

Welcome to the Fall/Winter edition of the VOR Voice! This issue focuses on our family members in Intermediate Care Facilities, the importance of ICF's as part of the continuum of care, and the level of care and security that larger congregate care facilities provide. We also feature articles on two programs that are available to some ICF residents: a horseback riding program at Texas' Richmond State Supported Living Center and a music therapy program offered at Connecticut's Southbury Training School. Also in this edition Susan Jennings describes how her fight for her son's care led to her becoming a grass roots advocate, putting together an organization, uniting families in Pennsylvania's state centers, and going to the state capital to stop a bill aimed at closing all of her state's ICF's.

VOR News Update: *Caroline Lahrmann resigned as President of the Board of Directors on September 25th. In accordance with our by-laws, and with the support of the Board of Directors, Vice President Joanne St. Amand has assumed the role of President. We are grateful to Joanne for taking on this responsibility and have confidence in her ability to perform the duties necessary for VOR to continue its mission.*

Message from the President

I am honored to serve as President of VOR. For those members who don't know me, I have been a long-time supporter of VOR and a Board member since 2013. I will do my best to meet the ever-increasing challenges we face to insure choice, and a full continuum of high quality care and appropriate services for our family and friends with intellectual and developmental disabilities (I/DD).

My brother and I are co-guardians for our 62-year-old sister, Rosemary who has profound intellectual disabilities. Rosemary cannot walk or talk but she melts my heart with a glance of her eyes and an ever so slight squeeze of my hand. She needs to be fed pureed food and her liquids are thickened so she does not choke. Rosemary's cognitive level is at 3 months old and she needs help with all activities of daily living. Like many of our VOR members, my brother and I became guardians and unwavering advocates for our sister as we matured and our parents aged.

Rosemary lived in an ICF in New Jersey since she was 20 years old. In 2012, NJ announced the closure of two ICFs, one of them was Rosemary's home for 39 years. The move was traumatic and many individuals died within the first two years of moving. We consider ourselves among some of the more fortunate families in that we were able to secure a transfer for Rosemary to another ICF in NJ.

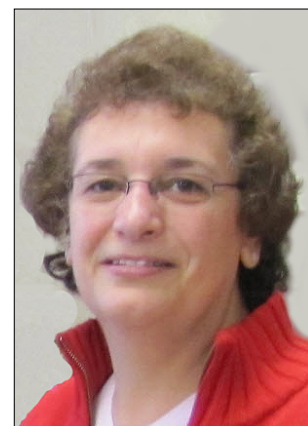
During this most difficult time, VOR was our lighthouse in the storm. In addition to the very important advocacy and legislative work VOR does in Washington, VOR advocates for individuals with I/DD and their families in every state of the country. They provided NJ families with support every step of the way, empowering family members with expert advice, testimony, professional contacts, and the experience and knowledge from members across the country.

As the year draws to a close and the holiday season approaches, we are in the midst of our year-end giving campaign. As you know, VOR is 100% privately funded. This valuable work and advocacy could only be accomplished through the volunteer efforts and generous financial support of our members and friends.

This year, we are pleased to announce that the Association for Individuals with Intellectual Disabilities (AIID) based in NJ has offered to match donations up to a maximum of \$10,000 between now and December 31st.

Every member is important and every gift counts. We are grateful to you for your years of continued support to VOR and ask that as you plan your year-end charitable giving, you would again please consider a gift to VOR.

Thank you,
Joanne St. Amand
President, VOR Board of Directors



My Journey into the Grassroots

**By Susan Jennings, Mother and Co-guardian of Joey, VOR State Coordinator for Pennsylvania
Founder of KIIDS (Keeping Individuals with Intellectual Disabilities Safe) www.thekiids.org**

We live in Pennsylvania. Our son Joey has autism and intellectual disabilities. We could not manage his autistic temper tantrums safely at home. But he was suffering greatly in the community group home service system. In four years' time, Joey was discharged from 3 different group homes in Pittsburgh, Philadelphia and Allentown and languishing in 5 different psychiatric wards for up to 6 months at a time, between inappropriate and inadequate community group home placements. His eye socket was broken, he was exposed to pornography, he was forced onto 22 different psychotropic drugs with horrific side effects, including psychotic breaks with reality, development of female breasts, permanent neurological tremors and intractable insomnia.

