

President's Message

Dear VOR Friends and Family,

My name is Sam Friedman, and I am honored to serve as VOR's newest president.

I'm from New Jersey. In 2012, my sister Jackie faced eviction from the state operated IC where she was fortunate to have received good care for nearly half a century. I plunged into advocating on her behalf, and for all of the other residents of her center. Soon enough, I began to speak out for the wider population of individuals with intellectual disabilities and for the endangered ICF level of care. Thanks to VOR's Joanne St. Amand and Cindy Bartman, I widened my sights from New Jersey to Washington, D.C. There, I saw VOR in action - a national community of likeminded souls, joining political know-how to passionate devotion, in service of America's most vulnerable people – and was awed.

As 2020 began, VOR faced our familiar but continually-challenging political landscape. Well-funded and -connected political and economic forces were, as before, arrayed against choice for individuals with severe and profound intellectual disabilities.

Then COVID-19 hit, and it hit those for whom we advocate extra hard. As the virus continues to spread and grow across the country, it continues to hit our loved ones the hardest. Why? Primarily because people with severe and profound intellectual disabilities also disproportionately have comorbidities that place them at higher risk for exposure to, and worse outcomes from, the disease. Consequently, so many of our loved ones and their peers find themselves contending not only with the virus itself but also with the damages that the virus, and efforts to protect them from the virus, have wrought – on their health and well-being, their programs and services, staffing and resources, human connections and continuity of care, routines and structures, and spirit and peace. This is true across settings: one's own or family's home, HCBS, and ICF care, among others.

If this weren't enough, ICF residents and supporters have now had to endure new campaigning by those who oppose their right of choice - cynically using the pandemic to justify their preconceived notion that large congregate care facilities are unsafe, isolating, and must be eliminated.

Consequently, dealing with COVID-19 in *all* its manifestations has become an overarching theme in the majority of VOR conversations I've participated in since its onset in late January. This will be the case at least until an effective vaccine is widely distributed and perhaps even beyond. VOR must squarely face and take on this challenge to stay true to its mission.

Fortunately, VOR has considerable resources with which to take on both the familiar and novel struggles. We have on our side both wise old hands and new blood eager to take on these tough jobs.

That's where you come in. VOR needs you as a member, well beyond your financial contribution (as important as that is). Please call us on our toll-free number (877)399-4VOR, or e-mail us at info@vor.net and let us know what issues are facing your family, your center or your state. Please send us articles that we may include in our weekly email newsletter. Check out our website at www.vor.net and follow us on social media through Facebook, YouTube, and Twitter. And of course, please be on the lookout for our e-mailed *Action Alerts* that empower you to urge elected officials to legislate and vote so as to protect our loved ones -- their quality of life, residential and treatment choices, and indeed, life itself.

Wishing all the best to you and yours, and a safe and Happy Holiday Season,

Sam Friedman

Sam Friedman

President, VOR Board of Directors





In My Own Words

Wendy English with Joanne St. Amand

Rarely do we hear the words from our family member or friend with intellectual or developmental disabilities. Wendy has mild intellectual disabilities but is severely medically impaired. We have been close friends since 2012 when we fought together against the closure of her and my sister's home in a NJ Intermediate Care Facility (ICF/IID). Now, Wendy and my sister live together in another ICF/IID in NJ.

Wendy understands everything but because of her cerebral palsy, she has trouble being understood. This is from a letter she dictated and sent to her state legislator:

"My name is Wendy English, and I am my own guardian. All my life I have been disabled but not as much as I am now. I have moved 20 times in my life. I lived at Woodbridge Developmental Center (WDC) from April 30, 1996 until July 30, 2014. I had to leave because it was going to close. WDC was a great place to live. It had a great staff and lots of things to do. And they could take care of all my medical need, especially my stomach and my special diet. My mother did not want me to move because she knew how happy I was at WDC.

The centers have a nurse on all shifts and a doctor. They can call the doctor on the weekends. I have depression and am bipolar. Sometimes I wanted to stay in my chair all night. I feel no group home can take care of me and all my needs. The doctor told me one time that it may be a couple of years before I will need a feeding tube. I got pneumonia in August, but I was able to stay here in my developmental center instead of the hospital. If I get sick again and go back and forth to the hospital, they will have to put a feeding tube in me. But I would rather eat. I like root beer and ice-cream. I hope I will always be able to eat. Here they watch the texture of my food, so it is not too dry.

