularly review those individuals in nursing homes to see if anyone may be appropriate to return to a community home. Ensure that referrals are sent, or if one was already sent, check on the status. Check the master list for appropriate vacancies within the district.
- Remember the Care At Home Waiver for children. In addition to receiving services through regular Medicaid, children are also provided several waiver services that help make home care a viable option for parents who would otherwise need to seek institutional care for their children with disabilities.



"LISTEN" TO PEOPLE.  
IMPLEMENT INNOVATIVE STRATEGIES THAT ADDRESS SPECIAL NEEDS  
AS PEOPLE AGE.

THE TOTAL NUMBER  
OF ELDERLY PERSONS  
IN THE UNITED  
STATES WITH  
DEVELOPMENTAL  
DISABILITIES IS  
ESTIMATED TO BE AS  
HIGH AS ONE-HALF  
MILLION PERSONS.  
THIS NUMBER IS  
EXPECTED TO DOUBLE  
BY 2030.

Joyce is a 48 year old woman who is dually diagnosed. She has lead a rich life in the community in an independent living arrangement. She was even married for a time. People know Joyce to be a very pleasant and strong-willed individual who values her independence. However, due to mental health and medical issues, she sometimes is not able to make decisions and care for herself.

In the spring of 2007, Joyce began a downward spiral, both medically and mentally. Her cognitive processes caused her to lose the ability to walk, bathe herself, and do many of the things that make us all independent. Joyce was admitted to a nursing home after many months of hospitalization in Binghamton. At the nursing home she obtained intensive occupational and physical therapy services. These therapies proved successful, and she resumed walking and implementing her own daily care. After two months there, she was ready for discharge with no place to go.

With the supportive services and person-centered planning provided by Broome DDSO, Joyce had the opportunity to transition from the nursing home to a more independent, family-style setting. Her mental health needs proved challenging for this residential opportunity. She subsequently moved to another SOIRA and received day services in a community program where she looks forward to working for pay. Joyce advocates for herself and accepts assistance from others when needed. The opportunity to make decisions and to experience life while receiving guidance from staff in this home have proved successful.

Joyce has been able to reestablish independence, maintain her health and well-being with the assistance of dedicated staff. It is anticipated that with continued support, Joyce will be able to meet her personal goals, dreams, and aspirations and continue to live in a community setting.

*Shared by Lorna Service, Broome DDSO*



#### LESSONS LEARNED FROM JOYCE'S STORY

- Expect that the person may need help even with daily living skills as they adjust to the change from nursing home or hospital to a community lifestyle. They may feel overwhelmed.
- Empower the person by directly involving them with treatment considerations and decisions. Let them know their options and support their choice whenever possible.
- Encourage family involvement and participation in planning. Support networks are essential to treatment success.
- Work closely with the treating physician from the nursing home/rehabilitation facility during discharge planning. In addition, communicate often with all clinicians involved in the person's rehabilitation.
- Information is vital in supporting the person once back in a community setting. The staff who will care for the person need information so they can be proactive.

### MORE LISTENING!

Richard is a 59-year-old man from Rochester. He is highly capable and fiercely independent despite significant physical limitations related to Cerebral Palsy that included quadraparesis and muscle spasms. Richard had friends in Texas, so with the assistance of his service coordinator, he relocated to Austin. After two years, Richard decided to return to Rochester. He boarded a bus for New York State without support and did not make prior contact to his friends in Rochester.

Upon his arrival to Rochester, he had a fractured right tibia, and no way to contact his friends. Personnel at the bus station were unable to understand him and called the police who made a referral to Adult Protective Services (APS). Richard was taken to a local hospital for treatment and evaluation, and offered placement in an OMRDD group home or nursing home. He adamantly declined ~ he wanted to live independently.

The Center for Disability Rights (CDR) helped make his dream a reality. CDR first educated the hospital on the community based service options available and then developed a detailed care plan. It helped Richard secure an apartment, apply for and secure personal care services, medical equipment/services and OMRDD service coordination, environmental modifications, individual support services, residential and day habilitation services. CDR also assisted in benefits advisement to ensure Richard had Medicaid, Medicare, food stamps and SSI.

What an accomplishment! Richard lives independently because of the availability of OMRDD Service Coordination, Residential and Day Habilitation, Individual Support Services and Family Support Services. He has services 24 hours a day seven days a week in his home through these OMRDD services and his Consumer Directed Personal Care Program. He continues to be a strong self-advocate of his own independence. Richard is also a long time member of ADAPT and participates in actions to effect systems change at the local, state and national levels to increase the availability of community based services and ensure that all individuals can live in the most integrated setting.

EVERYONE  
EXPRESSES NEEDS  
AND FEELINGS  
EVEN IF THEY  
DON'T USE WORDS  
TO SPEAK.  
BEHAVIOR IS  
COMMUNICATION.

### LESSONS LEARNED FROM RICHARD'S STORY

- Educate the community providers involved in the individual's discharge planning on the *Olmstead Decision* and the individual's right to live in the most integrated setting.
- Build knowledge of community supports and services available through NYS Waivers and Medicaid State Plan services. Many people have needs that cannot be met through one waiver or system; therefore, having an unbundled approach to service planning will give the most options to the individual.
- Individual advocacy is the key in coordinating services for the person. Be a strong advocate to support an individual's main outcome of living in the community.
- Do not hesitate to ask for the time needed to coordinate services, even when other professionals pressure you to accept services that do not support the individual's long term goals.



### RELATIONSHIPS ARE KEY.

PROMOTE PERSONAL CONNECTIONS, AND MAINTAIN THEM EVEN AS PEOPLE'S NEEDS CHANGE.

THE NEED FOR FRIENDSHIP IS UNIVERSAL, LIFE LONG, AND HAS NO AGE BOUNDARIES.

Home is more than a place to come to at the end of a day. Home is about connections with those who care about us and about whom we care. Home is what we carry in our hearts because of all the special memories, even when we can't remember them anymore.

Charlie has been involved with AHRC-NYC almost his entire adult life, receiving services and supportive relationships that have survived many years and numerous residences. He first moved to a community residence, one of the first of its kind for people with developmental disabilities, where he made many friends among peers and staff. Through the years, he continued working in the "jewelry exchange" on the lower East Side. He was known as a flatterer and chatterbox. In fact, a couple of his housemates sometimes paid him 25 cents for every 10 minutes he would maintain silence!

By 1991, his service coordinator recognized his potential to live in his own apartment. While he had a good memory and could travel independently, he was not able to read or write. Therefore, the service coordinator made flash cards of food labels and they went shopping together. She helped him to learn to cook simple meals. In short order, he moved into his very own place in Manhattan! Although romance followed, it was not to be. Charlie was heartbroken, and his AHRC "family" was there to help him move on.