Desperate to save our son from the living hell his life had become, I called upon the ARC and the Disability Rights Network. I begged the Office of Developmental Programs and Joey's county social workers for assistance for Joey. They subscribe to the idea that only one residential model of care, the community group homes, is appropriate or adequate for the entire spectrum of developmental disabilities. Joey's experiences were proving otherwise, but they seemed to be in denial. I received no answers and no practical help from any of them.



Joey's Birthday at White Haven

I stumbled across the existence of Pennsylvania's State Developmental Centers and toured two of the Centers. I was so impressed with the care I saw.

Pennsylvania State Centers are intermediate care facilities for the intellectually disabled that meet strict regulations for active treatment and provide an appropriate and therapeutic environment for the most vulnerable of Pennsylvania citizens. Residents at the State Centers live in a warm, supportive environment with family picnics, barbecues, parties, dances that allow them to form friendships with other residents. At White Haven, for example, they have an on-campus pool, a café, a chapel, a gymnasium, a workshop and other facilities that give them a quality of life in a safe environment. Additionally, those residents take trips to the movies, shopping malls, restaurants and other events.

Imagine my surprise and shock when I discovered I would have to petition the Court for Joey to gain admission and battle the Office of Developmental Programs, the very agency that was supposed to help and protect Joey.

We were so alone in our struggle and floundering helplessly. Then I found VOR. VOR Founder and Pennsylvania State Coordinator, Polly Spare, advised, encouraged and mentored us. She was our only friend when we had no friends.

We were successful in gaining admission for Joey to White Haven Center. His life turned around and he is happy and healthy in a community he loves. Joey's home at White Haven Center, his choices and his future are threatened by legislation written by the ARC, House Bill #1650 to eliminate all State Centers from Pennsylvania's service system. Again, I found myself lost, alone, confused, terrified for Joey and floundering helplessly. We attended the VOR Conference in Washington D.C. From the other strong, compassionate VOR members, I learned how to be an advocate and the strategies to succeed in the battle to preserve the vitally needed intermediate care facilities for our loved ones.

What I learned from VOR gave me the confidence and a blueprint to fight the one-size-fits-all "closure advocates" for Joey's sake and for all the Joeys to come.

Using time tested strategies from VOR advocates, members of all the Pennsylvania State Centers united to form KIIDS – Keeping Individuals with Intellectual Disabilities Safe to negotiate with the policymakers in Harrisburg.

We launched a petition to oppose House Bill #1650 and in 2 months' time, we have garnered over 8,500 signatures supporting our position that the State Centers should remain as part of the continuum of services for the developmentally disabled in Pennsylvania. A delegation of KIIDS members met with the Health Committee members in Harrisburg and lobbied for the needs of our loved ones. Over three days, we walked the halls in the state legislature and we educated, persuaded and opened new insight for our lawmakers and I am happy to report that several sponsors for the bill have dropped their support and many other legislators expressed their opposition to HB #1650.

VOR really is the voice of reason, promoting an enlightened service system that includes a full range of care for our most fragile, challenging and vulnerable people. Joey and his parents will be forever grateful to VOR for the knowledge, guidance and compassion in a dark world.

WHY INTERMEDIATE CARE FACILITIES ARE SO IMPORTANT

By Rita Winkeler, Member of the VOR Board of Directors, President of the Murray Parents Association

In the past year seventeen individuals have moved to Murray Center, a state ICF/ID. They have come from many different situations.... home based care, 4-6 bed group homes, two bed group homes one bed homes, exclusive, very expensive private small out of state centers.... all “community” homes. Never did their parents think their child would move to a state operated developmental center. Many of them were led to believe by so called advocates that state centers were evil, dark, dank places where developmentally disabled residents sat around and drooled all day. These parents/guardians were confused, scared, and worried about the care their loved one would receive in an “institution”. Each and every one of these parents now tell me they cannot believe how safe, happy, and well cared for their loved one is. Also, they can’t believe how involved their loved one is in the community, and how many fun activities they participate in.... some at Murray, most in the community. Some of these individuals will eventually move back to a small community placement, and some will choose to remain at Murray. That’s what **CHOICE** is all about. There cannot be choice if that choice is taken away.



