



### **President's Message**

As another year comes to an end, it is a good time to reflect and think about the role each one of us has played in advocating for our family members with I/DD, both by working with our local organizations and by supporting VOR in various ways. I am honored to have served as the president of VOR for this past year and I thank you for your support of our very important mission. Your participation is so important in advocating for the highest quality of care and human rights for all persons with intellectual and developmental disabilities.

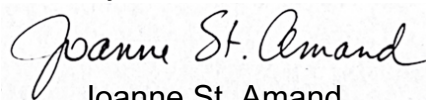
There are several reasons why your participation in both VOR and your local "Family and Friends" associations are so important. Decisions need to be made and your ideas and feedback are important in making the best decisions for everyone. Regardless of your qualifications or experience, everyone has something to contribute. You know what supports your family member requires, you have an opinion of what needs to be done, and you know the priorities.

Opinions, whether from federal agencies such as Protection and Advocacy, Disability Councils, Community Provider organizations, or voiced at public hearings, or in media editorials are often heavily one-sided. Decision-makers need to hear from all of us to get a balanced understanding of the issues and what our family members need to thrive. The more views gathered, and voices heard during the process of decision-making, the better the chance of getting a solution that will address our issues. For public agencies with political leaders, the total number of people engaged is very important to them. Our family members with severe and profound intellectual disabilities represent only about 5% of the entire population with I/DD. If we do not speak up for them, who will?

The end of the year is here, and we are in the midst of our giving campaign. As you know, VOR is 100% privately funded. Our mission could only be accomplished through the volunteer efforts and generous financial support of our members and friends. Every member is important and every gift really does count. We are grateful to you for your years of support to VOR and ask that as you plan your year-end charitable giving, you would again please consider a gift to VOR.

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

Thank you!

A handwritten signature in black ink that reads "Joanne St. Amand".

Joanne St. Amand,  
President, VOR Board of Directors

*VOR is registered as a 501(c)(3). All donations to VOR are tax deductible to the full extent of the law.*

## Executive Director's Message:

### Tom Dwyer Speaks to The President

My brother Tom turned 62 on November 8<sup>th</sup> of this year. He lives at the Southbury Training School, a state-operated ICF in Connecticut. STS has been Tom's home for his entire adult life, and I can honestly say that I don't believe Tom would be alive today without the quality care, love, and community that STS has given him.

Tom probably doesn't know what a birthday is. He is severely developmentally disabled. Tom has autism, bi-polar disorder, Pica, Parkinsonism, and what was once called profound mental retardation. He has one detached retina and his vision is poor. He uses a wheelchair but he can be walked with a gait belt. **And Tom is non-verbal.**

I did not go to Connecticut to bring him his birthday present that day. Instead, I took a train down to Washington, D. C. to give him his gift. ***I went to Washington, D. C. to give Tom a voice.***



*Hugo Dwyer*



*Tom Dwyer at Southbury Training School*

I attended a meeting of the President's Committee for People with Intellectual Disabilities (PCPID), hosted by the Administration for Community Living (ACL). I addressed the committee on behalf of Tom and on behalf of all of our loved ones with severe/profound intellectual and developmental disabilities. My voice, Tom's voice, your voice, was the only voice that spoke on behalf of the most severely impacted members of the I/DD Community.

No one told me that the public wasn't allowed to address the Committee at this meeting. Fortunately, no one had told the first speaker that either. When the Liaison from the Office of Health and Human Services to the Office of the President finished his opening remarks, centered around the committee's intent to speak about Competitive Integrated Employment, he asked if there were any questions. I put up my hand, and not knowing any better, he picked me.

I introduced myself to the committee, and told them about Tom, that it was his birthday and I was there to speak for him, and for our VOR families with loved ones who need and want services in Intermediate Care Facilities (ICFs). I told them that our families have been marginalized and overlooked for decades, our preferred services closed down or cut back, that admissions to ICF's have been closed in many states, including at STS. I told them that we were being denied our right to choice, and that as parents and siblings and guardians, we had the right to make these choices. I went on to say that many other individuals with intellectual disabilities are being denied the opportunity to work in center-based employment with specialized wages. The choice of sheltered work environments is being denied by people who see this as detrimental to the wishes of those who seek competitive employment. I told them that our voices have not been heard in their meetings, and that I was there in hopes that the more severely intellectually disabled populations would have a seat at the table at the President's Committee for People with Intellectual Disabilities.

