
President's Message *By Caroline Lahrmann*

Recently, I attended a presentation at which an attorney suggested that the choice of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) is not protected under *Olmstead* because it is not an “informed” choice. This person proceeded to list the litigation their organization supports to take away ICF/IID care, sheltered workshops and specialized education programs.

I was taken aback at the arrogance of this statement, suggesting the choices of others are not informed. This person seeks to nullify the decisions of tens of thousands without knowing any of the circumstances or individuals involved. And, given the frailties of people needing higher levels of care, who would risk another's safety when your own rationale is based on conjecture?

This is what we face as loving family members of individuals who need close care and supports. Unfortunately, there exist those who willfully undermine our decisions with their ignorance and disrespect of the individual rights of others. It is why it's so important to spread the true, compassionate meaning of *Olmstead*: individual choice and a range of services.

In this issue of the Voice, long-time advocate Joan Kelley shares her family's path to finding appropriate services and supports for their grandson, Aidan. Joan shows us that these choices are made with a great deal of care, diligence and love.

We hope you will join us in Washington this June for our annual conference, “Protecting Individual Rights Through *Olmstead* Choice.” It is the choice enshrined in *Olmstead* that recognizes that individuals with I/DD have the same rights that non-disabled people have under the Constitution – the right to choose where to live and work and with whom to associate. This June in Washington, we hope to further this truth.



Caroline Lahrmann
President, VOR Board of Directors



Realities in the Field

Our journey to find adequate resources in the world of disabilities

Joan Kelley, VOR Kansas State Coordinator

“My grandson will never go to an institution!” I declared to well-meaning friends who saw first-hand the exhaustion and daily challenges my husband and I were experiencing with our toddler-age, severely autistic grandson. Suggestions toward the unthinkable - an institutional placement, brought awful visions of the abuse and neglect uncovered at facilities like *Willowbrook* in the 1970's.

Our beautiful 2-year-old grandson had come to live with us as a bright-eyed, engaging, talkative toddler. Within six months he began to exhibit odd behaviors, extreme sleep issues, and lost ability to use his 3 and 4 word sentences. We remarked that he “seemed to be in his own little world,” but little did we know that a diagnosis of autism awaited us, or what that would mean.

In the early 1990's, community-based services were being praised as the solution for everyone in need of disability services, regardless of the level of disability. My husband and I were determined to make the community work for our grandson.

“Our boy” was accepted into the Head Start preschool program at age 3, but para-educators found it difficult to help our grandson “fit in” without him disturbing or destroying other children’s activities. No one, including us, understood the “why” of his behaviors, but research showed great promise with behavioral therapy programs for children with autism, and this gave us great hope.

The Special Education system at large, however, was not interested in these therapies, and decided it was adequate to simply provide one hour per week of speech and occupational therapy. They were not about to “spend money they didn’t have” on this intensely challenging child. In addition to stress at home - sleepless nights, extreme behavioral issues, including daily cleanup of feces smears in various places throughout the house, we were now faced with opposition from the school system, and their narrow interpretation of the Individuals with Disabilities Education Act. (IDEA)



Sonny, Aidan, and Joan

We hired a Ph.D. level Autism Behavioral Specialist to travel from Denver, paying out of pocket to cover the flight, lodging and compensation for several days to assist us. The local Director of Special Education Services was at first embarrassed by the lack of services the district was providing, but then the Director began a war of limiting provisions of much needed training and oversight necessary for a child with extreme needs.

After several years of diligent advocacy, we decided against suggestions to sue the school district, and in April 1998, planned our move back to the Midwest, where a Kansas school district had an excellent autism program. Someone had already sued this particular school district, setting a precedent, and families like ours flocked there to get the help our children so desperately needed.

That same year, the Kansas Winfield State Hospital* had closed its doors, releasing money for community services. We were excited when told by Community Service Providers that funds and services were available for our grandchild. When we arrived just four months later in August, however, our grandson was already on the Home and Community Based Services (HCBS) waiting list. We were never informed what “happened to all the waiver money” in four months period of time.

