

Additional Photos from VOR's Annual Meeting



Mary Kay Cowen's welcoming smile at the Registration Table



Mary Vitale reports on Guardianship Rights vs. Supported Decision Making



Jill Barker speaks on the challenges of finding proper dental care in community settings



VOR President Caroline Lahrmann (OH) addresses the conference



Monica Sobczak (IL), Brad Whitehead (CA, VOR Board Member), and Joan Kelley (KS State Coordinator, VOR Board Member)



Peter Kinzler (VA) commiserating with George Mavridis (MA, VOR Board Member)
Peter: "Every time I think I'm out, they pull me back in."
George: "I'm cutting out before they start handing out those darned awards!"



L-> R: Rita Hoover (AR State Coordinator), Carole Sherman (AR) and Susan Jennings (PA State Coordinator)



Linda Lotzi (PA, VOR Board) , Paul Keipert (IL), and Laurie Stengler (IL, VOR board member)



Terry Lafleur (LA, Secretary of VOR) and Mary Kay Cowen (LA State Coordinator, VOR Board)



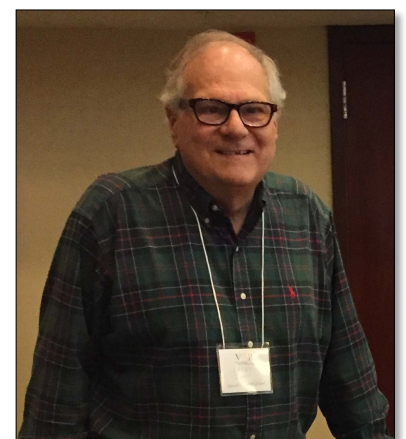
Dana Halvorson (American Health Care Association) and Joanne St. Amand (NJ, 1st Vice President of VOR)



Cindy Bartman (NJ State Coordinator) and Jane Anthony (VA) receiving a donation from Laurie Stengler (IL, VOR Board Member)



**Rita Winkeler (IL, VOR Board Member)
Caroline Lahrmann (OH, VOR President)
Hugo Dwyer (VOR Executive Director)
on Capitol Hill**



Larry Innis (MD, Treasurer of VOR)



George Mavridis left the conference before the VOICE Awards were handed out, not suspecting that one of them had his name on it. We had to track him down later at the dinner at the Dubliner to bestow the honor upon him.



Michael Johnson (WA), Laurie Stengler (IL), Mary Reese (MD), Paul Keipert (IL), Monica Sobczak (IL) Nancy Langhauser (IL), Rita Winkeler (IL), and Bob Hazard (CA) send greetings to Ronald and Susan Fox (OH) at the other end of the table.



Mary and Steve Vitale (MO), Terry Lafleur (LA), Susan McIlwain (LA), Mary Kay Cowen (LA), and Carole Sherman (AR).



Hugo and Cristy Dwyer (NY) enjoying this year's Dinner at the Dubliner.

JOEY JENNINGS' STORY

By Susan Jennings, Mother and Co-Guardian

Our son, Joey, age 25, is big, strong and handsome with a mischievous sense of humor and a dual diagnosis of autism and mental retardation. 80% of the time he is joy to be around, but obsessive, compulsive thoughts circle relentlessly in his mind, periodically building up into an anxiety that culminates in a destructive temper tantrum. There is no malice in his anger, he just lashes out wildly, breaking furniture and glass, punching holes in walls, bruising direct care staff in his path, until the neurological storm passes. Afterwards he is remorseful and apologetic, saying "I'm sorry, I'm sorry," over and over while he tries to undo the damage he has wrought.

Because of his disability, our son requires close supervision and understanding assistance in a safe place. As a teenager, he attended a residential school where he went to school, held a job, engaged in social activities and made many friends. His maladaptive behaviors were safely managed by the caring, professional staff at the school.

As an adult, he entered the Community Group Home system and his life spiraled into a traumatizing, living hell. Joey was discharged from three different community group home organizations in short space of four years. Because none of the group home staff in any of the three different community group home businesses were able to safely manage our son's behaviors, they arranged for him to be unceremoniously thrown into **five** (5) different psychiatric wards against his will (using the handy legal mechanism of Section 302), and forced onto 21 different powerful psychotropic medications in varying combinations. Joey spent up to 6 months at a time confined to a psychiatric ward while social workers searched for the next new community group home willing to take him.