In 1995, Charlie incurred a tear of the anterior cruciate ligament of his left knee. He was hospitalized and did poorly in rehabilitation. He couldn't walk, and refused to even try. He languished at the rehabilitation facility. The treatment team and his AHRC "family" met to see how they might help Charlie regain his will and zest for life. Fortunately, an opening was available at an AHRC Individualized Residential Alternative. Although Charlie could not go back to his own apartment, everyone agreed this could be just the ticket to help him progress. Sure enough, with the support and encouragement of peers and staff, Charlie started to walk again. While he could not do all the things he did before, Charlie was back among those who cared about him. He was "home" once again.

*Shared by Gloria Cumberbatch, AHRC-NYC*

WHENEVER YOU FEEL LIKE THIS IS MORE THAN A JOB, REMIND YOURSELF THAT IT IS!

### LESSON LEARNED FROM CHARLIE'S STORY

- It is important to be clear about the individual's vision for his/her future. Plan with the individual and his/her "circle of support" to translate their vision into reality. The greatest challenge is to consider how services will support the person's vision as needs change; and to foster special relationships that develop over time and across programs.
- Include familiar staff when planning for a residential change. Particularly when people don't use words to "speak," the insights of familiar staff will ensure that the person's interests and preferences are recognized and incorporated within their new home. Take pictures of housemates and special staff and bring over to decorate their new bedroom.



# Putting People First

## MAINTAIN COMMUNITY CONNECTIONS FOR AS LONG AS POSSIBLE.

I first met Robert when he was 61 years old and living in senior housing with his wife Helen. He was a Willowbrook class member, who was discharged from the facility in the mid 1970's. Although he was married and living in the community with his wife, the Staten Island DDSO continued to maintain contact with him and arranged supports to maintain their independence. Helen and Robert had homecare through Medicaid. Helen was non-ambulatory, and Robert was devoted to taking her around the community in her wheelchair. Helen died of heart failure in 2000, leaving Robert alone and grieving.

Robert, who had always been involved with the church where he got married, became more so after the death of his wife. Every morning he would put up the flag at church, and give out the programs on Sundays. He developed relationships with many people at church in addition to the Pastor of the church. When Robert started developing signs of dementia, his friends at church and his neighbors checked on him regularly. Homecare services were reinstated through Medicaid and he was watched closely by good friends and neighbors who would contact the service coordinator regularly.

Robert had a stroke on his way to church one day, and died shortly after. With the care and concern of his church, service coordinator, friends and homecare, he was able to live out his life as an independent person.

*Shared by Ellen Bleckman, Staten Island DDSO*

SUPPORT A PERSON'S CHOICE FOR BELIEVING, BELONGING AND BECOMING A MEMBER OF THE FAITH COMMUNITY THROUGHOUT THEIR LIVES.

## STRATEGIES TO SUPPORT RELATIONSHIPS OVER TIME AND ACROSS SERVICES

- Take the lead from the person knowing what type of life he/she always wanted to live, and respect that even at the end. While it may be easier to support the person in a nursing home or other congregate setting, respect their need to be independent, and live and die as they choose.
- Support people's heritage and connections to community senior centers and faith based associations that support their preferred rhythm of life.
- If a person moves to a new home, identify ways for the person to shop in the same stores, dine in the same restaurants, maintain hobbies and membership in clubs and organizations.
- Holidays, birthdays and family gatherings are important to all of us, especially as we age. Help people stay connected to friends and relatives. Remind them to make phone calls and send cards, emails, pictures, birthday gifts, etc.
- Schedule visits to old neighborhoods. Take pictures. Make a history journal or scrap book. Arrange for staff and people to visit their former homes and enjoy activities together. Create occasions to bring people together so they do not lose touch.





CAREGIVERS,  
INCLUDING  
FAMILY MEMBERS  
AND PAID STAFF,  
NEED TO BE  
TRAINED IN  
OBSERVATION OF  
SYMPTOMS AND IN  
ADVOCACY FOR  
OBTAINING  
PROPER HEALTH  
CARE.  
THEY NEED TO  
DIFFERENTIATE  
BETWEEN AGE-  
RELATED CHANGES  
AND AGE-RELATED  
DISEASES.

#### DON'T ACCEPT THE UNACCEPTABLE.

WHEN SERVICES IN A NURSING HOME AREN'T APPROPRIATE FOR THE PERSON,  
THINK ABOUT ALTERNATIVE OPTIONS.

When I first met Annette at the Health Care Center, she seemed frightened and confused. She reached out, held my hand and asked to go home.

For Annette, home was with her mother and her aunt in Brooklyn; however, in 2004 her mother and her aunt were diagnosed with Dementia and could not take care of themselves. Annette was moved on an emergency basis to another skilled nursing facility. It was difficult for Annette to be separated from her mother and aunt. Soon after, Annette joined them at the facility. During her stay there, Annette preferred to be left alone and slept a good deal. The only time Annette connected with anyone was during twice weekly visits with her mother and aunt. Annette would hug them and was happy. When her mother passed away, Annette became sad, anxious and withdrawn.

A court appointed attorney advocated for Annette to move to a home with people that she could communicate with. A variety of agencies screened Annette, but each time she displayed her displeasure by screaming incessantly. Not so with the Brooklyn DDSO staff. She moved to our IRA and made an excellent transition. She shares a room with another communicative woman and Annette seems to enjoy having her roommate around. Annette smiles and initiates conversation, not only with her roommate but the others with whom she lives. She has a preferred friend, Franklyn, who she will seek out to sit with and talk to. Annette has become curious about her surroundings and will walk around, look around, and sit and talk with her peers (especially Franklyn). Annette has also become attached to staff and initiates conversation with them. Soon after her move to the home, she suffered a broken ankle and required a stay in a rehabilitation facility. Annette's IRA "family" visit her at the rehab facility and hope to bring her home soon.

We are all committed to helping Annette have the best life she can have with us, and are happy to have the opportunity to know this wonderful lady. What has evolved is a relationship of mutual appreciation that will endure this most recent challenge.

*Shared by Shirley Smith, Brooklyn DDSO*

#### LESSONS LEARNED FROM ANNETTE'S STORY

- Observe. Annette's behavior in the nursing home suggested that she was depressed, which was compounded by the loss of her mother.
- Provide a surrogate family. When we experience loss, we often lean on other family members and/or surrogate family. Feeling love and concern consistently from these people helps us to heal.
- Promote and continue new relationships. The team continues to visit and spend time with Annette at the rehabilitation center, shows her love and affection and looks forward to her return home.