People like me in developmental centers are getting old. We need a lot more help now like nurses who are here when we eat, speech therapists who check the texture of our food, and a daily schedule.

At one meeting before WDC closed, people (self-advocates) had me crying because I didn't want to go to a group home. I don't know why they want my home to close. Once I had a really bad time when they told me that I had to be out by the next year. My Dad died the same year. It was very hard for me to adjust.

Here at Green Brook, I have the doctor and nurses to help me. I take a lot of medicine. I am doing well here and am much happier.

Please don't close anymore developmental centers and let people come and live here who want to. The people need this place. We are home. I would like it very much if you would come and visit me here. You need to see the people who live here and the help they need. Thank you for listening to me. I hope you come."

*Sincerely,
Wendy English*

This is the reason why so many of us continue to support the VOR mission. Many members still do even after their loved ones have passed on because we know that many still need our help. Please contribute what you can this year so we can continue our fight. Every donation really does help. Thank you!

Joanne St. Amand

Joanne St. Amand

Sister of Rosemary

Vice President, VOR Board of Directors

Holiday Letter from Jane Anthony

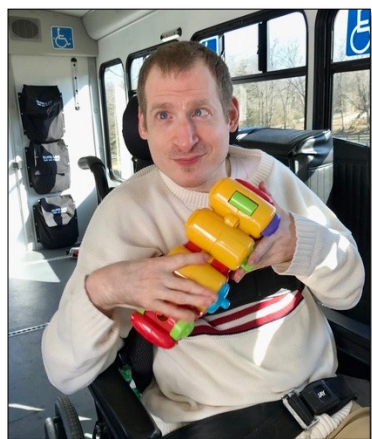
I am Jane Anthony, a long-time member and activist with VOR since the 1990s. My son Jason Kinzler, now 45 years old, has Angelman Syndrome deletion positive—a spontaneous mutation to the 15th chromosome. Jason has no language, has pica (which means he eats inappropriate items and has a high risk of choking), has no understanding of cause and effect, and has a high pain threshold. In short, he has the mental age of a 6-month-old in the body of a middle-aged man, and as I frequently say, he is an accident waiting to happen.

From 1978 to 2015, Jason happily lived and thrived at the state-run Northern Virginia Training Center (NVTC). Many of you are familiar with NVTC as it initiated the outstanding RCSC (Regional Community Support Center) program that provided medical, dental and other therapeutic services to those who lived in the community and either could not afford services or could not access them. This medical model was extended to all Virginia's other four Training Centers and later became a role model across the country. NVTC offered residents truly integrated care, offered training to group home providers, and community engagement with over 400 volunteers for the 155 residents. It promoted tight bonds among residents, staff, families, and the surrounding community. Our parent's group also showed up in large numbers regularly visiting our legislators at the state capitol to represent our "loved ones".

Well, all that changed when the Department of Justice (DOJ) visited one of the other state Training Centers in Central Virginia and filed a class-action law suit demanding there be a path for those in Centers to transition to the community if they wished. Unfortunately, the Department managing the Centers and those of the political philosophy that everyone deserved a "home like yours in the community" saw this as an opportunity to close all of Virginia's five Centers. A coalition of parents from the five Centers led by NVTC parents fought back by suing both DOJ and the Department in Federal Court. The judge ruled that one Center would remain open and that Virginia must track mortality among those leaving Centers, so their well-being would not become invisible. But even after gaining widespread legislative support, four of the Centers shuttered including NVTC. I tell you this story because we as parents may have been forced to move our children, but we are still their guardians and advocates, and must always look out for their welfare no matter where they live.

I have seen all this first hand from my many roles over the years at VOR—including First VP, Membership Chair, and State Coordinator for Virginia. In Virginia, I was President of PAIR, the statewide parents group representing all five Training Centers, and for the last decade of NVTC's operation, Co-President of the NVTC Parent's Group.

I have a simple message for those of us in VOR: we need state-run ICF/IIDs, some of us were forced to move, and all of us need what we learned from Centers to guide our advocacy regardless of whether they live in Centers or in the community. It is imperative that we all work together, and VOR helps us find one another to join our voices. VOR uniquely advocates for quality integrated care wherever our children might live. VOR has relentlessly represented those at the far end of the DD spectrum, who are forgotten by other major advocacy groups. VOR represents us on the Hill, networking parents to become the unified voice that we all need. With the closure of so many Centers across the country it is ever more important that families stick together as a group and make themselves known to their legislators.