After I spoke, the committee announced that members of the public were not to be granted the opportunity to speak at this meeting. Except for two women who had been hired as ASL interpreters if needed, I was the only person attending as a member of the public. But I stayed and watched introduced myself to individual members when on breaks. I made sure the members of the committee were very aware of who I was and who I was there to represent.

The President's Committee appears to have already set their agenda. It will focus on the less severely impacted members of the community, their hopes for inclusion, for integrated competitive employment, even for attending college. These are all noble, admirable goals. We all want all of these things for all of these individuals and their families. **Inclusion** is fine, but ***we want our loved ones to be included, too.*** A report to the President of the United States about the community of people with intellectual disabilities is not complete if it excludes the most severely intellectually disabled.

I hope that the Committee did hear Tom's voice that day, and that they will see fit to invite our families to be part of their discussions next year. And I hope that maybe someday, Tom's voice will be heard by the President himself. Or herself, if it takes that long.

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

## Who Is Most Precious To You?

**Who needs your protection from those who would do them harm?**

**It could be your elderly parents, your spouse, or your children.**

**You would do everything to help them and protect them!**

Our daughter, Kim, is that precious someone for us. She needs our every effort to make sure that her life is safe and full.

Kim is “multi-handicapped”. She has cerebral palsy, profound intellectual disabilities, is physically impaired, and does not know how to defend herself from harm. She is trusting of everyone. Kim does not know how to express hurts. She requires other individuals to assist her with all of her personal care needs. Kim must have someone feed her, clothe and bathe her, and is incontinent. She says about 21-words. Kim requires 24 hours a day/7 days a week care, with well-trained and attentive care staff.

Kim’s life at the Conway Human Development Center is very full. She loves her home, and all of the activity. Kim is busy everyday with training classes, recreational swimming, speech therapy, trips to the mall, movies, the zoo, restaurants, bowling, church, and even horseback riding from time to time. Her care givers love her and want what is best for her, too! We are thankful for them! We remain very much a part of Kim’s life!

As her parents, we want to make sure that her life continues to be safe and have quality to each day! Please do everything you can (and would do if she were yours) to help keep her home available to her and the other individuals that need these services.



←  
Kim’s physical age is  
43 years old.

However, Kim’s  
mental age is  
around  
2 years old.  
→



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## What’s Happening in Your Community?

We try to keep our members informed by posting articles from across the country in our Weekly Newsletter. The news media doesn’t always cover our stories. When they do, they often fail to include our perspective. We rely on our members to keep us informed of issues, legislation, and activities that affect their loved ones and their families. Help us to help our families stay informed.



## On Language: The "R" Word, the "I" Word, and the Subtext of Discrimination

While attending the meeting of the President's Committee for People with Intellectual Disabilities (PCPID) in Washington D. C. last month, I heard a number of participants mention their strong dislike of the "R" word. The general consensus was that the "R" word is hurtful, that it had been used to insult and marginalize people with intellectual disabilities. One speaker compared using the "R" word to using the "N" word.

We can all agree that the "N" word has always been a term associated with ignorance, racism, and hate. We can all pretty much agree that the "R" word has deviated from its original clinical usage to describe an intellectual condition, mental retardation, to become a derogatory, insulting, and disenfranchising term. As a result, we have stopped using the "R" word.

What struck me was the fact that most of the participants freely used the "I" word, ***Institution***, as a demeaning term, without ever seeing the irony of their using this term in a manner that is hurtful, and disenfranchising to those who believe that Intermediate Care Facilities (ICFs) are the best solutions for a minority of individuals with intellectual and developmental disabilities, complex medical problems, and behavioral disorders.

ICFs are a legitimate, valuable component of our full continuum of care. They deliver a higher level of service for people with higher levels of need. ICFs are certified by CMS, and are thereby held to a much more stringent set of guidelines than HCBS waiver settings.

When members of the I/DD community derogatorily refer to ICFs as "institutions", their intent is often to invoke memories of the past, where people with I/DD were cruelly warehoused without treatment in places like New York's infamous Willowbrook State School or Pennsylvania's Pennhurst State School and Asylum. Modern day ICF's bear no resemblance to those institutions. The use of the "I" word is just as hurtful, just as demeaning and marginalizing to our families as the use of the "R" word might be to theirs.