## USE AN IRA AS AN OPTION FOR NURSING HOME DIVERSION.

I met Martha in March of 2003 at Monroe Community Hospital. She had just had a second brain surgery and her service coordinator was exploring residential options for her.

Reportedly, Martha had a brain tumor as a child and as a result had cognitive impairments. She came from a large family with nine siblings. Prior to her recent illness Martha had been caring for her own children, but now needed 24-hour care and monitoring, as well as follow up medical care and significant supports to meet her daily needs.

Although Martha was upset that she could not return home with her family, she and her family were willing to look at other homes where she might reside. A respite was secured with the DDSO and then Martha was able to move to an Individualized Residential Alternative as her new home.

The changes for Martha were significant, both in meeting her medical care and her emotional needs. Martha became a member of the Lady's Red Hat Club at the DDSO's day program and enjoyed knitting, playing Bingo and exercise classes. Her children and other family members visited often and Martha made friends with other individuals in her home and community. Martha remained in her home with contractual nursing services. She was also assisted in developing a Living Will and Health Care Proxy and was able to make choices in her end of life decisions.

Martha had the dignity and comfort she deserved as a person with a terminal illness. Martha's family were also very relieved and thankful that she did not have to be moved to a nursing home throughout her illness.

*Shared by Sharon Kimmel, Finger Lakes DDSO*

HOSPICE IS NOT A PLACE BUT A CONCEPT OF CARE; AN INTERDISCIPLINARY APPROACH TO END OF LIFE SUPPORT.

## LESSONS LEARNED FROM MARTHA'S STORY

- It takes a village to support people in such situations. The IRA staff were dedicated to making changes to accommodate Martha's needs. Martha was seen as part of the IRA "family" and everyone was committed to having her stay in the home.
- Sometimes you must learn as you go. Many dedicated staff and administrators worked together to provide end of life services within the IRA setting for Martha.
- Keep open the channels of communication with the person, their family and staff when planning for necessary supports and care.
- Become familiar with health care decision options that are available in New York State to assist a person in choosing the kind of care they want. Then support the person in decisions related to Health Care Proxies, do-not-resuscitate (DNR) orders and Living Wills. While a person can have one or all three of these provisions, the decision to enter into any should be done with the support of family, friends, physicians and other appropriate advisors.



KEEP THE CONNECTIONS. IF ALTERNATE SERVICES ARE NEEDED,  
TAKE STEPS TO MAINTAIN THE PERSON'S SAME COMMUNITY.

John is a man in his 60's with Down Syndrome, who has osteoporosis and has shown signs of dementia. He had lived since 1982 in a community residence operated by the DDSO. He was part of the family of that home, well loved for his social personality. He is known as being a bit of a jokester who liked to create nicknames for everyone he knows. John enjoyed his day program, bowling in the evening, and any social activity that included singing and dancing. For more than 25 years, John had been able to navigate within his environment without trouble, including his second floor bedroom. Unfortunately, he fell in June 2007 and broke his left hip.

After a one-week hospital stay he was transferred to a nursing home in Queens where he began the formidable task of relearning to walk. Walking, either independently or with a walker, was complicated by his symptoms of dementia. Regardless, his service coordinator and staff from his home visited often and reported that he would always ask, "When am I getting back home?"

Although staff at the nursing home reported he had developed a fear of climbing up or down stairs, John was motivated to learn to walk again. Finally, in September he was discharged from physical therapy services at the nursing home. The physical therapy determination was that John's maximum potential was being able to walk using a walker, and that he would need hands-on assistance to navigate stairs.

It took a few more weeks, but a home was found within the same residential team with an available first-floor bedroom. Staff in the new home were then trained to always assist John with any stairs, and to re-cue John whenever necessary to use his walker in the way he was taught. John is now back in his previous day program, reconnecting with friends, and creating nicknames for his new friends and staff in his new home.

*Shared by Annette Black-Eddy, Bernard Fineson DDSO*

WHAT DOES  
DEMENTIA LOOK  
LIKE?

EARLY: SYMPTOMS  
GRADUAL, MAY  
NOTICE MEMORY  
LOSS FOR RECENT  
EVENTS, CHANGES  
IN PERSONALITY  
AND WORK  
PERFORMANCE.

MID-STAGE:  
SYMPTOMS MORE  
NOTICEABLE,  
DECLINE IN SKILLS,  
CONFUSION AND  
DISORIENTATION  
MORE COMMON,  
CHANGES IN  
PERSONALITY.

LATE: LOSS OF BASIC  
SKILLS, WEIGHT  
LOSS, LOSS OF  
ABILITY TO WALK,  
DIFFICULTY  
RECOGNIZING  
OTHERS AND THE  
ENVIRONMENT.

LESSONS LEARNED FROM JOHN'S STORY

- Educate all who care for the individual regarding the probable course of future health, especially as it relates to the specific developmental diagnosis. For example, people with Down Syndrome are at higher risk of dementia as they age.
- Be tenacious with rehabilitation. While it may progress slowly and not achieve the original end goal, progress is often enough for a person to return home.
- Look for all opportunities to move older individuals to less challenging physical environments before an injury occurs.
- Celebrate all achievements large and small when a person reclaims any level of independence.



## MORE ON KEEPING CONNECTIONS!

Steven is a 47 year old man who lived with his parents until 1998, when he moved to the YAI community residence and quickly became part of the family. He was upbeat and fun. He enjoyed politics, was interested in world events, and read books. He loved baseball, especially the Yankees.

In 2007, Steven's mobility and health started to decline. He found it difficult to negotiate stairs from the 4<sup>th</sup> floor (where he lived) to the ground floor. In May 2007, Steven moved to an IRA that was wheelchair accessible and would offer him the greatest mobility: all the rooms were on the same level, the bathrooms were large and specially equipped with handrails, and there was increased staff support. He adjusted well but soon after experienced a deep brain stem stroke, which affected his basic functioning levels ~ walking, eating, toileting, and speech.

Steven's residential needs had once again changed. He had a gastrostomy tube with continuous feedings, was unable to walk, unable to speak, needed total assistance with his ADL needs, and now required 24-hour nursing care. Steven could not return to the IRA. He needed to live in an environment with enhanced nursing care and medical support.

Steven has since moved to an Intermediate Care Facility with YAI. After less than six months and several short hospitalizations he is thriving. He is receiving physical therapy, learning to use a customized rolling walker with arm supports, and starting a day service program with people from the community. He acknowledges familiar faces with smiles, guttural vocalizations, reaching and touching staff member's hands, wearing his Yankee cap.

The YAI team met Steven's medical, functional and emotional needs throughout his long and winding road from community residence to IRA to ICF. He went through many challenges during each residential transition and conquered his medical adjustments with grace.