The psychotropic medications caused Joey permanent neurological damage (Parkinsonian-like tremors in his hands), development of disfiguring female breasts (Risperdal), welts which can lead to life threatening Stevens-Johnson syndrome from Lamictal, intractable insomnia that did lead to psychotic breaks with reality, pre-diabetes and Serotonin Syndrome.



Since there were no clinical studies or medical research to indicate that any of the psychotropic drugs he was given were effective as treatment for his disability we suspected the drugs were intended for behavioral management by the community group home *but the chemical straitjacket just wasn't working*. His behaviors became more frequent, violent and dangerous to himself and staff.

While Joey resided in the community group homes, his eye socket was broken and he required 36 stitches in an altercation with community group home staff. We frequently found him covered with mysterious bruises.

Joey went unwashed for days at a time, there was sometimes no soap, no shampoo and no towels made available to him in the community group home apartment. Upon visiting, we were shocked at how badly he smelled. We often found Joey sleeping on a bare mattress in the community group home apartment, fully clothed, with his shoes on. Joey was fed an unhealthy diet of processed food and gained a significant amount of weight.

Joey in the group home system

Joey was always isolated and segregated in a **one-person** community "**group**" home with two staff because the group home would not be able to keep other residents safe with him. He was so lonely he phoned us up to 18 times per day. In one group home, on more than one occasion, Joey would elope into the nearby busy street from the apartment risking serious injury and death.

In one community group home, staff members also called 911 so frequently that I was told the police warned the group home that the police are "not part of your behavioral program" and if the group home staff continues to call police, "the community group home will be fined".

Joey was denied access to the community swimming pool because of the potential of behavioral outbursts that community group home staff could not handle in public settings.

In one inappropriate example of "community integration", Joey was taken to see the sexually sadistic movie "Fifty Shades of Grey" by community group home staff which disturbed him so greatly that he phoned me to declare "Tell the police, tell the judge, tell President Obama, I don't like inappropriate video!"

(Continued on following page)

(Continued from previous page)

Desperate for appropriate services for our child, we searched and learned about the Pennsylvania state-operated centers for individuals with developmental disabilities. Although Joey was eligible for admission, we learned that the Pennsylvania state developmental centers have been arbitrarily closed to admission to Pennsylvania residents. So we petitioned the Pennsylvania courts with a 406 Petition in order to gain entrance for our son to White Haven State Center. After a protracted court battle with the Office of Developmental Programs in Harrisburg, PA, which we won at every level, through State Appeal Court review, Joey finally gained admission into White Haven State Center in July, 2016, and his life turned around.

In less than one year at White Haven, our son is off all medications, taking only fish oil, magnesium and Vitamin D. He still has outbursts but his maladaptive behaviors are safely managed with behavioral techniques by the professional White Haven staff. He is a normal weight, clean, safe, happy and healthy, engaged in many social activities (parties, dances, cookouts, celebrations, movies, games) with fellow residents in a “college campus” type of environment.



Joey in White Haven State Center

Why did Community Group Home Isolate and Fail to Keep My Son Safe, while the “Institution” Succeeded in Keeping Joey Safe and Giving Him Quality of Life?

Community group home advocates might argue that Joey wasn't placed in the “right” community group home to be successful, but since Joey was placed in three different community group home organizations in different parts of the state, (Pittsburg, Bethlehem, Philadelphia) we would argue our son has suffered enough; his horrific experiences proved that community programs are not always the most appropriate and there exist inherent community group home systemic flaws that harm people with disabilities like our son, having a history of profound problems, often compounded by mental illness, requiring round-the-clock supervision for his safety and the safety of other residents.

For Joey, inclusion in the community was a myth. My son ***was never more isolated*** than when he lived in his one person “group” home. He never felt like he was part of this community. His neighbors never invited him to their backyard barbecues. He was more like a prisoner in solitary confinement in a very small prison with two prison guards. What is restrictive for one person may be the **appropriate** setting for another person. Restrictiveness is an important concept but to have any meaning, it must be personalized to the needs and wants of each individual. In reality, what appears to be one of the least restrictive settings for Joey ... a 1 person group home in the community ... became the most restrictive for him because it was most inappropriate for his complex behavioral needs.

Our family will be forever grateful for White Haven Center.

Please join with us in support of its important work and in support of open admissions for eligible persons to the Pennsylvania state-operated developmental centers.