My son is adjusting to community care, but our family still remembers all that we learned from Training Center living. We have and hope to bring those lessons to the community. We must stay active, and VOR is one of the organizations that will always have my membership and support. And after each of us is gone, we will depend upon those we have encouraged to pick up the baton to watch over the "Jasons" of the world.

For those Centers that remain open, we hope they remain examples of integrated care, staff stability, and the flexibility offered with more staff. For the many others whose Centers have closed, no one can tell whether something like a Center will re-emerge, but for now, we can be the ones who help bridge the gap by staying active and involved. Thank you VOR.

Happy Holidays to all of you and may you all be healthy!

Jane Anthony (mom to Jason Kinzler)



Olmstead is not a Community Integration Mandate [[Olmstead v. L.C. U.S. 581 \(1999\)](#)]

Supporters of so-called community-based services (ones other than ICFs) point to the fact that, under the ADA, everyone has the right to ICF care. They view this as an institutional mandate, and misinterpret *Olmstead* as being a mandate for community-based services only – an integration mandate. Despite the fact that ICF care is not available for all those who might want it an individual, their parent or guardian must waive their right to this level of care in order to receive Home and Community Based Services (HCBS). VOR opposes this misrepresentation of *Olmstead* as an integration mandate:

- There is no “integration mandate” in the ADA or *Olmstead*; the only mandate is for CHOICE.
- *Olmstead* dealt with when an individual has a right to leave an ICF and seek care in the community. One of the three tests that *Olmstead* established for such a decision is that “the affected persons do not oppose such treatment.” (*Olmstead v. L.C. 527 U.S. 581 at 607*) Thus, the plain language in *Olmstead* supports the right of choice for individuals, their families and guardians to select where they wish to live. Several justices specifically called for the preservation of “institutional” settings for those who need such care.
- Justice Ginsburg cited VOR’s brief in the case to the effect that, “Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution.” (*Olmstead at 605*)
- Justice Kennedy added, “It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” (*Olmstead at 610*)

The Disability Integration Act (DIA) [H.R. 555](#) & [S.117](#)

The DIA has been around in various forms for over two decades. The present version would create an entitlement for HCBS waiver services; anyone who requested them would receive funding. The DIA contains provisions that would have the effect of eliminating ICFs. VOR opposes the DIA because:

- It would eliminate the ICF option for residential care, an option that has provided lifesaving care for our loved ones with I/DD, most of whom need 24-hour around-the-clock care for their survival.
- It would overturn existing law – the ADA and the Supreme Court decision in *Olmstead* – which leave the choice of residence, including an ICF, up to the individual with I/DD or their family or guardian.

It is also important to note that its cost would be astronomical. No version of the DIA has ever been evaluated (“scored”) by the Congressional Budget Office. In the mid-1990s, CBO scored a narrower bill sponsored by Rep Newt Gingrich that would have created an entitlement to personal attendant care services at an annual cost of \$10-20 billion.

Money Follows the Person (No current bill number, but likely to appear in an Appropriations bill this month)

Money Follows the Person (MFP) was enacted as a demonstration program in 2007 with the intention of “re-balancing” the amount of funding states provide to larger congregate care facilities and HCBS services, with the goal of providing more funding for people in HCBS care. MFP provides states with enhanced federal matching funds for services and supports to help seniors and people with disabilities move from long-term care facilities into HCBS services. They provide funds only for the transition to “community” services and expire after one year. VOR supports transitional funding for people who choose to move from larger congregate settings into the community, but oppose the use of MFP funds to push people out of ICFs:

- MFP has been used by advocates to drain resources from ICFs, eliminating the economies of scale that are vital to their ability to provide a wide range of quality services. ICFs require larger numbers of residents to spread out the costs of doctors, nurses, DSPs and other staff. The “rebalancing” only moves people out of ICFs, reducing the number of beds, especially in facilities closed to new admissions.
- When MFP funds are used to close ICFs, it is the state exercising choice rather than the individual or their family. *Olmstead* endorses individual choice, not choices determined by the state or by federally funded P&As.

Talking Points *(Continued)*

Transformation to Competitive Employment (TCE)

There are currently bills in the House and the Senate that support the transformation to competitive employment, or as its proponents call it, competitive integrated employment.

