

## President's Message *By Caroline Lahrmann*

VOR members are active with state and federal officials to help them understand the complex needs of our family members with intellectual and developmental disabilities (I/DD). Our members also meet with officials to seek answers as to the source of policies which conflict with the ADA and the U.S. Supreme Court *Olmstead* decision. Oftentimes, these policies take away the right of individuals with I/DD and their parents and guardians from being the primary decision maker when making personal choices about residential care and employment.

Answers to our questions are not always forthcoming. Instead, we are often greeted with finger pointing between state and federal officials. For families who have made the rounds, you begin to feel like a ping-pong ball batted about willy-nilly.



## President's Message

This is no way to treat families who daily face the stress and pressure of caring for individuals with I/DD, but it's the reality we face and it's the reason VOR exists. VOR strives to arm families with materials and information to help them advocate and make a tangible difference in the lives of their loved ones.

In this edition of the *Voice*, we aim to do that with an article about sheltered workshops, which are coming under increasing attack. State officials far too frequently are bending to this pressure and tell families that federal government regulations are to blame. Federal officials will in turn note the autonomy states have in making policy.

Most recently, state officials point to CMS rule changes as the reason for proposing closures of sheltered workshops. State officials will tell families that sheltered workshops are not allowed under the new regulations because they are considered "segregated" facilities. These same officials, however, fail to take advantage of the aspects of the regulation, which enable states to go to bat for sheltered workshops and facility-based day programs so that these vital services can remain.

For instance, CMS guidance tells us that the new rules are "*more outcome-oriented...rather than one based solely on a setting's location, geography, or physical characteristics.*" Further reading of the guidance points to a process by which states can document and provide evidence as to why a program/setting complies with HCB requirements. States need to take advantage of these elements of CMS guidance that recognize the importance of specialized settings so as to protect their constituents with I/DD who depend upon these programs. We've cited some of this guidance in our article and hope that you can share this with your state and local officials.

At the same time, the federal government must properly administer and comply with the ADA and the *Olmstead* decision and end DOJ actions and HHS support of federally funded initiatives, such as lawsuits from Protection & Advocacy agencies, which directly attack sheltered work. State must not roll over in face of these wrong-headed challenges. Too much is at stake, namely the health, safety and welfare of individuals with I/DD.

As we approach year's end, VOR hopes we have been a valuable resource for you in your advocacy. We wish you and your family health and happiness this holiday season and are deeply grateful for your support and your commitment to individuals with I/DD.

Caroline Lahrmann  
President, VOR Board of Directors

## **My Friend Wendy**

*By Joanne St. Amand, Vice President of VOR's Board of Directors*

What better time of the year is there than the holidays to pause and reflect, to count our blessings and to give thanks?

I would like to take a moment to share my thanks for my friend Wendy and for the support and empowerment of VOR, and to ask you to share a little with us.

Wendy is 53, has crippling cerebral palsy and mild developmental disabilities. She struggles to keep her arms from flailing about. She needs help with all of her self-care and feeding. Wendy has difficulty speaking clearly, but she has a voice and will make herself understood. When words are not clear, she points to letters, words or pictures in her notebook to communicate. Wendy can make her own decisions and even vote in elections, but she couldn't control the thing that was most important to her: the decision to remain in her long-time home, Woodbridge Developmental Center.



Joanne and Wendy

I met Wendy in 2013 when she lived at Woodbridge, an Intermediate Care Facility (ICF) run by the state of NJ, which was also home to my 61 year old sister with profound intellectual disabilities. I became active in the Woodbridge Parents Association as our parents became older and it was at this time that I learned about VOR. Later, when I was president of the Parents Association, it was VOR that provided the families with guidance and support to fight against closure of the center. VOR empowered us to unite and testify at public hearings, and they participated in conference calls with our attorneys.

Wendy lived at Woodbridge for 18 years until she was the state of NJ forced closure of the facility. Thanks to the strong advocacy of the Woodbridge families and VOR, Wendy and my sister were able to find another ICF home.