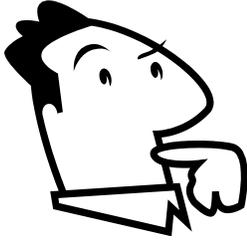
*Shared by Jane Litkoff, YAI*

KNOWING LIFE'S JOURNEY GIVES US THE CHANCE TO REFLECT AND USE LESSONS LEARNED TO SUPPORT PEOPLE THROUGHOUT THE AGING PROCESS.

### LESSONS LEARNED FROM STEVEN'S STORY

- Consider how to communicate with a person despite changing needs and conditions. When Steven wants his favorite staff's attention, he winks and smiles. He squeezes his favorite staff's hand to show that he agrees with the choices being offered. Staff know how to "listen."
- Think about ways to support a person's interests despite medical, functional and cognitive challenges. Steven continues to have an active social life - he goes to Atlantic City, keeps up with the Yankees, watches his old Clint Eastwood and Elvis Presley movies, and sits in the park and watches the kids and puppies play. Three days a week he goes to a recreational center where he socializes with his friends and gets to meet new people.





Changing the way we think is a start!!

WHAT CAN BE DIFFERENT? CONSIDER CROSS SYSTEM SUPPORTS AND ENHANCEMENTS TO A HOME, BE IT WITH STAFF, TRAINING OR LIVING ENVIRONMENT MODIFICATIONS TO SUPPORT PEOPLE IN THEIR HOME OF CHOICE.

Maria was placed in Willowbrook State School on 2/19/1959, when she was 14 years old. She stayed at the facility until 5/18/1978, when she moved to her own apartment with the help of the outpatient unit of the Staten Island DDSO. She worked as a cleaner for Willowbrook, and retained that employment until she retired in 2004.

Although Maria moved to the community, she possessed few skills necessary for survival in the community and fell victim to unscrupulous landlords and community people. There were few services available then to her from the community and she relied on her service coordinator, friends and coworkers for assistance. No matter how difficult her circumstances once out of the institution, Maria was resolved not to return to a group home setting.

As services became more available in the community Maria's service coordinator was able to access them for her. She eventually moved into an ISS with a voluntary agency, that was able to help her monitor her medical and financial affairs, and provided her with a comfortable clean apartment. Once retired she began to attend a senior center and go on trips with them, take part in parties, and other activities.

Regretfully, Maria was diagnosed with cancer in 2007. She began a long process of treatment that made her weak and sick. The hospital providing treatment recommended a stay in a rehab facility, but Maria was determined to stay home. The service coordinator and ISS agency were able to arrange for her services through a combination of Family Support Home Care, Residential Habilitation and eventually hospice care through St. Vincent's Health Services. The service coordinator was able to establish communication with Maria's family who assisted in the care at the end of Maria's life. Throughout her illness Maria was insistent that she remain at home. Maria died on 3/12/2008, in her home with her family, service coordinator, and friends by her side.

*Shared by Ellen Bleckman, Staten Island DDSO*

"AGING WITH CHOICE" REQUIRES THINKING ABOUT THE PERSON'S NEEDS IN ONE YEAR, TWO YEARS, FIVE YEARS AND SO ON.

#### LESSONS LEARNED FROM MARIA'S STORY

- Even in the face of serious illness, take the time to listen to what the person has to say. Actively respond to questions. Restate key points to affirm understanding and to confirm priorities.
- Consider services that will ensure the person has a normal rhythm of a day and identify activities that make sense for the person. Focus on the person's strengths by building on their skills rather than on their deficits.
- Consider the viability of community services, such as hospice, homecare, senior centers, to support the wishes of the individual served. Develop a service plan that incorporates the greatest scope of resources that the community has to offer.



## A DIFFERENT APPROACH TO IN-HOME SUPPORT!

About 10 years ago, Western NY DDSO received a call from Viola's family. Viola was 66 years old with a diagnosis of Cerebral Palsy; she was unable to communicate and only had the use of her left arm. She lived with her mother age 84 and her father who had just died suddenly in a car accident at the age of 94. Until that time, Viola was supported by her parents and a brother and sister-in-law who lived across the street from the family home. The DDSO referred Viola's mother to Aspire of WNY where Viola was linked with a Service Coordinator, who helped the mother access Waiver Services and obtain a power wheelchair that fit her small frame (she used to slip out of the back of her old wheelchair because it was too big). The home was also fitted with a ramp, automatic door opener and ceiling mounted lifts. Viola was able to remain at home with her mother.

The story continues. Several years later Viola's mother moved to a nursing home. With no one available to care for Viola, her family thought she would also need to be placed in a nursing home. However, the service coordinator learned through Viola's lawyer that since Viola had a disability and lived in her mother's home, it was possible to transfer the house to Viola. She did not need to leave her home and became the home owner! Viola's service coordinator helped her to obtain residential habilitation, speech therapy services and a communication device. Her family also purchased a computer and Viola was able to communicate her needs to her service coordinator via e-mail. She has become very technology capable!

Now at age 76, Viola has a plan with support from her family and service coordinator where the individual who lives upstairs (they share the same kitchen) provides support and is responsible for her needs from 9 PM to 6AM. She attends a day habilitation program 5 days a week where she volunteers her time setting tables and assisting with attendance charts at the Adult Day Program. Upon her return home from day habilitation she receives residential services from 3:30PM-9:00PM. Residential habilitation staff is very receptive to her wants and needs. Viola's church is also located across the street from her home and she enjoys making birthday cards for church members and baking for those church members/friends who are sick. Viola visits her mother at the nursing home every weekend. Today Viola is a wonderfully independent lady who has friends and lives her life to the fullest.

*Shared by Carmon Grigsby, Western NY DDSO*

"DUAL AGING," THE AGING OF PERSONS WITH DEVELOPMENTAL DISABILITIES AS WELL AS THEIR CAREGIVERS (FAMILY MEMBERS AND PAID STAFF) WILL CONTINUE TO PUT MORE DEMANDS ON THE SERVICE SYSTEM.



## LESSONS LEARNED FROM VIOLA'S STORY

- Help people pursue their personal dreams. Viola is now a home owner. She has her own schedule. She has learned to advocate for herself. She has a voice and she makes sure it counts.
- Never say "no", say let's take a look at it. It is okay to "push the envelope" of agency policy and mission when planning for people.
- Promote making choices. Allow capable individuals to take informed risks and respect their right to do so!



AS BOTH THE PERSON WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILY CAREGIVER AGE, THE NEED FOR RESPITE, LONG-TERM FINANCIAL PLANNING, GUARDIANSHIP ARRANGEMENTS, AND DETERMINATION OF FUTURE RESIDENTIAL OPTIONS INCREASES.