Why White Haven Succeeds for our Son

- Apartments are therapeutically designed with thick walls to withstand the force of behavioral outbursts and minimize sensory triggers of light and noise. There is safety furniture Joey cannot throw and break. Professional supervision, clinicians, nurses, fellow frontline staff are ***on the premises*** to handle and assist in behavioral crises. Also on-site supervision provides accountability, oversight and safety for the residents.
- A human rights committee provides further oversight.
- Clients have a ***community of fellow residents right on the campus*** facing the same challenges to socialize with in a safe environment.
- Facility staff are caring, understanding, supportive and stable. Other staff are on-site providing critical support and back-up. Frontline staff can meet with the clients' on-site professional Treatment Team to brainstorm solutions to problems.
- The campus environment is stable, structured and safe and appropriate for Joey. On-campus workshop, swimming pool, gymnasium, chapel, café and other facilities, scheduled parties, dances and events provide a wonderful quality of life for residents. Schedules are structured and predictable.
- Regularly scheduled trips into the outside community are available for residents ***who can successfully handle and negotiate the challenges*** of the community environment for a short period of time.

(Please see “Pennsylvania Update” on following page)

Pennsylvania Update

Earlier this year, Gov. Tom Wolf declared the closure of the Hamburg Center and the ICF unit at Norristown State Hospital. The closures came without warning or input from the state legislature, and have caught many families off-guard believing the issues had been solved through June of 2018 by the court's settlement in the Benjamin case.

Longtime VOR members will remember the name Nancy Thaler, former Deputy Secretary of PA DDS from 1993-2003, responsible for closures and lawsuits in PA. Ms. Thaler has returned to PA as Dep. Sec. of the Office of Developmental Programs. She and the governor now have their sights aimed at closing all of the state's ICF's/IID. VOR has been contacting PA families for several months, trying to find individuals willing to reorganize and unite against this effort. This summer, we were fortunate to find **Susan Jennings** (see *Joey's story on p. 8-9*), who has been working tirelessly to bring Pennsylvanians together to protect their centers and their family members who thrive there.

Susan has started an organization, **Keeping Individuals with Intellectual Disabilities Safe** (KIIDS) to educate families and encourage action. She has reached out to *A Team Pennsylvania*, who successfully lobbied to protect sheltered workshops earlier this year in Harrisburg, and has been contacting legislators willing to oppose the Governor and Dep. Sec. Thaler's plans. We urge Pennsylvania families to visit the KIIDS website at <http://www.thekiids.org>, and we encourage all of our readers to visit the site to see her impressive advocacy work, and to contact Susan with your suggestions and experiences that may serve to help the families of PA.

Texas Update

State Senator Juan "Chuy" Hinojosa introduced SB 602 this year, in another attack on Texas' State Supported Living Centers (SSLC's). The bill would have set up a commission to review the thirteen SSLC's. The intention of the bill was to close several of the facilities and to move residents into HCBS waiver settings or into the remaining centers across the state. This effort followed Hinojosa's failed attempt to close the Austin SSLC in the previous legislative session.

More than 3,000 people live at the 13 centers. Families say the centers allow their loved ones to be a short driving distance away, have constant care and have a community where they can make friends. They fear moving them out of the facilities into group homes could put them in danger.

The bill passed in the State Senate, but was roundly defeated in the House, where legislators refused to even bring it to a vote. Much of the credit for this goes to the family advocacy group PART and others in the state who lobbied their members in the House while the Senate debated the bill.



Note: VOR's Marketing Committee is compiling a list of media contacts who have proven friendly to VOR's issues or who have not exhibited a bias against ICF's, Sheltered Workshops, etc.

If you have any connection with a reporter or media outlet in your state or region, please send their name, media outlet, and contact information to us at info@vor.net

New Jersey Update

The state legislature approved Governor Christie's proposal to divert \$1 billion in voter-approved lottery revenues away from critical programs for the intellectually disabled and mentally ill, and using the funds prop up the New Jersey public employee pension system each year for the next thirty years. Christie's plan will rob social programs of \$30 billion in constitutionally mandated, secure funding.

The funding of these programs was the key priority in the creation on the entire state-run lottery system.

According to the State of New Jersey, "since its inception in 1970, the Lottery has dedicated more than \$24.8 billion to programs and institutions that benefit millions of New Jersey residents". These include state-operated developmental centers serving the intellectually and developmentally disabled, state psychiatric hospitals, homes for New Jersey's disabled soldiers, the Marie H. Katzenbach School for the Deaf, a statewide school nutrition program and a few similar initiatives.

This state financial support was the result of a New Jersey constitutional amendment established in 1969, with the approval of voters, which requires a minimum of 30% of lottery proceeds to benefit "state institutions and state aid for education".