Prior to living at Woodbridge, Wendy had been moved 19 times. Her memories of those other places are not happy ones. She lived in psychiatric hospitals, rehabilitation facilities, nursing homes and other residential facilities, some out of state. At times, care staff would neglect to bath her. She spent much of the time in bed with her arms and legs tied down. *"I was very depressed there"* she told me. *"When I got the news of Woodbridge closing, I didn't know what I would do"*. Woodbridge was the first ICF she lived in, and the home she loved. Its closure was devastating to her. The stress of moving again was nearly unbearable. *"My family is here,"* she said.

Wendy has had many opportunities to move to a group home but chooses to stay in a developmental center. She is concerned that they cannot provide everything she has in her ICF, and about who will be her caregivers. *"The people here really know me,"* she said. *"In a group home, there aren't as many and they can change every day"*. Wendy's story attests to the fact that a home is not defined by its size or location, but as a place that offers safety and security, that provides love, stability, and quality care.

**Wendy became a member of VOR just recently. But VOR has been fighting for Wendy, and others like her, for over thirty years.**

# VOR, Politics, and You - Searching For A Champion

By Hugo Dwyer

Edited with insight and diplomacy by Peter Kinzler



The election is over. On a national level, the Republicans now control two branches of government. When the Senate confirms President Trump's first nominee for the Supreme Court, there will be a conservative majority on most issues in the third branch.

How does this affect families of individuals with intellectual and developmental disabilities (I/DD)? How will this influence VOR's advocacy in the coming years?

## Executive Director's Message

Under the Obama administration, the Department of Justice (DOJ), the Centers for Medicare and Medicaid Services (CMS), and the Administration for Community Living (ACL) worked to close congregate care facilities. Republicans in Congress were more inclined to stand against those efforts, largely due to their objections to restrictions on family choice and to class action lawsuits. They failed to make changes to the Developmental Disabilities Act (DD Act) but did impose some restrictions through appropriations legislation.

In the first instance, we know that the appointees to the key positions at DOJ and HHS will be instrumental in setting policy. Jeff Sessions, President-elect Trump's nominee for Attorney General, has a long history opposing frivolous lawsuits, albeit in the context of suits against businesses. The nominee for the head of the Civil Rights division, who has not been selected yet, will likely have a far greater impact on the future of DOJ suits to close congregate care facilities. Tom Price, the nominee for Health Secretary, favors privatizing Medicaid and Medicare and issuing block grants to the states. In 2015 he introduced a bill to overturn the Affordable Care Act and cut back Medicaid expansion in 31 states and the District of Columbia.

While we don't know who will be appointed to head CMS, ACL, and other federal agencies that have a direct impact on our families, we cannot expect any relief from Congress' authorizing committees in the short run because they will be preoccupied with repealing or revising the Affordable Care Act. Given the pervasive ideologies of the people staffing the key agencies and the influence of the Arc, we can expect little change on the state level in the near future, with the DD Act programs continuing to advocate for closing down congregate care facilities, sheltered workshops and intentional communities, **unless we can encourage the Appropriations Committees to take stronger action to restrict these activities.**

We can also expect Congress to push for budget cuts in the programs that support our loved ones.. Speaker of the House Paul Ryan has been trying to make major changes to the funding and operation of Medicaid and Medicare for years, and now will not see any changes vetoed by a President Obama. While Donald Trump indicated support for Medicare during his campaign, it is not clear what he would do if presented with legislation that would reduce funds for people with I/DD and others. Changes to these programs could be more detrimental to our families than even the regulatory actions of DOJ and CMS over the past eight years.

What does all this mean for VOR? **It means that we need a champion in Congress.** In fact, we need champions in both the House and the Senate, in both the authorizing and appropriating committees. We need for you, the members of VOR, to contact your Members of Congress and to educate them about the need for a continuum of care for people with I/DD, and the need to protect and even increase funding for these services. We need a voice, and to find that voice, we need to use our voices.