After applying pressure on the state agencies and community providers, we accessed waiver services, only to find out that significant restrictions prevented the implementation of a successful program for our grandson. Things such as overlapping of staff were forbidden under the waiver. HCBS would not cover staff meetings, critical to developing solutions for reducing maladaptive behaviors, which in Aidan’s case, were extremely pervasive. Nor could we pay more than \$8.00 per hour for direct care staff under the waiver. Due to Aidan’s self-injurious, aggressive, eloping, and other competing behaviors, direct support staff did not stay around long. We found ourselves continually recruiting, interviewing, and training new staff, along with constant 24-7 “surveillance” of our grandson, making sure he did not escape out the door in the middle of the night. We were exhausted and in crisis.

We finally found a unique solution, and in June of 2000 we became licensed, therapeutic foster parents. This program enabled us to access a funding stream, which paid a per diem on a tier rated system. This provided the flexibility to pay an incentive wage to direct support staff and hire professionals for support, oversight, staff training, and team meetings.

Aidan gained many skills over the next few years, until he began the journey through puberty. Self-injurious and destructive behaviors increased in complexity during puberty, and in order to keep him and others safe on community outings, we had to maintain a 2 to 1 staff ratio. We were grateful we could do this, but we, as well as school staff and other staff sustained injuries, as his aggression toward others continued to increase. When our precious young man became so strong and aggressive that I became afraid of him, our days with him at home were numbered.

At age 14 he was placed in what is now known as a Psychiatric Residential Treatment Facility (PRTF). Staff there were nice, but inadequately trained to handle the most challenging individuals they endeavored to serve. At that time Aidan began to lose skills, as the school there seemed ill-equipped to follow through with the intense behavioral program he had enjoyed previously.

* Winfield closed over a two year period, but worked with concerned parents who banded together to create quality community settings and oversight specifically for their loved ones, which included twenty-four-hour nursing care. Claims were made that “every one had a home”, yet there were families, some of whom I know personally, who were left scrambling as Community providers declined to serve certain individuals with the most complex needs. As the Winfield facility doors were shuttered, some of the residents were placed at KNI)

The PRTF also experienced staff oversight challenges; at one point we had to hot-line in suspected abuse. Shortly after that, the PRTF suddenly decided, that somehow, Aidan was “stable”, and it was time to discharge him.

We had spent 13 years pursuing every community option available, and none provided a lasting solution for Aidan. We were out of community options and had nowhere else to go. So, we turned to what I had originally thought was out of the question for our grandson - a state institution.

We decided to pursue an evaluation and medication wash at the Kansas Neurological Institute (KNI), an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). We were not comfortable with the amount of medication Aidan was on, especially since it did not appear to reduce his behaviors. Families like ours had heard for years disparaging remarks about large institutions, and even now, after the community had failed Aidan, the denigration of institutional care did not stop. Everyone we approached in the community system about our intended next step indicated that KNI was not equipped to provide the level of care Aidan required.

We pursued admittance to the Kansas Neurological Institute, knowing little about it, but we were desperate to help our grandson.

The State required us to thoroughly document that we had exhausted every community resource option, which we did for 13 years. However, Aidan’s doctor was exceedingly reluctant to sign for his admission to KNI. After a full year of continued pushback, prayers and persistence, Aidan was admitted to KNI on a temporary basis.

The KNI staff were wonderful. They were able to not only safely reduce the years-long, toxic mix of medications from 5 down to one, but KNI had already been incorporating the Person Centered Care Model for a number of years. They developed a comprehensive program for Aidan, which included frequent community outings, exercise, grocery shopping, part time supported employment, etc. while reducing medications and addressing extreme behaviors. Aidan was beginning to live the full life we had always hoped for him.

The increased structure, expert staff and individually-driven services worked so well, and we were delighted to see Aidan’s behavior improve. He was happy, being integrated and supported, as appropriate for his needs. We even looked forward to trying a community setting again closer to our home.

As we looked at community options, we visited several single and duplex group homes. To our surprise, some were so poorly maintained that I would not have wanted to see a pet dog live in them, let alone our precious grandson.

While this was disturbing enough, we were also shocked when numerous community providers refused to serve him! High risk, high staffing ratios and high cost related to his intense behavioral needs, revealed once again that community services, deemed by well-funded DD act entities as “superior,” and the answer were once again proving to be a false promise for individuals with the most complex needs. This now clearly included our grandson.