The families of people with severe and profound disabilities support the goals of inclusion and competitive employment for those who have the ability to participate in these environments. But we cannot help but feel marginalized and discriminated against by others in our own community, when we hear the word "institutions" used in a demeaning manner, when we are told that equivalent services are available in "the community",. Families who support these choices are often told that we are uninformed, afraid of risk, or that we just don't care enough for our loved ones to put them into waiver settings. That is hurtful. That is demeaning. That marginalizes us.

It's time for us all to acknowledge the breadth of the disability community, and work to support one another in our individual goals of making better lives. Please don't allow others to use the "I" word to demean and marginalize those who make this choice.

### **"Institution" is Not a Dirty Word**

The next time you hear someone try to speak disparagingly of ICFs by using the word institution, interrupt their diatribe and ask them to clarify what they mean by "institutions".

**Dictionary.com defines institutions as:**

- An organization, establishment, foundation, society, or the like, devoted to the promotion of a particular cause or program, especially one of a public, educational, or charitable character.
- The building devoted to such work.
- A public or private place for the care of persons with physical or mental disabilities.

**Therefore...**

- By the first definition, institutions are some of the most important ways that people get together to work for the common good and promote their shared interests.
- By the second definition, an institution is a building. Nothing more, nothing less.
- By the third definition, small 3 – 4 person HCBS waiver settings are institutions, too.

**That's right - "group homes" are institutions, too!**

**By definition, "group homes" are buildings operated by corporate entities, run with public and private funds, that provide for the care of persons with intellectual or mental disabilities.**

**Larger, intermediate care facilities are less isolating, providing more peers for better interaction and stimulus.**

**ICFs provide nursing, psychiatric, medical and behavioral services and a wider range of treatment options.**

**Larger facilities offer more interior space and larger campuses to the people who call them home.**



## **Opening Doors for Some, Closing Doors on Others**

One of the presenters at the President's Committee for People with Intellectual Disabilities spoke of the benefits of competitive integrated employment, and the benefits of closing sheltered workshops and ending specialized wage provisions under Section 14(C) of the Fair Labor Standards Act. The speaker's contention was that closing these opportunities would somehow open doors to full-time jobs at minimum wage or better for people with intellectual or developmental disabilities. When asked if she thought everyone with I/DD would be able to take advantage of this opportunity, she replied that some would not. She was then asked what would happen to those people. Her answer was that they would probably spend more time on the sofa watching TV or being driven in vans for meaningless trips to the local shopping malls. Asked if she thought that was a good thing, she replied that it was not, but that the plan was not to close sheltered workshops all at once, but to "phase them out" over time.

Obviously, that doesn't solve the problem for those consigned to long days on the couch or at the mall, but it might take care of the public relations problems of those who believe they are doing what's good in spite of evidence to the contrary. Opening a door for some, closing doors on others.

This led me to thinking about how the same misguided self-righteousness has governed our residential policies for the last thirty-five years. Admissions were closed at Tom's home of Southbury Training School in 1986. The good people of Connecticut sought to "phase out" this type of residential opportunity, admitting that those fortunate enough to have that opportunity might continue to benefit from it, but closing the door on others who might need such a level of care. I don't get it. Do they think that people will just adjust to having inferior care? Or do they just not want to think about the possible consequences of their actions?

At the House Judiciary Committee's hearings examining class action lawsuits against Intermediate Care Facilities last March in Washington, D. C., Allison Barkoff of the Consortium of Citizens with Disabilities testified that a settlement agreement in Virginia enabled a single mother, who was #1,025 on the Community Waiting List, to receive HCBS waiver services. Earlier in the hearing, a mother from Virginia testified that the settlement agreement Ms. Barkoff cited had forced her twin sons out of their ICF home and into insufficient, inappropriate care in HCBS waiver settings. One of Mrs. Bryant's sons died as a result. Opening doors for some, closing doors for others.

Who are these people, opening and closing doors? Why do they believe this is a good thing? Can't they see the pain they are causing?

We need to open all the doors. We need a system that supports all levels of care and all opportunities for employment for all people with intellectual and developmental disabilities.