### IN-HOME SUPPORTS CAN MAKE THE DIFFERENCE!

Christine and her father *George* are especially close, having lost Christine's mother and brother at an early age. They wanted to live together as long as possible. *George's* increasing needs and their lack of extended family support would have jeopardized this were it not for creative implementation of services for both of them.

Christine had fired her previous Medicaid Service Coordinator (MSC), and when service coordination resumed, the new MSC became aware that her assistance was needed in managing Christine's mental health, medical, and other needs. A year or two later, it became apparent that *George* could not keep up with maintaining a house or his checkbook. The Senior Caregivers Program from Exceptional Family Resources (EFR) referred him for help with managing his money. Christine's MSC connected him with a realtor to sell the house and helped them find an apartment. Not long afterwards, *George* had a car accident and realized he should no longer drive. Within a few months, his mobility worsened. He also wasn't taking his medications properly. The Senior Caregivers Program referred *George* to the Program of All-inclusive Care for the Elderly (PACE). PACE and EFR worked together to coordinate services and to keep the household running smoothly and safely. PACE provides *George* with coordinated medical services, assistance with taking his medications, physical therapy, a day program, meals on wheels, and home health aide services. EFR increased Christine's residential habilitation hours and added goals of grocery shopping, doing laundry, learning how to cook, and budgeting.

Christine has really risen to the occasion, developed more independent skills, and become a significant source of support for her father without being expected to do more than she can handle. EFR also referred *George* to a lawyer to update his will and to establish a Supplemental Needs Trust for Christine. For now things are stable for *George* and Christine. They are happy with their services and happy to be together.

*Shared by Deb Gibson-Jaworski, Exceptional Family Resources*

### LESSONS LEARNED FROM CHRISTINE'S STORY

- Effectively serving people with developmental disabilities can involve referring parents to support services as well.
- People with developmental disabilities can take pride in and be successful at helping their families if they are provided with the proper supports and reasonable expectations.
- Developmental disabilities services and senior services can work together to serve a household.



## MORE IN-HOME SUPPORTS!

Dawn uses a power wheelchair, needs total care support, and has significant articulation challenges. She has always dreamed of having an apartment, job, and friends like everyone else in spite of the limitations that people have tried to place on her.

Dawn had always lived at home. However, her elderly mother developed significant needs and instead of being able to provide Dawn's care, needed care herself. Dawn's sister wanted her to live with her niece. Dawn had no desire to move away from her community to live isolated in the country and dependent on her niece. Dawn's service coordinator wanted her to move into a group home and put her name on the list for a home without talking with her. Dawn reasserted her desire to move into her own apartment. With an aide's help, she contacted the Senior Caregivers Program with Exceptional Family Resources (EFR). A meeting was set up and for the first time, Dawn heard a professional say that her dream could be pursued. The first step was to find a new service coordinator who was willing to do the creative work.

What a difference once Dawn found a service coordinator that followed her dream! The new service coordinator worked with Dawn to establish a Circle of Support. Using Self Determination, they developed a plan for Dawn. An apartment was found. Door openers and an adapted phone system were installed so that she could safely be home alone. A budget was put together which increased her aide support. Closed circuit cameras were installed which Dawn's trusted cousin monitors to ensure her safety.

Dawn loves her apartment. It has not been without problems. She waited a year for a roll-in shower and has to hire new aides. However, having her own space, having her future settled for now, and being able to entertain—she hosted her family's Thanksgiving the last two years—makes it well worth it. And she has a job. Life is good.

*Shared by Deb Gibson-Jaworski, Exceptional Family Resources*

ACCESS IN-HOME SUPPORTS FOR FAMILY CAREGIVERS WHO NEED TO TAKE CARE OF THEMSELVES SO THEY CAN REMAIN HEALTHY AND ABLE TO CONTINUE THEIR CAREGIVING ROLES.

## LESSONS LEARNED FROM DAWN'S STORY

- Listen to the person and help them pursue their dreams.
- Support dignity of risk and work out creative safeguards so that the person is safe and making personal choices.
- Respect concerns raised by family members. Help them envision a positive, ongoing role in their loved one's more independent life.
- Recognize, support, and honor the crucial role that both service coordinators and advocates play in creatively supporting a person's independence.





### KNOW YOUR RESOURCES.

#### LOOK FOR PROGRAMS THAT SPECIALIZE IN UNIQUE SERVICES.

Kevin is a 57 year old man who has lived in several Central New York DSO homes for the past 28 years. In 1983 Kevin moved to the Central New York area from Nassau County and resided at the Rome Developmental Center until it was closed in 1989. In March 1989 Kevin moved to a small IRA located in Rome, New York. This home was specifically designed to address Kevin's long-standing PICA behaviors in the most integrated setting possible.

In January 2007 Kevin was hospitalized with aspiration pneumonia. A videofluoroscopy revealed Kevin was aspirating significant amounts of food into his lungs. A feeding tube was necessary in order for Kevin to take nourishment safely. The placement of the feeding tube meant Kevin would require a home which could provide a minimum of 16-hour nursing coverage. Although a nursing home could address Kevin's medical needs they were ill-equipped to address his very special behavioral needs.

Fortunately the Central New York DSO had a specialized ICF, which offers medical services that mirror those provided in skilled nursing facilities. Upon discharge from the hospital Kevin was admitted to this ICF. The medical staff from the home worked with Kevin to adjust to bolus feeding while Developmental Aides addressed Kevin's ongoing behavioral needs.

After two weeks of rehabilitation at the specialized ICF Kevin moved to a small IRA which provides 16 hours of daily nursing coverage. One-to-one staffing continued for several weeks to ensure Kevin's transition was successful. Today Kevin attends a day habilitation program on weekdays. He rides the bus independently to and from the program. His adjustment to his new home is complete and he regularly participates in a variety of community activities.

Kevin's story has a happy ending because specialized medical and behavioral supports were available to address his unique needs.

*Shared by Patricia Bates, Central New York DSO*

TAKE FULL  
ADVANTAGE OF  
AGENCY OPTIONS  
AND COMMUNITY  
RESOURCES TO  
CREATE THE  
BEST PLANS.

### LESSONS LEARNED FROM KEVIN'S STORY

- When behavioral supports are needed in addition to enhanced health care, develop a treatment plan for implementation immediately upon discharge from the hospital.
- Be proactive. Be prepared. Research the individual's support needs. If you don't know any particulars about the person, find out. Network with multiple agencies or DDSO services to maximize available services. Facilitate a sense of teamwork and cooperation amongst service providers.
- Integrate services to maximize the person's independence. Utilize 1:1 services and develop a strategy to fade as appropriate.
- Expect positive outcomes.