Some advocates continue to say if only there was “enough” money everyone could live in the community. Please read “Joey’s story” http://www.vor.net/images/stories/2017-2018/Joey_Jennings_Story.pdf to see that this just isn’t true. If I changed Joey’s name this could be the same story about a young man who moved to Murray last year.

Justin (not his real name) lived in three CILAs in Illinois. He was sexually abused in one, physically abused in the next, and totally isolated in the last one. He and his family (a very involved family) and the provider went through all the steps to make the last placement work. They went through a very structured Support Services Team effort, that included psychiatrists, behavior analysts, music therapy, and the best practices ideas put in place.

Justin ended up living in a one bed CILA home with two direct care staff.... basically a prisoner in his home. He rarely left the home; maybe for a ride every two weeks, and to the doctor when his mom took him. The staff would no longer take him to the doctor because of his behavior issues. Finally, the provider issued a discharge letter to his mom saying the agency just could not (even with increased funding, supports, etc. etc.) provide Justin with quality, safe care.

Justin moved to Murray almost a year ago. He began with two to one care; now he is not even one to one. He is eating again; his seizures have decreased, and most of all is happy, safe, clean, and enjoys life. His mom is so happy and relieved to finally see her son happy and safe. When I hear the stories our new parents have to tell me I just cry. Their stories of abuse, neglect, tasing by police, being handcuffed and arrested, jailed, raped, and not just in one situation, but in several different community placements are heartbreaking. Most of the parents who have placed their child at Murray never, ever thought their child would live in a state “institution”.... now they are grateful every day that they have been given the “choice” of this quality, safe care.

This is why VOR is so important. VOR is the only national organization that advocates for ALL choices of care for the disabled. Your donation to VOR will help keep these choices open, as VOR advocates for all the disabled across the country. Your donation will make sure the choice that Justin and the other new residents had is available for all. All disabled individuals deserve the right to be safe, happy, and well cared for, and for many this choice is a large congregate care facility. Your donation to VOR DOES make a difference in the lives of so many.

Eric can be loving to family and friends, but has the potential to become easily frustrated with outbursts of aggression; this is characteristic of autism. Because of his size, he could easily injure another person, especially with inadequate numbers of staff to supervise him. What would staff in a community home do if he becomes aggressive? Call the police? In January, 2012 a teen with autism was shot and killed by police in Calumet City, IL, in his parents' home when police, who had been trained to work with him, shot him. National stories have reported the use of Tasers on autistic persons in the community. In my professional opinion as an experienced mental health nurse, moving a low functioning autistic person into a minimally staffed group home is tantamount to placing toddlers in an understaffed day care center. Safety of both the residents and the staff are threatened when low functioning autistic persons are placed in programs that are inadequate to meet their unique needs.



Eric's stepdad and I visit with Eric at Murray Center about every 2 weeks, taking him out for lunch or dinner, shopping, and other social experiences. Staff and volunteers from Murray Center often greet him when we take him out in Centralia. Every 3 or 4 weeks, we bring him home to O'Fallon for a weekend visit where we try to engage him in family activities in the St. Louis community, including church, malls, restaurants, baseball, and local attractions, like the grounds of the Gateway Arch. For Eric, Murray Center is an appropriate and least-restrictive environment. He is close to family and has opportunities for activities in the community around Murray Center and in the St. Louis area.

Our Family's Choice

By Sybil Finken - Mother of Seth, Former VOR Board Member, and Iowa State Coordinator

I was so grateful when Seth was born. Coming in at just under 9 pounds, my third son was healthy and perfect. Unfortunately, that all changed. Meningitis, incurred at age 7 months, left him with profound brain damage, deaf and blind with a significant seizure disorder. He has never walked, or talked, dressed or fed himself. He has around the clock needs for his most basic comforts - food, shelter, warmth, etc. Seth depends on others for everything in his life.