Conclusion

Aidan has lived well on a campus of homes at the KNI for almost nine years; this facility has been a God-send to us. Aidan’s condition is also lifelong. As with many fragile DD individuals affected with the most complex conditions, he needs a level of care that is difficult to find, maintain, and oversee in a fragmented, community system.

The importance of the centralized care model is clearly recognized in our Supreme Court’s Olmstead decision. This important level of care however, is being dismantled by community-for-all advocates, most of whom have never lifted a finger to care for such profoundly affected individuals, or endured the pain family members feel, when the much championed, “de-institutionalization” policies lead to untimely deaths.

I believe in community, for who choose and can benefit from them. I also believe, as most people do, that Intensive Care Units in our hospitals across the nation are a critical part of our health care system. *Intermediate Care Facilities (ICFs) are the Intensive Care Units for our DD loved ones.*

Shall we devalue the lives of the weakest among us – ignore their unique challenges and needs – by closing the facilities which sustain them? My husband and I say a resounding **NO!** - joining with thousands of families across the nation, who also know first- hand what it takes to care for our most fragile citizens.

Seeing our loved ones with extreme needs thrive in the setting of THEIR choice is for family members, our just reward for a lifetime of advocacy on their behalf.

Please note: Your membership expiration date is listed on the bottom of the address label on the back page.



*Speaking out for people with
intellectual & developmental disabilities*



VOR 2017 Annual Conference and Washington Initiative **June 3 - 7, 2017**

“Protecting Rights Through Olmstead Choice”

All VOR meetings will take place at the Hyatt Regency Capitol Hill, 400 New Jersey Ave., NW, Washington, D.C.

Saturday, June 3, 2017

Registration: Network with families from across the country	Noon
VOR Board Report to Membership	1:00 pm
Time will be provided for member questions and comments	
Reports from the States	3:30 pm
Participants report on news from their states. Session is moderated by VOR Board Members	
Networking and Hospitality Reception	6:00 pm
Join VOR board members and staff for an informal reception. Due to an overwhelming response in past years and hotel limitations, only certain participants will be invited to bring food. Everyone is welcome to attend.	

Sunday, June 4, 2017

Registration: Network with families from across the country	11:00 am
Welcoming Messages to Conference Attendees	1:00 pm
Caroline Lahrmann, President and Hugo Dwyer, Executive Director	
Committee Reports and Presentations	1:30 pm
VOR Committee Chairs update members on recent activities and coming goals VOR Members share their personal stories about the ongoing struggle to keep their facilities open	
Legislative Briefing	3:00 pm
Panel Discussion and Issue Briefing. Folders for Congressional visits will be distributed.	
Awards and Events	4:30 pm
Q & A for conference attendees and one other annual event	
Installation of VOR 2017-2018 Officers and Introduction of Board Members	5:30 pm

VOR Dinner at The Dubliner - 7:00 pm

This year's dinner will be a sign-on event. Information is on the registration form.

Monday, June 5 – Wednesday, June 7, 2017

The Washington Initiative

Visits to Capitol Hill - Personal meetings with Members and Congress and their staff are the most effective way to educate and influence federal lawmakers. Join choice advocates from around the country as we work together to convey the importance of residential choice and family decision-making directly to Members of Congress. Plan time to cover your state's Congressional Delegation.

Monday, June 5	Informal De-briefing	6:30 - 8:00 pm
Tuesday, June 6	Informal De-briefing	6:30 - 8:00 pm

To register for the conference and legislative initiative or make a dinner reservation at the Dubliner, go to: <http://weblink.donorperfect.com/VORac2017>

If you prefer to mail in your registration or to make a reservation for dinner at The Dubliner, Please use the form below:

VOR 2017 Annual Conference and Legislative Initiative

Register online <http://weblink.donorperfect.com/VORac2017>

or use this form and return to:

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

Fax: 877-866-8377; Email: hdwyer@vor.net

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INITIATIVE REGISTRATION

I / We will attend the Washington Initiative and will make Congressional visits on:

___ Monday, June 5 ___ Tuesday, June 6 ___ Wednesday, June 7

ANNUAL CONFERENCE REGISTRATION: Fee includes all Saturday and Sunday events, including conference presentations and materials for the Washington Initiative

VOR Members:

___ \$75 per member if paid by April 8, 2017.
___ \$90 per member if paid by May 7, 2017.
___ \$110 per member if paid after May 7, 2017.