**ANOTHER MOVE FOR SPECIALIZED SERVICES!**

Gonzalo is a Latino man, 73 years old and a Willowbrook class member. He had been residing in a State Operated IRA since 1983. As he aged, he began to experience various medical issues, primarily due to his Non-Insulin Dependent Diabetes. Hospitalizations were becoming increasingly frequent. Following his last hospitalization, Gonzalo was placed on insulin in an effort to better control the Diabetes. Although the residential staff are trained to dispense medication, in state operated homes, an LPN or RN was required to administer insulin due to Civil Service requirements. The DDSO looked into Visiting Nurse Services of New York coming into the residence to administer the Insulin as ordered. Given that Gonzalo was ready to discharge, the hospital recommended that he be placed in a nursing home where the necessary medical care and attention could be immediately provided.

Several planning meetings were held, and his team members agreed that Gonzalo would have difficulty moving to an unfamiliar environment, where new caregivers may not understand his needs and potential. His advocates and service coordinator strongly advocated that the DDSO identify an appropriate community alternate for Gonzalo. The DDSO had an opportunity in its State Operated IRA in Manhattan that provided 24-hour nursing; however, the opportunity was for a woman. But the program planning team and team leader worked diligently to create a vacancy for Gonzalo. We are pleased to report that Gonzalo is currently residing in the SOIRA, where his medical needs are being met and his health has been stable. He is receiving love and kindness from staff who are trained and compassionate, as well as knowledgeable of Gonzalo's specialized needs.

Because of the love and care of some very special staff, working hard to maintain a rhythm of life for the individuals in our care, people with developmental disabilities live full, meaningful and longer lives.

*Shared by Sherri Hollington, Metro New York DDSO*

EVERY CHALLENGE  
IS AN  
OPPORTUNITY FOR  
GROWTH.



MAKE IT WORK. IF A TIME LIMITED STAY IN A NURSING HOME IS NECESSARY,  
PLAN THE SUPPORTS TO MAXIMIZE SUCCESS.



Estella was born in Puerto Rico in 1944, lived in several developmental centers and finally moved into the community with an LPN who was also certified as a family care provider. When this provider moved out of state, Estella moved in with the provider's sister. It was a great option ~ she continued to live with the same family and maintained contact with her extended family as well.

One afternoon, while stepping onto the bus from program, Estella injured her knee and refused to bear any weight. She was immediately taken to the hospital and doctors stated "she would never walk again". With this diagnosis, Estella could not return home as the residence was not and could not be wheelchair accessible. Estella was discharged from the hospital with a new wheelchair to the nursing home. This was a very difficult transition for Estella. She does not speak, but her sadness was evident to all. She stopped eating and when fed ate only a little. She began to lose weight.

As her service coordinator, I sought assistance from the DSO's physical therapist. The physical therapist pressed the hospital doctor in regard to his diagnosis. She asked for further testing. He said it was unnecessary. They disagreed and she contacted the nursing home physician. Would he be willing to order an MRI to confirm the injury? He would and subsequently ordered physical therapy. The physical therapy staff at the nursing home were not able to communicate to Estella the importance of trying to walk. They didn't know her! And she didn't know them! But they did allow me, as her service coordinator, to work with her. They observed and were able to encourage her to trust them. Estella began to walk and to go up and down stairs with assistance and soon she was independent again. The DSO physical therapist visited Estella's family care home. Grab bars, bath chair and several other changes were made and Estella was welcomed home!

I saw Estella yesterday. She continues at the same home and same day program. And yes, she is still walking...all by herself. I firmly believe if we hadn't worked together as a team, Estella would still be in the nursing home and in a wheelchair.

*Shared by Eleanor Pearlman, Central NY DDSO*

"EXPRESS YOUR  
APPRECIATION TO  
PEOPLE WHEN  
THEY DO THE  
RIGHT THING.  
EVERYBODY  
WANTS TO KNOW  
THEY ARE  
APPRECIATED."

#### LESSONS LEARNED FROM ESTELLA'S STORY

- Think about your agency's supports and who is the expert in regard to the situation. For Estella, the service coordinator sought the help of the physical therapist. Get their recommendations/suggestions.
- When going to the nursing home present yourself as an advocate and support for the person. Estella's service coordinator offered to meet with the PT Dept at the nursing home to help them — Not to TELL them what to do. Remember you can get a lot more "flies w/honey than with vinegar". Also, explain to them that you are with an agency-it doesn't hurt to let them know that!



## HELP PEOPLE RETURN TO THEIR FAMILY CARE HOMES!!

Marie is an elderly woman who lived in a Family Care home for many years. As she aged, she developed severe osteoporosis. Eventually, Marie had to use a walker to prevent her from falling. To enable her to remain in her family care home, environmental modifications were made to the bathroom which included grab bars, a higher toilet, and wider doorway. Since the home was a raised ranch, a stair glider was installed. Despite these efforts, Marie did eventually break her hip and was admitted to a nursing home for rehabilitation. While at the nursing home her medical status was monitored by the DDSO and advocacy was provided as needed. Marie and DDSO staff were involved in treatment planning. Marie's Family Care provider, along with her family, maintained contact with Marie at the nursing home until she was discharged and returned back to the FC home. Due to health issues, Marie was eventually transferred to an Individualized Residential Alternative in close proximity to her former Family Care home.

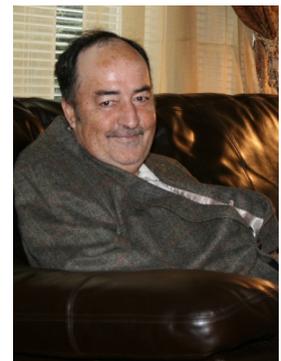
Jane, a woman in her mid-50s, was living in a Family Care home when she was suddenly hospitalized with kidney failure and chronic bladder issues. She was eligible for skilled nursing level of care. A return to the Family Care home required a huge commitment from the FC provider. The provider learned catheter care, was diligent in following a toileting schedule and maintaining accurate daily records of Jane's bladder function. The provider also received training in specialized diets low in potassium, and arranged appointments with physicians on an as-needed basis. At the present time, the possibility of increasing the reimbursement level to this provider is being explored.

*Shared by Jeanne Zanta, Capital District DDSO*

TREAT EVERYONE  
NOT HOW YOU  
WANT OTHERS TO  
TREAT YOU,  
TREAT THEM  
BETTER!