When Seth was 5, we made the decision to place him at Glenwood Resource Center (GRC) a state run ICF in Glenwood, Iowa, the town where we live. ***We made the decision. We made the decision.*** In the early 80's, it was an option to place a loved one in an ICF facility. Family members were allowed to choose the living arrangement that would best meet the needs of their loved ones. Not today.

Across the country many, many options in care have been removed. Facilities in most states have closed, or have been significantly downsized. The ideology of "community living for all" has put the most severely affected percentage of the disability community at risk. Only one advocacy organization speaks out for the level of care needed by Seth and others with complex needs...

I shudder to think what my life and Seth's life would have been without VOR. VOR has been on the political forefront, teaching families how to reach out to lawmakers at the state and national level. VOR has helped to fund lawsuits in various states enabling family members to fight for the rights of their loved ones. VOR has helped state organizations organize their parent groups by putting families in contact with other families whose loved ones also require the high level of care needed for their safety and well-being.



Seth has been cared for by loving, capable, professional staff for over 30 years. VOR has been around for over 30 years. That is NOT a coincidence. VOR has been an invaluable partner and I credit this organization for keeping the conversation going and preserving the level of care my son and so many others need. VOR is *our* voice.

YEAR END GIVING TO VOR

We are most grateful to all of our friends who support us on an annual basis. Many donors make their annual gift at the end of the year and further minimize their taxes by gifting through appreciated stock and IRAs.

Gifts of appreciated stock/securities: *A gift of stock will help in two ways. First, you could avoid paying taxes on the capital gains from the appreciated stock. Second, if you itemize on your tax return, you can take an immediate charitable tax deduction for the full market value of the stock.*

Gifts from an Individual Retirement Account (IRA): *If you are over age 70 1/2, you are able to make direct gifts from your IRA to VOR. By making a gift through your IRA, you do not have to recognize this IRA distribution as income, and it would count toward your Required Minimum Distribution (RMD). It is important that your financial institution sends the IRA directly to VOR and notifies us that the gift has been made on your behalf.*

For more information on end of year giving, please call Hugo Dwyer at 646-387-2267 or email info@vor.net.

Meet the Big Dude

By Dr. Karen Kelly, VOR Member, Murray Center Parent, Mother of the Big Dude

Let me introduce my son to you: Eric is severely impaired by autism and has lived at Murray Center in Centralia, Illinois, since June 1999. He is 44 years old and functions at the cognitive level of a three-year-old. Eric stopped talking around 30 months of age; other cognitive skills and behavior regressed at that time too. Today Eric can feed and clothe himself, but needs help with basic hygiene: bathing, tooth-brushing, and toileting. He cannot use a knife or tie his shoes. He is 6'5" and weighs 235 pounds, a toddler in the body of an NFL player. His dad and I lovingly call him "Big Dude." Eric communicates with a vocabulary of about 100 words in signed speech and gestures. His IQ measures around 38-40; but I know he can sight-read some words and he recognizes the logos of several restaurants. He also knows his way around several malls in the St. Louis area and recognizes the neighborhoods of his favorite restaurants; he breaks into smiles and makes his "happy noises" when we get close to his favorite places to eat.



Eric spent four years at a residential school for disabled children (1991-1995), but was close to aging out a few months before his 22nd birthday. He then lived in a community-based residence (ICF/IID) for four years (1995-1999), but the home was not able to provide him with the day programming he needed because of the severity of his disability and his tendency toward dangerous meltdowns, throughout his middle twenties. In addition, the private ICF/IID in which he lived was a block off a busy state highway. Eric eloped from the building several times during the four years he lived there, putting my son, who does not understand the dangers of crossing busy streets, at grave risk. The placement was only 20 minutes from his family home which allowed us to bring him home one or two evenings each week.

In 1999, Eric was next admitted to Murray Center, a state operated developmental center (SODC), an ICF/IID, an hour's drive from the suburban town where his dad and I live. Eighteen years later, he continues to thrive, growing his social skills beyond our expectations. There are still not appropriate residential opportunities for him near our community in southwestern Illinois, twenty minutes east of St. Louis, MO.