- **The Transformation to Competitive Employment Act - [H.R. 873](#) & [S. 260](#)**

This bill supports the development of new programs in order to create more opportunities for people with disabilities to find competitive employment. The bill also contains provisions to eliminate facility-based work centers (Sheltered Workshops) and 14(c) Wage Certificates, claiming that everyone with a disability is capable of competitive integrated employment. VOR supports the creation of new work opportunities but opposes the portions of the legislation that would harm people who are incapable of working in such environments.

- **The Raise the Wage Act - [H.R. 582](#) & [S. 150](#)**

The primary focus of this bill is to raise the minimum wage nationally. Written into the bill, are provisions similar to those in the TCE bills, which would eliminate vocational centers and wage certificates. While VOR takes no position on raising the minimum wage, we oppose the portion of the legislation that would limit work opportunities for individuals with I/DD who are not able to adapt to competitive, integrated settings.

As with the previous bill, this legislation would undermine opportunities for many people with I/DD, denying them an opportunity to be more integrated into the community. It is worth noting that the opponents of vocational centers often misrepresent the holding of Olmstead as an “integration mandate” as a justification for eliminating this opportunity.

(See related article “Myths and Facts on Vocational Work Centers” on page 7)

Stopping Actions by the Department of Justice and the P&As to Use the Legal System to Close ICFs against the Wishes of the Residents and their Families

For over a decade, VOR has rallied against the practice of agencies of the federal government using taxpayer funds to initiate lawsuits aimed at shutting down federally-approved treatment facilities (CMS-certified intermediate care facilities). VOR members, their families and friends have fought these suits in Virginia, Georgia, Illinois, Arkansas, Nebraska, Pennsylvania, Ohio and other states, all at a great expense to the families involved. Success in stopping these suits has varied. In general, DOJ actions have proven much harder to fight than those initiated by state P&As.

VOR has used the federal legislative process to try to stop these suits that undermine the right of choice. As it was unlikely that we could ever prevent these lawsuits outright, we took the approach of trying to enact legislation that would grant families the right to opt out of such actions, thereby confirming to the court that the lawsuit was not in the interest of everyone who had been included in the class. If a large enough group of people were to opt out of the class, the court would be likely to rule against closing the facility, as has happened in the Conway case in Arkansas and in cases in other states.

Representatives Barney Frank (D-MA) and Bob Goodlatte (R-VA) sponsored bills to accomplish this objective over a ten-year period. (Bills expire every two years, at the end of each congressional term, and must be re-introduced in the next session of congress.) In 2018, three VOR members, Martha Bryant, Caroline Lahrman and Peter Kinzler testified in favor of the Goodlatte bill before the House Judiciary Committee. Despite strong lobbying for each of these bills by VOR members, they failed to pass.

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Glossary of Frequently Used Terms and Abbreviations

ACL - The Administration for Community Living, part of HHS that promote Community Living as the prevailing ideology for the care of seniors and persons with disabilities, applying a singular solution to the diverse needs of two separate populations. The ACL administers funds provided by the DD Act.

ADA - The Americans with Disabilities Act of 1990 is a civil rights law that prohibits discrimination based on disability.

CMS - The Center for Medicare and Medicaid Services is the branch of HHS that works in partnership with state governments to administer Medicaid, the Children's Health Insurance Program (CHIP), and other services. CMS writes the regulations and requirements that govern all states' Intermediate Care Facilities (Appendix J).

DD Act - The Developmentally Disabled Assistance and Bill of Rights Act is a law passed in 1975 providing federal funds to Councils on Developmental Disabilities, Protection and Advocacy Systems, as well as University Centers.

DD Councils - State Councils on Developmental Disabilities are federally funded, self-governing organizations. Every state or US territory has one. Their funds are administered by the ACL. Their goals and objectives are overseen and charged by the ACL.

DIA - The Disability Integration Act (see *Talking Points*)

DOJ - The US Department of Justice. In recent years, DOJ has used (*abused?*) its resources to force the closure of ICFs in Georgia, Virginia and other states through class-action lawsuits.

DSP - Direct Support Professionals, the caregivers who attend to persons with I/DD.

HCBS - Home and Community Based Services are services in smaller settings that are provided by HHS to persons who waive their right to ICF level care. They include residential services in group homes or supplementary services in the family home or the individual's own home. They do not cover intentional communities, farmsteads or other residential options not endorsed by the ACL or CMS.

HHS - The Department of Health and Human Services is a cabinet-level department of the executive branch of the federal government, tasked with protecting the health of all Americans and providing essential human services.