Non-VOR Members:

___ \$110 per person for non-member if paid by April 8, 2017. Fee includes 1 year membership.
___ \$125 per person for non-member if paid by May 7, 2017. Fee includes 1 year membership.
___ \$145 per person for non-member if paid after May 7, 2017. Fee includes 1 year membership

Donations to help defray the event's costs are appreciated

___ An additional donation of \$ _____ is enclosed

Total Amount to Charge: _____

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HOTEL INFORMATION

Hyatt Regency Capitol Hill
400 New Jersey Ave., NW
Washington, D.C. 20001

[Hotel Reservations due by May 7, 2017](#)

All Conference, Dinner and VOR Meetings held at Hyatt Regency Washington on Capitol Hill. The VOR Group rate is \$272 for single or double rooms, plus tax, per night. Larger rooms & suites are also available.

To make your reservations online, go to: <https://resweb.passkey.com/go/VOR2017>

If you do not have internet access, call 1-800-233-1234 and mention "VOR's Annual Conference" when making the reservation.

My Life as a Direct Support Professional

By Brad Whitehead, Chair of VOR's Quality of Care Committee



I first began to learn about the I/DD community in February of 1978. I enrolled as a student at Mount San Antonio College in Walnut, California, studying to take the State Board Licensure Examination and qualify as a Psychiatric Technician. In this program, we were taught extensively about both the I/DD community and the Mental illness community and went through medical and surgical nursing practices, pharmacology and psycho-pharmacology, and nearly 2,000 hours of clinical experience in providing care for both communities.

The Psychiatric Technician license requires 30 continuing education units for every license renewal period every two years.

After completing this program, I sought employment at Lanterman Developmental Center in Pomona California and was hired there permanently in 1980. It was helpful that many of my required clinical practice hours were at Lanterman.

At the time, Lanterman had a 300 plus acre campus, which housed approximately 2,000 individuals with a variety of intellectual, behavioral, and physical challenges. Over 90 % of the population functioned in the Profound to Severe level of I/DD. This meaning that their challenges were much greater than someone who fell in the level of moderate to mild level of I/DD, presenting, in turn, greater challenges to the staff who attended them.

Lanterman was a beautiful community in Southern California, which took on the feel of a large residential community with several homes or residences spread out throughout the acreage. We had a workshop on grounds as well as classrooms for the younger residents, Day Treatment Facilities and Activity Centers, There was an abundance of trained staff, nurses, doctors, dentists, social workers, and other professionals, all working together make this a real home to those living there, offering each individual living there a safe, loving, and protective environment with a program that served each individual's best interest.

As a Psychiatric Technician at Lanterman my role in my first 10 years there was to assist a group of residents that I provided care for in activities of daily living such as bathing, dressing, and eating, always with a focus on equipping each individual with skills to help them become as independent as possible. This can be such a great challenge when you are dealing with a majority population that was learning at a very slow rate and whose progress was measured by very small steps. Many were non-verbal, behaviorally challenged, or sensory deprived. Most exhibited a unique combination of all of these.

Since we served a community of individuals with challenges that ranged from intellectual to medical to behavioral to sensory deprivation, it was very important that we developed plans and habilitation programs for each of the individuals that would cater to their specific needs. The importance of having well trained staff that were patient with this process and who understood the importance of teamwork was vital to the success of the treatment. Everyone who worked there understood that we were coming into the homes of these individuals each day with the intent of making their lives as full and meaningful as possible. There was a team attitude that always reminded each employee that it was not about us, but about those we were there to serve. It was not unusual for us to work an extra shift when needed, to make sure there would not be a shortage of workers on any shift. The teamwork that I was privileged to be a part of at Lanterman was the best I have ever seen.