In February of 2012, then-Governor Quinn of Illinois announced plans to quickly close two state-operated developmental center (SODCs) to reduce costs of care for those with intellectual disabilities, shifting the residents to two to four bed small group homes, with or without the consent of guardians. The governor's plan also included the eventual closure of all SODCs in Illinois, which are licensed as intermediate care facilities (ICFs) for those with intellectual disabilities. The plan to close all SODCs was largely denied publicly by the governor's office and the Department of Human Services. This announcement, during the governor's annual budget message, resulted in a mobilization of parents/private guardians to stop the closures and the transfer of SODC residents into small group homes in communities. Illinois faced, and continues to face, a budget crisis like none before, created largely by the state's failure to fully fund the multiple pension systems of state employed workers, including staff and faculty of the state's public universities and those employed by state agencies, like SODC employees, in addition to the state's public-school teachers. Though the state was successful in closing one SODC, the other SODCs currently remain open with no closure plan on the books. The consolidated efforts of the organizations of parents/guardians that are part of each SODC stopped the closure effort with a class action lawsuit in federal court, grassroots lobbying of state legislators, and effective use of print and electronic media across the state. Our grassroots efforts continue.

Eric continues to need around the clock care to ensure his well-being, including nursing care, which these small, community group homes do not provide. Eric and the other residents of all the SODCs in Illinois have 24/7 nursing care, on-site pharmacy services, on-site physicians and nurse practitioners, social workers, psychologists, a range of therapists, activity staff, and well-trained direct care providers. While the governor, his staff, and the leadership of the Department of Human Services lauded the potential savings from moving all SODC residents into small group homes in the community to legislators and the media, they failed to note that the cost comparisons were inaccurate. The care provided in small group homes does not compare favorably to the care provided in an SODC. As a registered nurse for over four decades, a former health care administrator, and a psychiatric nurse, I found the suggestion that the care provided in small group homes with unlicensed staff as sole caregivers was comparable to care in Illinois' SODCs outrageously dishonest.

About a year after he came to Murray Center, in the spring of 2000, Eric had an acute bowel obstruction. He could not tell anyone he was in pain, but Eric took the hand of the nurse who gave him his morning medicines and put it on his abdomen. The nurse immediately assessed Eric, notified his physician, and sent him to the local hospital where he had surgery a few hours later once he was stable. If a nurse had not been present, he may have suffered a rupture of the distended bowel with sepsis, a massive infection that could have been fatal.

(Continued on following page)



**VOR's 2018 Annual Conference and
Legislative Initiative
June 8 – 13, 2018
Hyatt Regency Capitol Hill, Washington, D.C.**



How Texas' State Supported Living Centers Faced Hurricane Harvey

By Ileene Robinson and Ione Moran

Texas HHS prepared well for Hurricane Harvey last August. Before the storm even hit land, all residents and staff from the Corpus Christi State Supported Living Center (SSLC) were evacuated overnight to San Antonio. Corpus Christi was hit hard, but the residents of the CCSSLC were safe.

Harvey made landfall in nearby Rockport, but cut a huge swath through the Southeastern part of the state, leaving huge bowls of dangerous, fetid waters in many places. These floods kept family members from congregating together in many cases, and left others scurrying to escape their soaking homes. At the Richmond State Supported Living Center, outside Houston, an "amazing network of devoted staff people", helped avert many emotional crises Texas with their efficient reactions and *PRE*-actions responding to Hurricane Harvey. Many staff, including Director Al Barrera, moved in and remained at the center for several days during and following the hurricane to ensure the safety and comfort of the residents. Some even evacuated their families to the safety offered at RSSLC instead of weathering the storm at home.

When the unexpected visits those without the available resources to cope, an SSLC can stand ready to cope for them.

For more information on the Richmond State Supported Living Center, go to <http://www.familiesofrssl.org>



Evacuations Not Taken Lightly

From the Texas Department of Aging and Disability Website

All Texas SSLCs are required by the Department of Aging and Disability Services (DADS) to have an evacuation plan.