## SOME STRATEGIES FOR AGING IN FAMILY CARE!!

- If a person shows signs of dementia, review all possible medical and environmental factors to determine etiology. Some medications and medical problems are significant in "producing" forgetfulness, dizziness and confusion. Medical problems can also contribute to dementia/mood swings and reclusive behaviors. Once a medical condition is properly addressed, "behavior" is evaluated and addressed in a respectful manner, providing the individual as much choice and control as possible.
- It is helpful when family care providers are able to read formularies and report side effects. Providers benefit from ongoing training as well as sitters, i.e., Elder care issues, medication administration, health and safety, behavior management, etc. In addition, all provide training specific to the person's needs.
- Document and trend visits to the emergency room from the family care home.
- Environmental modifications are provided to the extent possible to enable an individual to remain in a family care home for as long as possible.





### HAVE HIGH EXPECTATIONS. BE OPEN TO SURPRISING RECOVERIES.

Lewis has always been a very active person and good artist who had even participated in a semester of art at a local college. While he had seizures for most of his life, in August of 2006 Lewis had a seizure on the stairs and fell, breaking both hands and an arm. Just as he started to recover, he developed a kidney infection and his hands swelled so much that this artist could not hold a spoon. He was in and out of consciousness and in constant pain. At one point it seemed that his kidneys would fail completely and he was taking little nourishment, even through tube feeding. Many care givers and staff privately felt that Lewis was nearing the end and that it might even be a blessing due to his constant pain. However, during this crucial period Lewis was able to communicate his wish to continue his fight. Months later Lewis would say "Somebody told me I was dying. I wanted to prove him wrong."

Wonderfully, his medical condition began to improve. In November of 2006, Lewis moved to a nursing home for rehabilitation: the end of an impossible journey; the beginning of another. Lewis gradually learned to move his hands again, to sit, to stand, to walk a few steps and then across the room. Once believing he would never draw again, he learned to hold a pencil and sketch. In physical therapy he pushed himself to the max, his goal to return home.

In March of 2007 Lewis returned to his Family Care home and to day services a short time later. A welcome home party at his home was attended by more than 70 of his peers and staff.

Lewis is truly back. He recently won two awards in an art contest and has become very involved in his church and is a valued member of a men's group. Oh yes, he has had a special lady friend for over a year!

Lewis recently showed some of his pictures to his men's group, then asked them to express what they felt or thought about when looking at the picture, and what the character in the picture was feeling. Of course professionals call that "art therapy." To Lewis it is what he does naturally: sharing with others and helping them to share back.

WORKING ON  
EXISTING  
STRENGTHS  
IS AS IMPORTANT  
AS OVERCOMING  
WEAKNESS.

*Shared by Lorna Service, Broome DDSO*

### LESSONS LEARNED FROM LEWIS' STORY

- Maintain a network of support for the individual ~ their collective energy can make a difference.
- Consider the possibility of rehabilitation, even when the individual seems to be very frail. Look forward to a positive outcome for the person. Rejoice in small steps.
- Always provide opportunities for the individual to express discomfort, sadness, fear, as well as joy. Use humor whenever possible.

### ANOTHER SURPRISING RECOVERY!

I was fortunate enough to meet a very strong willed young man who beat all odds of ever leaving a nursing home. At the time, Jeffrey was 31 years old, living in an Individualized Residential Alternative. However, his life was forever changed when he was 16. It was the last day of school and he accepted a ride on the back of his friend's motorcycle, without wearing a helmet. They hit the back of a school bus. Jeff sustained a Traumatic Brain Injury and became paralyzed. He was in rehabilitation and returned home to be cared for by his mother.

Eleven years later, his mother sustained a stroke and Jeff's grandmother became his primary caregiver. Then two years later, Jeff moved into a group home. He was enjoying life and after having lived here for four years, another crisis developed for this young man. He was admitted to the hospital with acute respiratory distress and aspiration pneumonia. Jeff was placed on a ventilator with little to no hope of ever breathing on his own. There are only seven facilities on Long Island that provide ventilator-dependent care, none within the OMRDD system of services. Jeff was placed in a nursing facility about an hour away from his family, though on a waiting list with a facility closer to them.

A few months later, he was transferred and progress became a way of life for Jeff. He not only was on a ventilator and had a tracheostomy, but he also needed a feeding tube and a bi-pap machine at night. However, Jeff worked very hard and seven months later, the social worker called me to relay very good news. Jeff no longer needed the ventilator or the tracheostomy. They were even successful in having the feeding tube discontinued. Jeff was ready to return to community living. I called his former residence and nothing short of a miracle happened. Almost to the day, one year after Jeff was hospitalized, not only did they bring Jeff back home, he returned to his old bedroom!

WEANING FROM A VENTILATOR OR TRACHEOSTOMY IS MUCH LIKE GROWING UP: THERE IS LESS RELIANCE ON MECHANICAL SUPPORT AND INCREASING PERIODS OF INDEPENDENCE UNTIL YOU ARE FINALLY "ON YOUR OWN."

*Shared by Patricia Weber, Long Island DDSO*





"FAMILY"  
IS MORE THAN  
BIOLOGY!

### TREAT PEOPLE LIKE FAMILY. BE THERE TO SUPPORT END OF LIFE.

I can't remember the first time that I met George. I was probably sitting in my supervisor's office when he came by asking for money or a smoke. My supervisor gave him one but reminded George that he himself no longer smoked. In 1999 I was promoted and moved into the office and quickly realized that this office was shared by George and whoever else worked there. George had lived at Willowbrook, then at a house in Manhattan and due to issues with steps came to this residence. George was able to tell me about everyone he had ever worked with in AHRC and had nicknames for everyone. George would ask me about people and then we would call them on the phone. We would sit outside and he would talk to everyone as they went by and everyone knew him.

In my eyes George was just about as close to perfect as anybody could be. He was funny, charming and always honest. I transferred after George went through his first surgery for cancer. I will never forget the nurse asking if I was his daughter, I sat in the waiting room with house staff for seven hours. There was no way he would not have people waiting outside for him. That started one of the first changes in our agency. Nobody has surgery without someone waiting outside.

When George's cancer came back I was with him every step. Even when they said nobody could be with him, my supervisor arranged for me to have a radiation badge so I could have access to his room. George died in hospice on 2/14/05 surrounded by a dozen people ~ although he had no blood relatives his "family" was with him. He had a funeral mass at the church he went to every week and proper burial.

George's passing has made a difference in many lives. In his memory I started doing quality of life at the end of life trainings for our department. We have made it a mission that nobody should ever die alone and have kept that promise to the others who have passed since.

*Shared by Monica Santos, AHRC-NYC*

#### LESSONS LEARNED FROM GEORGE'S STORY

- When we know and care about someone who dies, it is a learning process. Share your feelings with co-workers and supervisors. Seek counseling from an expert in the field on 'Death and Dying' if it is not suggested by someone else. Offer this support to housemates, workmates, and/or friends in the community as you mourn someone's loss. It is a painful journey we all need to experience. Honor the need to grieve personally and communally.
- Keep personal possessions and/or show pictures of individuals who have passed. It helps to keep someone's spirit alive.
- If you are acting as a family "surrogate" you may take the lead and honor the individual's preferences during his/her passing. If relatives are making decisions our familial role will be a different one. Step back and respect the family's wishes.