The last time we had a champion, it was Rep. Barney Frank, who authored bills that would have stopped the single most destructive policy of P&A, the ability to initiate class action lawsuits in the name of a few individuals. Prior to that, we had a champion on the Supreme Court in Ruth Bader Ginsburg, who wrote protections for choice and larger congregate care facilities ("institutions") into the frequently misinterpreted *Olmstead* decision. Our champions, it would seem, have been too few and too far between. Given the current political tides, it is essential that we enlist new champions support the rights of all people with intellectual and developmental disabilities.



## **Marjorie's Story**

*By Peggy Strong*

My daughter Marjorie lived in a CILA (Community Integrated Living Arrangement – group home) for over fifteen years. During that time her health deteriorated and as her mother I was put in the unenviable position of being her doctor, nurse, behavior analyst and mother as I daily coordinated the services she needed. Although the staff at the CILA were kind and wanted to help Marjorie, her needs could not be met by a staff that was frequently young, untrained, and constantly changing. The consistency Marjorie needed was not available in the CILA system. Although Marjorie can walk, her life in the CILA consisted mainly of sitting in the small home she lived in or at the workshop she attended daily. During the last three years of her CILA placement she was unable to attend workshop due to her increasingly fragile medical state. Finally, her health deteriorated to the point where she could no longer drink any liquids and her kidneys were failing, I began to look at Hospice Care. Thankfully, I found out about Murray Center, a State Operated Developmental Center in Centralia, Illinois. The following will tell you more about Marjorie and her success at Murray Center.

Marjorie has 28 acute, chronic, complex and degenerative life-threatening medical diagnoses. Although 24 of those diagnoses are linked to Phelan McDermid syndrome, 8 are also related to Duchene Becker Muscular Dystrophy. Not only are these diagnoses dangerous on their own, but they interact, causing her medical state to be incredibly complex and fragile. Every one of her anatomical systems is affected and compromised. From her digestive system, circulatory system, and respiratory system to her renal system, lymphatic system, and neurological system, she has acute and chronic disorders. These chronic medical conditions are progressive and degenerative, and she is increasingly impaired. Marjorie has had over 40 ER visits in the last 3 years. I sought a medical placement for Marjorie at Murray Center because it is the least restrictive environment where she will be safe, remain mobile, and live a more pain free life.



Phelan McDermid syndrome affects 1 birth in 8 million. It is astonishingly rare and for Marjorie produced extremely painful symptoms. Marjorie needs daily medical attention and daily medical decisions need to be made in order to keep her out of pain and ameliorate these life-threatening chronic conditions. Marjorie's muscular dystrophy is also degenerative and requires vigilant medical oversight. With not one, but two rare degenerative diagnoses, you can imagine how fragile and complex the state of her health can be from day to day. That said, her medical decisions must be made by doctors and nurses that are assisted by well-trained and consistent staff. This is not available in a CILA placement or an ICF-DD. The fact that Marjorie is both non-verbal autistic and profoundly mentally retarded, yet still ambulatory adds another layer of challenges to the constant process of assessing the state of her health and making medical decisions about her care.

Despite all these complex diagnosis if Marjorie's medical and physical needs are met she is content with a subtle smile and a contagious laugh. She loves to be outdoors and adores walking. Although she was scheduled to walk for 30 minutes twice a day while living in a CILA placement, walking was only available when weather permitted, or when staff could take her to stroll around a store when the weather was inclement. Often Marjorie was not active and sat most of the day. A CILA cannot provide the medically appropriate rest, care, and activity that a larger facility like Murray Center Elm Cottage can provide.

When Marjorie arrived at Murray Center Elm Medical Cottage in July of 2016 she was welcomed by warm and caring staff, nurses, and doctors. She began to freely walk around the wide brightly lit hallways at will. She was immediately comfortable, happy, and content despite her autism. She slept through the night for the first time in years. She experienced the freedom to walk around whenever she wanted to for the first time in years. Since Marjorie arrived at Murray Elm Cottage and has received the proper medical attention and has the new found freedom to walk throughout the day her renal function has improved from stage 3 kidney disease to within almost normal functioning and her ability to drink liquids is present for the first time in 3 years.