Evacuating an SSLC in the face of a hurricane is not a decision that is made lightly. It requires an enormous amount of work and coordination among a number of parties. Additionally, SSLC residents often don't respond well to changes in their routines, so moving them is done only as a last resort.

When a hurricane is 5 days from anticipated landfall, the decision-making process — which includes many executive-level staff — begins. "We look at the strength of the storm, its projected time and place of landfall, and what facilities we have in that area," DADS Emergency Coordinator Russell Cook said. "When the storm is 60 hours from landfall, the evacuation commences."

At that point, HHSC personnel contact staff at the facility under evacuation and the one where evacuating residents will be relocated. Residents are moved using HHSC fleet vehicles, other vehicles provided by the state, as well as specialty vehicles for medically fragile residents.

"When you're talking about people who are medically fragile, you don't want to move them unless you absolutely have to," Cook said.

DADS transports only residents of state-operated facilities. However, the agency does coordinate with other agencies — including the Texas Department of State Health Services and the Texas Department of Public Safety — when non-state facilities are threatened.

SIRE and the SIRE Families Seek a New Normal

By Joe Wappelhorst, Executive Director, SIRE

A month after Hurricane Harvey, many families are still reeling from the devastating floods. Although SIRE's three riding center came through the storm relatively unscathed there is a bigger picture to be seen. According to Executive Director Joe Wappelhorst, SIRE's horses and facilities came through the storm fine, but many of our riders and volunteers are still picking up the pieces after Harvey. SIRE is not back to normal until all of our families are back to normal.

Gains found through therapeutic riding tend to fade with a prolong break from riding. It was critical that SIRE get back in action so the riders could continue to make progress on their goals. The gains made in riding lessons translate directly to life skills. These may be physical skills such as opening a refrigerator, cognitive skills like pattern sequencing, or social skills learned through the interaction with a horse.

Remarkably, it was the volunteers and riders who were calling SIRE to help. One of the biggest concerns throughout the storm was the welfare of the horses. Riders and volunteers alike called to offer assistance to make sure all 37 of SIRE horses were safe and well cared for before, during and after the hurricane. At the Fort Bend riding center the horses remained safe due to the heroic effort of three SIRE staff members who camped out at the site for 6 days. The Richmond State Supported Living Center (RSSLC) staff worked diligently during the storm to make sure every resident was safe and comfortable.

With a lot of hard work the Fort Bend riding center was able to open with only a two-week delay. For the residents at RSSLC this is one step toward a normal routine. For many people with developmental disabilities routine is an important aspect of daily living. Therapeutic riding not only builds life skills, but becomes a defining part of who the rider is in life. Too often people with disabilities are defined by their diagnoses. Through the partnership between SIRE and RSSLC many residents proudly state, **"I am a skilled horseback rider."**



Please note: Your membership renewal date is listed at the bottom of the address label on the back page of this issue of The Voice.

Music Therapy for Individuals with Intellectual Disabilities

By Julie Andring Ph.D., MT-BC

I have not met anyone who does not respond in some manner to music. Unconsciously, feet tap, shoulders shrug, voices hum. Music affects us all.

I am a music therapist. The field of Music Therapy uses our innate connection to music to accomplish individualized goals within a therapeutic relationship by a credentialed professional. A music therapist purposely designs approaches to address goals for each individual. Activities in music therapy sessions are not haphazard; the instrument that a person plays or the songs that are sung are planned and expanded on depending on the initiation of the clients.



Music Therapy at Southbury Training School, Southbury, Connecticut

These research-based interactions are called interventions. For example, if a person has a weak arm and tends to not use it then an intervention might be having that person use an instrument requiring the use of two hands. The music provides the motivation to engage, playing the two-handed instrument helps to strengthen the arm. Contrary to general music making for entertainment purposes, music therapy sessions are designed to help individuals achieve established goals.