The spirit we had on the campus extended well beyond those 300 plus acres. The lives of the individuals who lived at Lanterman were always balanced with numerous community immersion opportunities that put each person in touch with the larger community around them, and the community around Lanterman always saw the residents of Lanterman as part of their larger community. We had a relationship that functioned like a symphony.

I was fortunate to be able to participate in many recreational activities both in house and in the community, often working alongside members of the Recreational Therapy staff. One of the real perks for me was to be involved with the Special Olympics program at Lanterman. We would have meets on grounds, at different cities in the surrounding communities, and at the State games that were held on the UCLA, UC Berkeley, and UC Long Beach campuses.

All of the workers at Lanterman participated in an interdisciplinary team that would assist in evaluating and implementing goals and outcomes to the individuals that we served. There was a great communication between the team members in making sure the plans were followed. We would maintain records and charts and keep vital data in order to measure the effectiveness of each program. The Nurses and Psychiatric Technicians would administer medications according to the

recommendation of the Doctors and Psychologist on staff. Meals were served according to the needs, wants and diets of each individual. Health and safety of all the individuals was primary and safeguards were in place to make sure that all felt safe where they lived. This included slow driving (15 MPH) on the grounds, and facility police that guaranteed that these were observed by all. Safety was a primary concern at Lanterman.

We were also blessed to have many clinics at Lanterman during the last 25 years I worked there. On site we had two Dentists, numerous Doctors, a Neurologist, a Psychologist, Social Workers, and a Wheelchair Clinic. We also had an Orthopedic Surgeon and an Ophthalmologist who came from their community clinics to provide services at Lanterman, services which they would not have been able to have provided at their local offices because of the various challenges that were present with many of the clients that we served.

In closing, I would like to add that I truly believe that it is very important that people who dedicate their lives to providing care to the most vulnerable of our population be adequately compensated for their efforts, I do not believe that we should cut costs when the outcomes of these choices could cost lives.

We were fortunate where I worked that the employees received a decent living wage to be able to provide for their families at home while providing care to those at work who eventually come to feel like their second families. I believe that this enables them to create the type of environment that provides the greatest possibility for the success for the individuals that live there, whether their home is a DC, an ICF, a group home, or independent living.

Sadly this great facility was closed at the end of 2014, despite the fact that we had regularly passed our licensing surveys that we would go through with regularity. I retired after the closure of Lanterman but remain an advocate for the best living options available to any individual who has I/DD whether the best place is independent living, group home, an ICF or a DC like the one I worked at. I believe choice is vital to providing this population with the very best for them and their families.

Afterword

By Hugo Dwyer, Executive Director of VOR

Thank you for reading this issue of the Voice, for allowing us to share a few of our voices with you. And now it's your turn. We need you to share *your* voice.

Please write us and tell us your story. Describe what is happening in your state. Ask for help if you need it, or pitch in to help if you can. Use your talents, your background, and your experience to help us. Don't just be a member of VOR. Be an active member of VOR.

VOR is a true grassroots, kitchen table organization. We always have been, and we always will be. Our message is simple and reasonable. *We support the widest range of residential, educational, and employment options for individuals with intellectual and developmental disabilities. We believe these options should run efficiently and effectively, that they should be well monitored by state agencies to promote safety and prevent abuse, and that the needs of the individual, and when appropriate their families and guardians, should be the primary concerns in determining the best options.* We oppose any organization, agency, or ideology that would limit these options.

We need you to help us to stand up for these principles. We don't have lobbyists in D. C. We don't hire 'experts' to go on speaking tours to speak against any other form of care for individuals with I/DD's. We just have you, and others like you. You are our experts. You speak from your own experiences, and you tell your own story. You have power.

This is a year of change in Washington, D.C., and we have to be part of that change. We have an opportunity to persuade Congress to tell CMS to stop funding litigation activities that work to close Intermediate Care Facilities, shut down sheltered workshops, or prevent families from building intentional communities where they may live with their loved ones and direct support professionals. We have a chance to address the problem of Justice Department lawsuits aimed at closing ICF's. We have a congress that is listening. We need to make them hear. We want them to hear your voice.



PLEASE SUPPORT VOR!

Renew your membership! * Encourage others to join! * Make a Donation!

“IF NOT US, WHO? IF NOT NOW, WHEN?”



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If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

April 2017NL