### **Don't Call Smaller Congregate Settings "Group Homes"**

The people who oppose larger congregate care facilities often refer to our ICFs as "Institutions". Don't let them call their smaller waiver settings "Group Homes". Call them houses. Call them waiver settings. But don't let them call these settings "Homes" and our settings "Institutions" without challenging those terms.

Home is a state of mind. It is the warmth, consistency, and comfort provided within a residence. It is not defined by the size of the building that encloses the home. Most college kids live in dorms. On holidays, they go "home" to be with family. Older people often move to assisted living or other communities. They are likely to say, "We sold our home and moved in here." For our loved ones with I/DD, ICFs provide a home. Waiver settings can provide a home, too, but again, that home is determined by the love and acceptance found inside, not size of the building or its location within a neighborhood.

### **Don't Let Them Call It "The Community"**

To refer to HCBS Waiver settings as "The Community" implies that ICFs are not a community. That's just wrong. An ICF home is a community. A well-run ICF can offer a larger, warmer community to our loved ones than an isolated 3- or 4-bed waiver home can. Larger ICFs offer larger campuses and more interior space than small settings. They offer more services, often including doctors, nursing staff, physical therapists, and dentists. ICFs are required to provide Active Treatment for their residents. HCBS waiver settings are not. They often retain staff better than smaller settings, providing more familiarity and identity for the residents.

Just thinking about raising a family of 7 children with 2 of those 7 having developmentally disabilities and physical disabilities makes me wonder how my mom, Kay, got through her days, weeks, months and years. Kay, at 94 years of age still visits with her daughters at Murray Developmental Center in Centralia, Illinois. Mom has been through so much, told her story many times and now I am proud to take over the reins, to continue telling our story and advocate for my sisters to remain in their home at Murray and receive the proper care they deserve.



**Donna**

Meet Madonna, "Donna", who is now 61 years old. My mom noticed delays in Donna's development months after her birth, but at age 2 it was obvious she had special needs. Mom and Dad searched for a diagnosis and answers through doctors and multiple tests, to no avail. In Donna's adolescent years, she started having seizures. Mom and Dad had to make a decision to get professional care. They could no longer do it alone. Donna started in congregate care in her teens. It was again a difficult, heart wrenching move. Our family would travel to Missouri to visit Donna and my mom would cry that she could not bring her home. Eventually the State of Illinois would no longer pay for her care out of state. It was then they found Murray, closer to home than she had been and able to visit more often.

Years continued to pass by and it was not until my Mom read an article in the St Louis Post Dispatch that our journey for a diagnosis was over. Donna was around 40 years of age when a blood test confirmed Donna had Rett Syndrome.<sup>1</sup> We cried as we read about the condition.

Donna was invited to participate in a national medical study on Rett Syndrome. With the help of Murray Center's staff and administration, Donna traveled to Chicago once a year for the 5-year study. In the study, Donna is recorded as the 2nd oldest living girl with Rett Syndrome in the United States. The goal of the study was to help find a cure, learn more about the condition, and help families with development plans, healthy weight, nutrition and develop proper care strategies.

We were told the lifespan for girls with Rett is late 40s. Murray Center was already providing the right care and we contribute Donna's long life span to the care she has received at Murray.

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Next, meet Angela, "Angie", who at 54 is the youngest of the family. Angie was born with club feet and low birth weight. My mom and dad described a baby that cried 24-7. Over the years, her diagnoses increased to include developmental delays, bi-polar II, schizophrenia and cancer.

Angie moved to Murray center 18 years ago after two failed community placements. After high school, there were no programs for Angie to attend, but she had a job folding laundry at a local nursing home until her schizophrenia took hold and subsequent struggles with doctor appointments and tests, Angie lost her job. Mom and Dad did their best to continue to care for her at home, until an overdose of her medications had them realize they needed help. They couldn't do it themselves, they needed professionals. They contacted a local workshop so she would have somewhere to go during the day to pass her time.

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<sup>1</sup> *Rett syndrome* is a rare non-inherited genetic postnatal neurological *disorder* that occurs almost exclusively in girls and leads to severe impairments, affecting nearly every aspect of the child's life: their ability to speak, walk, eat, and even breathe easily.

<https://www.rett syndrome.org/about-rett-syndrome>