Music therapy interventions can be designed to promote wellness, manage stress, alleviate pain, enhance memory, improve communication, and provide unique opportunities for interaction. Research in music therapy supports the effectiveness of interventions in many areas such as facilitating movement and overall physical rehabilitation, increasing motivation to engage in treatment, providing emotional support for clients and their families, and creating an outlet for expression of feelings. (www.musictherapy.org)

Research has also shown that a uniqueness of music is that it activates various areas in both spheres of the brain as opposed to a single region on one side of the brain. In music, the corpus callosum transmits the firing of neurons from one sphere to the other thereby involving the whole brain. This aspect of music contributes to the successes of music

therapy when other therapies are less successful. In many instances, a music therapist corroborates with a therapist from another field and, working together, work toward attainment of client goals.

Music also functions as an organizer of the brain's activities. There is meter, pulse, a flow to movement and voice. This organization diminishes difficulties when music is not present. As stated by world-renowned neurologist, Oliver Sacks, in *The Man Who Mistook His Wife for a Hat and Other Clinical Tales*:

What we see, fundamentally, is the power of music to organise [sic]— and to do this efficaciously (as well as joyfully!), when abstract or schematic forms of organization fail. Indeed, it is especially dramatic, as one would expect, precisely when no other form of organisation [sic] will work. Thus music, or any other form of narrative, is essential when working with the retarded or apraxic – schooling or therapy for them must be centred [sic] on music or something equivalent. (1987, p. 186)

I have always worked with people with intellectual disability across the age spectrum. The goals addressed vary with the needs of each person; they do not necessarily correlate with chronological age, however, there may be common trends in a given age group. Working with grade-school children I often focus on social skills (e.g. turn-taking, sharing) and expression (i.e., vocal or sign language). One memorable transformation was a child who was non-verbal but very musical. He could keep rhythm, change rhythm to different songs, and loved to listen to his stack of CDs. Music was his favorite leisure time activity. When working with this young boy I would sing using pre-verbal language (e.g. ba, ma) and encourage him to do the same. I mirrored his sounds and added rhythm as an organizer. This musical exchange regularly happened during the music therapy sessions however the teacher's aides also engaged him in this exchange throughout the day. Over a period of perhaps a year, this young boy began to find his voice in music and eventually developed full language. What a difference that made for this child. He truly found his voice through music.

Working with middle school and high school students may involve these same goals but the session content often reflects the classroom teaching. If the teacher is focusing on life in the ocean, then the songs used in the MT session might be "Deeper than the Ocean" by Randy Travis. Classroom teaching can be reinforced with the lyrics of the music. Focused teaching promotes greater learning by the student. The majority of my work has been with people who are no longer in school. The goals of social interaction, expression, and active music-making remain similar however the means of addressing them may change.

Other goals are in an emotional realm. A common intervention to help individuals deal with difficulties in life is to write original songs that reflect the feelings of the individual. Another intervention is discussing song lyrics such as Justin Bieber's song *Sorry* (2015). What is the story of this song ballad? Sometimes real or theoretical questions are posed. When should one say "sorry" and is it ever too late to say, "I'm sorry"? Although some people do not have verbal language to make clear choices or respond to questions, an astute music therapist will learn each person's 'yes' or 'no' indications as well as responses to different songs and genres of music, and favorite percussion instruments. Since response times vary between individuals, the use of live music allows the therapist to adjust the tempo of the song to the response time required.

(Continued on following page)

One of my favorite goals to address is the individuality and worth of each person through the contribution to the music; this often doubles as a means of catharsis. Imagine that you cannot exercise, paint, draw, play piano, write poetry, bake beautiful pastries or nurture a beautiful garden, etc. - things that express your inner self. It is sometimes difficult to find ways for everyone to be creative and emotionally expressive. Music is one way to meet these needs. We sing on "Ah", "Oh" or whatever sounds or words are being offered by those people attending. I reflect the singing on the piano and with my voice while keeping a steady ostinato on the piano. We sing until the contributions slow down and stop. Singing allows people to be expressive and creative while also being cathartic. They were always beautiful songs. I often used this intervention in one given group. There was one man who recognized the exchange and would occasionally cry as we did this. Other times he wheeled himself away from the group, putting his back to us, and then mournfully sing. For him, it was so personal that he sought out his own space.