ICF or ICF/IID - An intermediate care facility (or Intermediate care facility for individuals with intellectual disabilities) provides daily custodial care for people with I/DD. Residents of an intermediate care facility require less assistance with day-to-day living than people in skilled nursing facilities.

IDD or I/DD - Abbreviations for Intellectual and Developmental Disabilities. Either form is acceptable.

Institutions - Usually used by opponents of ICFs, this term sometimes refers to ICFs, sometimes to any form of long-term congregate care, including nursing homes, SNFs, Forensic Facilities, or even prisons. The term is usually employed as a slur against anything but HCBS options.

MR - Mental Retardation (*archaic, but still found in documents*) We now use the terms IDD or I/DD.

Olmstead - The Supreme Court Decision in *Olmstead v. L.C.* (1999) see VOR's Olmstead pages for more information: <https://www.vor.net/get-help/more-resources/item/olmstead-resources-2>

P&A - Protection and Advocacy Systems like DD Councils (*see above*) P&As are DD Act programs whose funds are administered by the ACL. While P&As are tasked with protecting the most vulnerable from abuse and neglect, most state P&As devote much of their time and funding to legal matters, especially to closing down ICFs. P&As have used federal taxpayer funds to try to close ICFs in Illinois, Ohio, and other states.

SNF - A skilled nursing facility is required to provide 24-hour skilled care. Residents of skilled nursing facilities need assistance with many aspects of day-to-day living and daily care. Skilled nursing facilities provide medical, nursing, dietary, pharmacy and activity services.

SOICF - A state-operated ICF, as opposed to a privately operated one. The DSP staff at SOICFs are usually union workers, as opposed to non-union workers in HCBS settings and many private ICFs.

TCE - Transformation to Competitive Employment (*see Talking Points, on page 5*)

MYTHS AND FACTS ABOUT VOCATIONAL WORK CENTERS

By VOR's Issues/Oversight Committee

MYTH: People with intellectual and developmental disabilities (IDD) and their families are dissatisfied with vocational work centers.

FACT: Vocational work centers (also known as sheltered workshops) are valued for the services they provide to people with IDD who are unable to adapt to competitive employment. When these centers are threatened with closure, employees with IDD and their families are the most fervent advocates for keeping them open.

MYTH: Vocational work centers are isolating environments.

FACT: These work centers are part of the greater community. Those who choose jobs at work centers develop a sense of accomplishment and self-worth because of work completed. Far from being isolating, they offer people a sense of camaraderie and a chance to interact with their peers.

MYTH: Vocational work centers are the only choice for work for people with intellectual disabilities.

FACT: There are many resources available through state vocational rehabilitation departments to assist with opportunities for competitive employment. No one can legally be forced to work in a vocational work center.

MYTH: Work centers do not provide opportunities to transition to competitive employment in the community.

FACT: For those who can develop skills to work in competitive employment, work centers provide opportunities to learn skills necessary to be successful such as being on time, working with others, and completing assigned tasks.

MYTH: All people, no matter the nature of their disability, can find competitive employment.

FACT: Some individuals have more difficulty adapting to competitive employment. Vocational centers provide opportunities for work while providing more specialized supports such as personal hygiene care, preventing and attending to seizures, or helping with behavioral issues and developing social skills.

MYTH: Work centers do not provide for meaningful jobs.

FACT: Examples of work opportunities include: manufacturing, item assembly, recycling, packaging, repair, and machine operating. <https://dese.mo.gov/special-education/sheltered-workshops/jobs-performed-sheltered-workshops>

MYTH: Oversight of vocational work centers is lax.

FACT: According to the Department of Labor: "All subminimum wages must be reviewed and adjusted, if appropriate, at periodic intervals. At a minimum, the productivity of hourly paid workers must be reevaluated every six months and a new prevailing wage survey must be conducted at least every twelve months."
<https://www.dol.gov/whd/regs/compliance/whdfs39.pdf>

MYTH: Vocational work centers violate the 1999 Supreme Court Olmstead decision.

FACT: The 1999 Supreme Court Olmstead decision supports CHOICE. Closing these centers contradicts the opinion expressed by the majority of Justices in Olmstead by eliminating a desired, chosen and helpful employment option.

MYTH: Eliminating 14(c) certificates of the Fair Laborers and Standards Act will increase employment rates of all individuals with disabilities.