The entire staff at Murray Center Elm Cottage has done a wonderful job making Elm Cottage a warm and welcoming home for Marjorie. For the first time in years I am not guessing about medical decisions and trying to keep her out of pain on a daily basis. So from hospice to happiness I am grateful for the services of a large ICF-DD, Murray Center.

# **VOR Statement on Sheltered Workshops**

*By Harris Capps and Joan Kelley*

Sheltered Workshops are private non-profit, state, or local government entities that provide employment opportunities for individuals with disabilities. Persons served in this environment may include those with developmental, physical, and/or mental impairments, ranging from mild to extreme/profoundly affected individuals. Sheltered workshops:

- Provide prevocational training, with the goal to prepare for competitive employment for available jobs in the open labor market
- Emphasize support of individual needs, based on ability to choose work activities that fit with a person's skills
- Often include additional training in personal care, living skills and developing social skills
- Honor the depth and scope of the DD population, recognizing that some individuals may not ever be able to be competitively employed

After completing a rehabilitation program, many individuals are able to leave the workshop environment and enter regular employment, if there is a job available for which they qualify. Individuals unable to obtain regular employment because of the severity of their impairments or unavailability of jobs can remain in the workshop environment. Individuals performing services are paid a fraction of, or up to minimum wage, depending on their capacity to perform the services.<sup>1</sup>

While work is the main focus at facility based programs, sheltered workshops also provide opportunities for people with disabilities to challenge themselves, further their self-esteem and self-confidence, develop friendships and engage in their communities. Because of the supports and protections in place, those with more severe/profound impairments can find success in meaningful and productive activities which may not otherwise be possible for them in mainstream businesses. Sheltered workshops often include adult day services which include personal care, living skills, developing social skills, etc.

Often, individuals with disabilities too severe for sheltered work rely on day programs for community integration and meaningful and constructive activities during the day. These facility-based programs also provide opportunities for building self-esteem, confidence, social skills and friendships so important for both mental and physical health.

## **Specialized Supports**

For those individuals with intellectual and developmental disabilities (I/DD) who enter the competitive workforce, specialized supports are often required to ensure a successful work experience. Proponents of “supported employment” contend that as long as the appropriate supports are in place, the goal of “real” employment should be achievable for everyone with a disability. While this is a laudable goal, society must recognize the pressures that exist in business that are driven by economic issues, deadlines and competition in the market. For many with I/DD, these realities interfere with their ability to maintain competitive jobs long-term and for a full eight-hour workday.

## **Eliminating Special Minimum/Commensurate Wages**

Provisions for Special Minimum Wage Certificates, under the Department of Labor, Fair Labor Standards Act (FLSA) of 1938, Section 14(c), help people with disabilities obtain jobs in a competitive workforce. Employers who receive a certificate from the U.S. Department of Labor's (DOL) Wage and Hour Division (WHD) have the ability to pay special minimum wages (below the federal minimum wage) to employees who have disabilities, if the disability affects job performance.<sup>2</sup>

This provision of the FLSA is often inaccurately referred to as offering a “Sub-Minimum Wage” in what appears to be an intentionally derogatory manner to dampen public support for the program. There have been formal attempts to eliminate Special Minimum Wage Certificates altogether. One example, H.R. 831, is a bill intended to phase out special wage certificates under the Fair Labor Standards Act.

*(Continued on next page)*

<sup>1</sup> Social Security, Program Operations Manual System, RS 02101.270 <https://secure.ssa.gov/apps10/poms.nsf/lnx/0302101270>

<sup>2</sup> Goodwill Industries, “Employment of People with Disabilities through FLSA Section 14 (c) <http://www.goodwill.org/wp-content/uploads/2013/06/Goodwill-14-Fair-Wages-Position-Paper.pdf>

Efforts to end the provision of special minimum wage certificates could adversely affect individuals with significant and profound disabilities if they are unable to produce goods at the same rate as less disabled or non-disabled workers. Liability issues, and the additional costs involved with providing necessary specialized supports in the work environment can also become disincentives to hire individuals with the most significant needs. Offering a special minimum wage incentivizes and enables employers to provide employment to individuals with disabilities who may not otherwise be given the opportunity to work.