My road to becoming a music therapist began in high school when I one time heard about it from another student. Since I didn't know a music therapist, I read all that I could find on the career. The decision was quickly made; what could be better than doing music and working with people? For me, it was a perfect match. I completed a four-year undergraduate program in Wisconsin and then came to Connecticut to do a required six-month internship. I decided to stay in CT for a little while before moving back to the Midwest. Well, as you may have guessed, I have stayed here since 1984 and during the 30 years I have been gainfully employed as a music therapist. My passion of using the inherent power of music to help people of all ages and varying needs continues.

FREE ONE YEAR DIGITAL SUBSCRIPTION FOR DIRECT SUPPORT PROFESSIONALS

VOR wants to show our appreciation to the people who provide the long-term care for our loved ones with Intellectual and Developmental Disabilities.

We are offering 100 free one-year digital subscriptions to VOR's weekly newsletter and Action Alerts. The subscriptions are available to Direct Support Professionals and Nursing, Medical, or Dental Staff at state-run or privately operated Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).

Members are encouraged to share this offer to caregivers in their loved one's facilities. There will be a limit of five subscriptions per facility. Subscriptions will be active until January 1, 2019.

To apply, simply send an email to info@vor.net with the subject line Free Digital Subscription and include:

1. The name and email address of each applicant
2. The name and address of the facility at which they are employed
3. The name of the VOR member who has referred them

Giving Thanks By Hugo Dwyer, Executive Director

The holiday season has arrived. It's the time we think about family and give thanks for the blessings we have received this year. In so many ways, VOR is an extension of our family. We share our hopes, our cares, our disappointments. We sometimes disagree, but we know that what binds us is stronger than our differences. We share our children, our siblings, our aunts or uncles with intellectual and developmental disabilities. We share a part of our lives that is unique to us.

I am grateful to VOR. I am grateful to the people who founded this organization, for the determination and foresight they brought in looking past their local and state issues, and creating this national forum. I am grateful to the people who have visited their statehouses, their elected officials in Washington and the administrations of various government agencies. I am grateful to those who fought class actions suits and instituted legal actions to protect the rights of their family members, to those who wrote letters and signed petitions and raised their voices in hope, sometimes in anger, but always in advocacy.

I am grateful to the caregivers, the Direct Support Professionals, and doctors and nurses and dentists and administration personnel, who protect and care for and love our loved ones.

I am grateful to those VOR members who wrote the Amicus brief speaking out for the rights of our loved ones under *Olmstead*, and to Justice Ruth Bader Ginsburg for so wisely including these protections in her Supreme Court opinion on *Olmstead*.

I am grateful to the members of our Board of Directors, the chairs and members of our committees, our state coordinators, to those who volunteer to serve, and to those who go the extra mile when asked.

I am grateful to all of our members and supporters, past, present, and future.

Thank you for being part of VOR.



Hugo Dwyer,
Executive Director, VOR



THANK YOU FOR YOUR SUPPORT!

To join or contribute:

- ☐ **\$45 per year per individual membership**
- ☐ **\$200 per year per family organization membership**
- ☐ **\$250 per year per provider/professional organization membership**
- ☐ **Additional donation included**

Thank you for joining or renewing. We depend on your generous extra donations.
You may pay by check or credit card.

Send completed form with payment to:

VOR
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Mobile Phone: _____

Work Phone: _____ FAX: _____

E-Mail: _____

Family/Professional Organization (if applicable): _____

Location your loved one calls home: _____

City: _____ State: _____

If paying by credit card, please provide the following information:

Type of card: ☐ VISA ☐ MASTERCARD ☐ DISCOVER

Amount to charge to card:

☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$150 ☐ \$100 ☐ \$50 ☐ \$25 ☐ Other Amt. \$ _____

☐ I would like to make a recurring monthly donation. Please charge my card each month:

☐ \$7 ☐ \$10 ☐ \$15 ☐ \$20 ☐ \$25 ☐ \$50 ☐ Other \$ _____

Card Number: _____

Expiration Date: _____/_____ 3-digit security code: _____

Cardholder's Name: _____ Signature: _____

This is a gift: ☐ In memory of: ☐ In honor of: _____

Please send acknowledgement to: _____