FACT: 14(c) wage certificates of the Fair Laborers and Standards Act allow employers to afford to provide the specialized services needed by people with IDD who are not able to adapt to competitive employment. Eliminating these wage certificates will force the closure of vocational work centers, eliminating jobs with no replacement in competitive employment.

Telehealth and telemedicine have been receiving a great deal of attention in the media lately. The COVID-19 pandemic has prevented many people from making in-office visits to their doctors, and many doctors have been reluctant to see patients in person as well. Visits by telephone or computer have become the new normal during quarantine.

Telehealth is nothing new. As far back as 1879, an article in the British medical journal *Lancet* talked about using the telephone to reduce unnecessary office visits. In rural communities where medical practitioners are few and far between, telehealth services have been in use for decades. Since the onset of the Coronavirus, more and more people across the country, in cities and suburbs as well as rural settings, have been having “visits” and consultations with their physicians, therapists, and other medical professionals via phone or some form of videoconferencing.

Just this year, more than a dozen bills have been introduced in Congress that promote expanding the use of telehealth services. CMS Director Seema Verma recently announced an expansion of the services that will be covered by Medicaid and Medicare. This is significant, because without this type of endorsement, many such services have been conducted without the practitioners receiving full compensation for their time and services. Even more recently, the Biden/Harris transition team has announced increasing the utilization of telehealth as one of their top five priorities during their first hundred days in office. As a result, the role of telehealth services within our health care delivery system is sure to increase over the years to come.

What does this mean for our loved ones with IDD?

There are pros and cons to replacing some services with tele-visits. One of the greatest advantages of telehealth are the time factors involved. It takes a significant amount of time and personnel to bring someone with IDD to a doctor's office. The time and costs of preparation, transportation, and staff hours required for a DSP or two to accompany the individual to the office and back will be significantly reduced. And since many doctors visit their patients with IDD at their home, group home, or facility, the time between visits is reduced, allowing the doctor to treat more patients without having to leave the office. The patient benefits as well, being able to stay at home, in familiar surroundings.



Another considerable time factor is immediacy. If an individual is exhibiting a physical symptom or a particular behavior, the consulting doctor may be able to observe it in real-time and consult with the DSPs as it is occurring, rather than hearing a description of the event afterwards and having to surmise what may have happened and advise what might be done the next time.

Expertise is another factor. As in rural medicine, where there is a shortage of doctors spread out over large areas, not all doctors are familiar with the intricacies of dealing with the IDD population. Through telehealth, a local doctor can consult with someone with experience in diagnosing and treating seizure disorders, behavioral therapies, or familiarity with rare or complex medical conditions.

Still, there are downsides. Obviously, there are times when a patient must see their doctor in person. Certain examinations, like an MRI or an X-Ray, require a trained technician or expensive equipment, and no one is suggesting that telehealth supervision will enable non-professionals to perform surgical or dental procedures. But at what point should telehealth substitute for an in-person visit with a medical authority? Can a doctor get to know a person with IDD if half of their appointments take place by telephone? Can an expert see the nuances of an individual's condition and make a thorough diagnosis via a telephone image? Might an important and otherwise obvious symptom be overlooked? With such a diverse, often non-verbal population as this, there really is no substitute for an in-person visit.

For most of us, a telehealth consultation with our doctor involves two people, the doctor and the patient. With the IDD population, it involves three people – the doctor, the patient, and the person on the other end of the phone, the caregiver who has to relate their perceptions of the patient to the doctor. Is this person a doctor? A nurse practitioner? A trained DSP or a relatively new and inexperienced caregiver? How familiar are they with the patient? If the patient is non-verbal does the person at the other end of the phone know how to read and interpret the individual's particular signs and nuanced communications?

If we rely for too long on telehealth for the availability of experienced professionals, whose years of in-person visits and observations have given them this level of expertise, how will we develop the next generation of experts? Where will they come from, if there are no IDD specialists or people who have years of hands-on experience or expertise with a particular syndrome? *(Continued on following page)*

Holly Center Strong!

Mary Reese

In 1975, as a part of visiting state employees, I first set foot on the grounds of Maryland's newest residential and treatment facility for persons with intellectual/developmental disabilities (known in those days as mental retardation), Holly Center located on the Eastern Shore in Salisbury, MD. Although she was known to me, little did I realize that Ginger would steal into my heart and by the '90's I would become her legal guardian. By early 2000, we were strongly advocating for her admission to Holly Center. On December 17, 2012, Ginger and I traveled half way cross Maryland to her new home, Holly Center."