### Why You Should Be Concerned

Many of the taxpayer-funded government agencies and non-profit organizations that disparage Intermediate Care Facilities (ICF's) as "isolating" use the same criteria to stigmatize sheltered workshops. They deliberately disregard the importance of sheltered workshops and facility-based day programs to the portion of the I/DD population who depend upon them. These organizations, often taxpayer funded entities, have legislated against sheltered workshops in the same manner in which they have attacked ICF's, despite the lack of employment opportunities for individuals with I/DD, and the fact that few employers have an incentive or the ability to hire individuals with profound disabilities. Integration into a non-disabled workplace is not the primary goal for all individuals with I/DD, and should not be given precedence over safety, productivity, or a sense of community among one's peers.

The continued, and many believe intentional, misinterpretation of the Supreme Court's *Olmstead* decision permeates numerous policies, including the **Work Innovation and Opportunities Act (WIOA)**, which severely limits work settings and rehabilitation programs for disabled persons. Such policies negatively affect individuals with the most extreme and profound disabilities by eliminating the individual's right to choose the work environment most appropriate to their unique needs.<sup>3</sup>

In its recently released 13-page Guidance document on Employment<sup>4</sup>, the **Department Of Justice (DOJ)** uses the word "segregated" or "segregation" no less than 40 times when referring to sheltered workshops. At the same time, it picks and chooses selective passages from *Olmstead*, deliberately ignoring those passages that address the needs of those individuals with disabilities who rely upon higher levels of care. In doing so, the DOJ marginalizes our most vulnerable citizens and even puts them at risk by ignoring warnings that permeate *Olmstead*'s majority and concurring opinions.

DOJ's selective interpretation of the Supreme Court *Olmstead* Decision amounts to an unwarranted attack on the portion of the I/DD population with the most complex need, in that it eliminates the settings that best support them. The DOJ refuses to acknowledge that individual choice is paramount in both residential and employment options, and thereby violates the civil and human rights of vulnerable citizens by refusing to meet the need for a wide range of programs to support that choice. People with significant disabilities deemed not qualified to work would be forced to stay at home, receive no wages, and be denied the tangible and intangible benefits of work.

### States Must Stand Up for Their Citizens with I/DD

Families seeking answers when they find their loved one's sheltered workshop or day program under attack are often told of recent CMS rule changes by state officials. State officials, however, often fail to take advantage of the opportunities CMS provides within the rule changes to allow states to maintain these programs with adjustments.

The Centers for Medicare and Medicaid Services (CMS) makes clear in their guidance that facility based settings are not prohibited and that states have flexibility in determining what those services look like. In fact, CMS guidance states, "*The rule creates a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics.*"<sup>5</sup>

CMS' publication of "HCBS FINAL REGULATIONS 42 CFR Part 441: Questions and Answers Regarding Home and Community Based Services"<sup>6</sup> provides further clarification to the new rules:

<sup>3</sup> U.S. Department of Labor Wage and Hour Division Fact Sheet #39H <https://www.dol.gov/whd/regs/compliance/whdfs39h.pdf>

<sup>4</sup> DOJ Statement on Application of Integration Mandate of Title II of the ADA and *Olmstead* to State and Local Governments' Employment Service System for Individuals with Disabilities [https://www.ada.gov/olmstead/olmstead\\_guidance\\_employment.pdf](https://www.ada.gov/olmstead/olmstead_guidance_employment.pdf)

<sup>5</sup> CMS Fact Sheet: Summary of Key Provisions of 1915(c) HCBS Waivers Final Rule <https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf>