In FY 2015 and 2016, the Lottery contributed \$960 million and \$987 million respectively to the care of intellectually and developmentally disabled New Jersey residents and state psychiatric clients. Christie's plan swaps out this dedicated and secure funding stream with unspecified and unpredictable revenue from the general budget. Care that was once steady and sure will be subject to the whims of an annual budget process. Robbing from Peter to pay Paul is no way to fix a pension system, nor make it sustainable. It kicks the pension problem down the road, placing the intellectually disabled and mentally ill at risk in the process.

Ohio Update

On March 31, 2016, Ohio's protection & advocacy agency Disability Rights Ohio filed a federal lawsuit, Ball v. Kasich, against the State of Ohio attacking programs for severely and profoundly intellectually disabled Ohioans including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), sheltered workshops, and day programs.

Ohio families fought back filing Motions to Intervene in the class action so that their loved ones' interests could be heard by the court. VOR played an important role assisting family efforts through an Amicus Brief in support of their intervention. Chief Judge Edmund Sargus granted families' motions stating, "This litigation is complex and important. Excluding individuals with disabilities who will be directly impacted is not the appropriate way to make this case less complex."

Families in Ohio still have a long road ahead, but now they have a voice in this case. The importance of the intervention of families cannot be understated. Chief Judge Sargus wrote, "Thus, the Court finds that the rights of those individuals who do not wish to move from their residence in an ICF, or those who are at serious risk of institutionalization who wish to obtain residence in an ICF, are directly impacted in this lawsuit. Those rights were not protected until the Guardians filed their Motion to Intervene."

The engagement of counsel, William Choslovsky of Fox Rothschild and Robert Cohen of Kegler Brown, has also been vital for families hopes in this case.

VOR wishes to express its gratitude to counsel, Michael Rato and his colleagues of McElroy, Deutsch, Mulvaney and Carpenter, for their fine work in VOR's Amicus filing.

The Last Word *By Hugo Dwyer, Executive Director*

By the time you've worked your way through this issue of The Voice, those lazy, hazy days of summer will be waning. Congress will be returning to Washington, your state legislators will be back in the capitol, and VOR will be gearing up our work on our fall and winter campaigns. Our work, unfortunately, is never finished. There is always a something brewing.

A few weeks ago, I attended a conference held by one of our peer organizations. One topic that came up in a forum on grass roots advocacy was how difficult it can be keeping members engaged, especially after losing a particular campaign or court decision, or worse – after winning one. Losing breeds frustration. Members give up. But winning can be even more dangerous. Winning breeds complacency. Complacency undermines advocacy.



So how do you keep your existing members engaged and attract new members to your family group or your state-wide advocacy organization after a win, a loss, or when there isn't a crisis on the table? How do you keep motivating your members?

Here's what some of our successful advocates have done:

1. Remind your members that there is *always* a crisis coming. You just don't know about it yet. As long as there is an Arc, or a Protection & Advocacy organization, an Administration for Community Living, or a Department of Justice, there is someone trying to close down an ICF/IID somewhere. They may lie dormant for a while, but they never really go away. Make it your group's job to stay on top of their activities.
2. Make sure your group is communicating regularly with your elected officials. Invite them to visit your facility and meet your loved ones. Get to know them. Get them to know you. Ask them to call you by your first name. Find out which legislators are on your side, and which ones oppose you, and which members of your group are in their districts. Reach out to their aides and other people in their offices, and ask them to contact you if anyone proposes legislation that concerns your organization.
3. Mentor, and be mentored. Learn from those before you, and pass your knowledge on to those who will follow.
4. Engage family members. Siblings, nieces, and nephews are the best hope for the next guardians and protectors of your loved ones with IDD.
5. Encourage members of your group to meet with your adversaries. Attend Arc meetings. Get on their email list. Know what their plans are. Speak with them, and tell them that you support family choice and the full continuum of care. Speak with people in other states, to find out how their state differs in approach, and what their experiences and strategies have been. Our adversaries share their strategies with each other. We need to share ours among our allies.
6. Always keep a positive attitude. Be respectful of others, whether ally or adversary. Encourage dialogue. Ours is a message of hope, and we believe in we are doing. Take the high road, and don't let others take away your dignity or composure.
7. And, of course, encourage the members of your group to join and participate, in VOR.

Thank you for being part of VOR.

A handwritten signature in black ink that reads "Hugo Dwyer". The signature is stylized with a large, sweeping "H" and a cursive "Dwyer".

Hugo Dwyer,
Executive Director, VOR