As a Governor-appointed member of Holly Center's Citizens Advisory Board, it was with great pride and gratitude it was announced that Holly Center's residents have made it through the national pandemic with no infections to date.

In late February and early March, Holly Center's Administrators organized an Incident Command Team that met three times a week. Led by the CEO and COO, the team covered Infection Control, Security, Nursing, Psychology, Program Services, Medical Director, Finance, Logistics (*i.e.* overseeing PPE supplies), Maintenance, and Human Resources, all with the ultimate goal of preventing entry and spread of COVID-19 among the residents and staff. They followed the guidelines issued by the Maryland Department of Health, the DDA, and the CDC. They devoted considerable time to educating staff about how to prepare for this crisis, and to protect themselves and their families as well as the Holly Center residents.

When the order to go into quarantine, Holly Center closed to family visits and restricted outside vendors. Non-essential staff teleworked from home or were placed on paid leave. Essential staff members have been screened with temperature checks and questionnaires as soon as they arrive on campus, and there is mandatory staff testing the first Monday of every month. Everyone is required to wear a mask. Holly joined with three nearby centers to share strategies on testing and training and to purchase PPE and to ensure that each center had enough PPE to meet their needs. In preparation for a possible outbreak, one building was designated COVID unit, which, fortunately, has never been needed, as there have been no active cases.



In spite of all the restrictions, the residents have participated in several special activities throughout the summer, when weather permitted. These have included long lazy walks on campus, water splashes, surprise summer edible treats with their housemates in the cafe and at home and of course, birthday celebrations. All annual team meetings as well as interim team meetings have been conducted in a timely manner. Several local medical specialist appointment schedules have resumed this month; other medical appointments have been successfully completed via telemedicine. The Psychiatric Clinic has been successfully held virtually on schedule.

On Friday, September 4, 2020, Governor Larry Hogan placed Maryland in Phase 3 in the state's plan to control COVID 19 infection spread. The patience of the residents and heroic efforts of the Holly Center administrative staff, medical staff, professional departments staffs, direct care and support staff are to be applauded. Appreciation too for the families, friends and guardians for honoring the "closed campus" policy which has been so emotional draining over 6 months. As restrictions may be carefully and gradually lifted, we all look forward to our new normal.

Telehealth *(continued from previous page)*

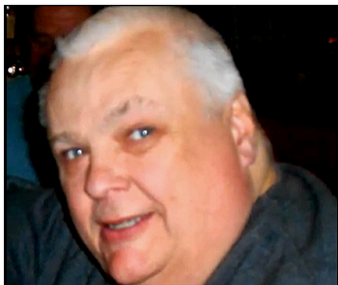
In the United States, high quality medical care is an ideal that is often determined by financial considerations. The medical insurance industry dominates the way we receive services, and CMS is very much influenced by what goes on in the private sector. Just look at how managed care companies are starting to move into covering long-term care services. Large private corporations are positioning themselves to hold a dominant position in the market for delivering telehealth services to people with IDD. How much say will someone who is not a doctor or a patient have in determining what sort of care our loved ones may receive, and from who? Will there be a target ratio of tele-visits to in-person visits?

The COVID-19 pandemic has rapidly increased America's acceptance of telemedicine. Overnight, telehealth services have become a vital component our health system, and it is likely that after this pandemic has passed telehealth will continue to be part of the fabric of our health care. We can only hope that as we reap the benefits of this new normal, we keep a watchful eye on the potential downsides, especially as they may affect our loved ones with IDD.

The 2020 Jordy Awards

Every year, the Engels family bestows an award to caregivers who make a difference in the lives of people with intellectual and developmental disabilities. This annual honor is made in the name of their son, Jordy Engels (1982 - 2005).

This year, the awards go to the memory of three Direct Support Professionals from the Southbury Training School in Connecticut, front-line workers who contracted COVID-19 and passed away during the first phase of the pandemic. The Engels family extends their sympathies to the families of Marlene Thompson, Pat Brellis, and Michael Mark, and to the memory of all caregivers who have passed while taking care of our loved ones.



In addition, the Engels family has recognized Joseph Aniello, Ed.D., of Miami, as recipient of this year's award for his years of service to people with intellectual disabilities as President of United Community Options of South Florida.