SUPPORTING PEOPLE TO UNDERSTAND DEATH AND DYING.

The following text was sent via email by Craig Becker, AHRC-NYC:

Tonight, all the Manhattan Apts. and group home residents/staff met so that I could bring them up to date on Irene's situation. I explained what had happened and the serious nature of her present condition. Jo El and I then fielded questions from all. They wanted to know about the difference between a "heart that stopped" and a "heart attack": was she conscious; could she hear us -- lots of smart stuff. We asked that everyone share their thoughts and feelings. What ensued was beautiful. EVERYONE in the room was able to articulate their feelings about Irene's condition, their hopes for her recovery, and their desire for her to return to us. They shared their feelings about Irene as a friend -- Susan said "the apartment is too quiet without her"; Verdell said she "missed their Sunday talks when they joked around"; Paul said he "missed their phone calls". They also talked about her importance to the community and how "everybody knows her": the staff at Joe Junior's, the Chinese Take-Out place, the Synagogue, and her friends at her prior residence. They suggested sending cards, flowers and balloons to her to let her know they were thinking of her. Natalie even DONATED a picture -- an almost unprecedented gesture on her part! We recorded a list of all her good (and feisty) qualities. Jo El asked everyone to "make one wish for Irene". The overwhelming response was that she get well and come back home. A high point was Steven pointing out that the Lord would look after Irene, prompting Ethan to suggest that we conclude with a prayer for her. Paul volunteered to lead us all in a series of Hail Mary's for Irene, followed by Jo El asking everyone assembled to think a positive thought for her before they went to sleep tonight. Quite an important evening for all.

IT IS ESSENTIAL  
TO HELP PEOPLE  
EXPRESS  
FEELINGS OF  
GRIEF AND TALK  
ABOUT THE LOSS  
OF SOMEONE  
IMPORTANT TO  
THEM.

AS AN UPDATE TO THE ABOVE MESSAGE: After a prolonged hospitalization, another surprising recovery. Irene recovered and has returned to her full potential. She is eager to move back into her apartment, and continue her life in her NYC community.

TO TELL OR NOT TO TELL: WHY TELL PEOPLE WITH DEVELOPMENTAL  
DISABILITIES ABOUT THE DEATH OF SOMEONE CLOSE?

It is important not to wait for death to occur; prepare individuals throughout their lives to deal with the loss of loved ones.

- Talk about death as an expected part of living.
- Prepare individuals for the expected death of someone close who is aging or ill.
- Use the death of pets or animals as opportunities to discuss death.
- Use community resources such as hospice and clergy to teach individuals about death.
- When faced with the serious illness of an individual, remember to be honest and truthful with their peers.

Death is a part of life. If we want to promote as normal a life as possible, we cannot shield the people we serve from the truth. Their thoughts may be worse than reality. If they are not told about the death, they will miss the deceased person yet not understand what has happened. As with us all, the people we serve will benefit from the chance to talk about the loss and express their emotions.



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*Carmon Grigsby, Western New York DDSO*

*Sherrri Hollington, Metro New York DDSO*

*Sharon Kimmel, Finger Lakes DDSO*

*Jane Litkoff, YAI*

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*Eleanor Pearlman, Central NY DDSO*

*Lawan Rickenbacker, Staten Island DDSO*

*Monica Santos, AHRC-NYC*

*Michele Schwartz, Center for Disability Rights*

*Lorna Service, Broome DDSO*

*Martha Schunk, OPWDD*

*Shirley Smith, Brooklyn DDSO*

*Jennifer X. Taylor, Staten Island DDSO*

*Patricia Weber, Long Island DDSO*



"ag-ing v.

1. To grow and mature,
2. To experience life (as in 'We all are aging; some with more experience than others')





LEARN MORE FROM THESE REFERENCE DOCUMENTS

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TREAT OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES WITH THE DIGNITY THEY DESERVE.

SOME INTERESTING REFERENCE LINKS

An excellent NYS Resource and Geriatric Training: [http://www.urmc.rochester.edu/pediatrics/divisions/developmental\\_disabilites/PADD/geriatricassessment.cfm](http://www.urmc.rochester.edu/pediatrics/divisions/developmental_disabilites/PADD/geriatricassessment.cfm)

Good general information and tips for working with elderly individuals: <http://www.opadd.on.ca/>

About the Hospice & Palliative Care Association in NYS: <http://www.hpcanys.org/index.asp>

On AAIDD: <http://www.aaid.org/Aging/index.shtml>

OTHER REPORTS FROM THE COMMISSIONER'S TASK FORCE ON AGING Subcommittee on Health, Prevention and Geriatric Assessment

- Preventative Health Care Screening Recommendations for People Aging with Intellectual and Other Developmental Disabilities [http://www.opwdd.ny.gov/document/image/hp\\_brochures\\_preventhealthfinal.pdf](http://www.opwdd.ny.gov/document/image/hp_brochures_preventhealthfinal.pdf)



NYS Office For People With Developmental Disabilities

## Putting People First

### The Vision Statement for

NYS Office for People with Developmental Disabilities

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities.

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### The Mission Statement for

NYS Office for People With Developmental Disabilities

We help people with developmental disabilities live richer lives.

For further information, please check  
the OPWDD Website:  
[www.opwdd.ny.gov](http://www.opwdd.ny.gov)

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518-473-9698

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COMMISSIONER'S TASK FORCE ON AGING  
SUBCOMMITTEE ON NURSING HOME DIVERSION & DISCHARGE

David Booth, Ph.D., Staten Island DDSO - Committee Chair

Jose Abraham, Staten Island DDSO

Craig Brown, Ph.D., OPWDD

Fred Feibusch, YAI

Jeanine Fox-Montemayor, Central New York DDSO

Helen Herzberg, Self Advocate

Carol Hodecker, Department of Health

Jerome Isaacs, Parent Advocate

Navlette James, Finger Lakes DDSO

Sharon Locke, OPWDD

Pat McGowan, Central New York DDSO

Denise Pensky, OPWDD

Jill Pettinger, Psy.D., OPWDD

Minna Ringrose, Central New York DDSO

Bernarda Rivera, Self Advocate

Nicholas Rose, Developmental Disabilities Planning Council

Bruce Rosen, Department of Health

Ellen Rosman, AHRC-NYC

Laura Robinson, University of Rochester

J. Rowe, ARC of Monroe

Kathy Serino, Commission on Quality of Care and Advocacy for Persons with Disabilities