Estate Planning - The Benefits of a Bequest to VOR

Federal Estate Tax Savings - An outright gift to VOR from your estate – whatever the amount, and whether it is expendable or for endowment – is entirely free from federal estate taxes. This means that VOR is able to use the full amount of the bequest, whereas if it were left to an individual, a significant amount might go to federal estate taxes. Also, bequests generally are not subject to state inheritance or estate taxes.

Types of Bequests

- **Cash Bequest** - VOR receives a specific dollar amount from your estate.
- **Bequest of Property** - VOR receives specific assets, such as securities, real estate, or tangible personal property.
- **Residuary Bequest** - VOR receives all or a percentage of the remainder of your estate after the payment of any specific bequests and expenses.
- **Retirement Plan** - VOR is designated as a beneficiary of the remainder of your IRA or qualified pension or profit-sharing plan.

Gifts of IRAs/Retirement Plan Assets

You can designate VOR as a beneficiary of part or all the remainder of your IRA or retirement plan.

Distributions from retirement plans at the death of the survivor of the account-holder can be subject to both income and estate taxes. In a large estate, these taxes can leave less than 30 cents on the dollar of the plan's balance for your children or other heirs.

By naming VOR as the beneficiary of the remainder of your retirement plan, 100 percent of the plan's balance is available for VOR's use, since the distribution avoids both income and estate taxes.

To Make This Gift:

- You must notify your plan's administrator.
- A "change of beneficiary" form will be required.

This is not intended as tax advice. VOR encourages you to contact your personal attorney and tax accountant to receive professional advice to determine the best way for you to make a lasting gift to VOR.

If you are interested in receiving additional information please contact Hugo Dwyer, Executive Director of VOR at hdwyer@vor.net

Giving Thanks

Thanksgiving is a time we take a step back from our day-to-day routine, and give thanks for the blessings in our lives. This is the season for gratitude, especially during times of sadness.

It is with both sadness and gratitude that I share here that my younger brother, Tom Dwyer, passed away last month, just ten days short of his 64th birthday. After three weeks in the hospital, Tom had finally been diagnosed with a very aggressive form of pancreatic cancer. It was first believed he had a few months to live, then weeks, and then just days. My wife Cristy, my sister Marty, and I were all fortunate to be able to visit with him before he passed. We hadn't had visited with Tom in months, respecting the need for isolation to protect the residents and staff at Southbury Training School during the COVID-19 pandemic.

I am grateful that Tom was able to spend his last days at home, in his own room at STS. Tom had lived there since his early twenties – more than forty years. STS was his home and his community, and Tom passed in the presence of those who had loved him and cared for him during many of those years.

Tom was in poor condition when my parents first moved him to Southbury Training School. He had been living for his early and pre-teen years at a smaller private facility on Cape Cod. His health and his behaviors had deteriorated seriously before years before the facility determined that they could no longer effectively meet his needs and called my parents to come pick him up. Tom was in and out of a few other facilities and finally ended up spending a several weeks in a hospital before he came to Southbury.

Tom's first years at STS weren't easy. Self-destructive behaviors were one of his chosen forms of communication. He had to be gradually taken off of some severe medications, and the long process of finding the right medications and the right therapies took years. His first decade at STS was difficult.



The long-term care Tom received gave his caregivers time to work with him to influence his behaviors, adjust his medications, and implement the right therapies for him gradually and carefully. Over the years, his health and his socializations improved. The positive qualities of his nature emerged and he became happier and more interactive, albeit remaining non-verbal.

I don't think Tom would have survived, much less thrived, over four decades in a different type of setting. The staff at STS learned to understand him, and Tom learned how to interact and have remarkable relationships with several individual staff members over the years.

The importance of an ICF was never as clear to me as it was during Tom's final days. His passing was revelation. It wasn't just the care he received, or the love that colored the atmosphere around him. Seeing the profound effect that Tom's last five days had STS on his caregivers will stay with me. Their need to see him, to say their goodbyes and shed their tears was one of the most moving experiences of my entire life.

In the days that followed Tom's passing, several of his long-time caregivers reached out to me with their own personal stories about Tom, sharing with me how happy he could be, how clever and how unique he truly was, and how they had grown to understand each other in ways that went beyond simple verbal communication. I had always been grateful that Tom lived and thrived at Southbury. We, the family, are truly grateful that he was able to pass away in his home at STS, surrounded by those who loved and knew him best, in dignity and grace.

Hugo Dwyer, Executive Director

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