<sup>6</sup> CMS, HCBS Final Regulations 42 CFR Part 441: Questions & Answers Regarding HCBS Settings <https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>

**Question 4, page 10:** “Does the regulation prohibit facility-based or site-based settings?”

**Answer:** No.

*“The regulation requires that all settings, including facility- or site-based settings, must demonstrate the qualities of HCB settings, ensure the individual’s experience is HCB and not institutional in nature, and does not isolate the individual from the broader community. In particular, if the setting is designed specifically for people with disabilities, and/or individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them, the setting may be isolating unless the setting facilitates people going out into the broader community.”*

*“We note, however, that states have flexibility in determining whether or when to offer HCBS in facility-based or site-based settings, as the regulation only establishes a floor for federal participation.”*

**Question 5, Page 10:** “Do the regulations prohibit individuals from receiving pre-vocational services in a facility-based setting such as a sheltered workshop?”

**Answer:** No

*“Therefore, a state could allow pre-vocational services delivered in facility-based settings that encourage interaction with the general public...”*

*“We note, however, that pre-vocational services may be furnished in a variety of locations in the community and are not limited to facility-based settings, and that states have flexibility in determining whether and when to use facility-based settings.”*

**Question 6, Page 11:** “Will CMS allow dementia-specific adult day care centers?”

*“The HCBS regulations do not prohibit disability-specific settings... the setting must meet the requirements of the regulation, such as ensuring the setting chosen by the individual is integrated in and supports full access of individuals...to the greater community...”*

**Question 7, Page 11:** “Can a day service that has both HCBS waiver participants and ICF residents provide Medicaid-covered HCBS in an ICF/IID?”

*“If the state believes that the setting meets the HCB settings requirements and does not have characteristics of an institution, the state can follow the process to provide evidence and demonstrate that the setting can or will comply with the HCB setting requirements or regulations.”*

**VOR encourages families to point this guidance out to state officials and hold them accountable for their duty to provide safe and appropriate services for the vulnerable individuals they serve.**

## **Conclusion**

**VOR** asserts that sheltered workshops and facility-based day programs **are also supported employment services**, allowing individuals with intellectual and developmental disabilities to pursue their skills and interests in the most integrated setting possible according to their individual needs and capabilities. They provide hundreds of thousands of individuals with productive employment, responsibility, necessary structure and the opportunity to achieve and to measure their own skills and to work toward improving them.

**VOR** believes in providing more, not fewer, service options to meet the wide range of intellectual and developmental disabilities. While expanding programming for individuals that can benefit from it should also be pursued, vital existing services that are clearly meeting needs should be retained.

**VOR** asserts that programs and services for people with disabilities, whether residential or employment focused, must be based on individual choice, need and capabilities in order to be successful, as stated in Olmstead

**VOR** supports supported employment services in community settings for individuals who are capable of working in this capacity and can benefit from these services.

**There is a place for both integrated and facility-based employment services, as we as a society provide for the full continuum of care for individuals with disabilities as required by the U.S. Supreme Court Olmstead decision.**



# Surviving The Inclusion Delusion: Danny at 40

*By Jill Barker, Reprinted from The DD News Blog, October 3, 2016*

My son Danny is forty years old this week. He has multiple disabilities resulting from brain damage acquired during his first few days after birth. He functions at the level of a 6 to 12 month old infant and always will. And, yes, I know he is not *really* an infant. We do not love him less because he lives and survives with profound developmental disabilities.

I'll spare you the details of his birth and the aftermath. It's enough to say that while the other mothers whose babies were being discharged from the hospital were learning how to give their babies a bath, I was receiving instructions on how to administer Cardiopulmonary Resuscitation to an infant.

I first heard the term Inclusion around 1990. Danny was 13 years old and attending High Point School in Ann Arbor. High Point was an outstanding program for Danny, bringing together services, expertise, and a supportive community to accommodate children with the most severe disabilities, including complex medical and behavioral conditions.



***Inclusion, when applied to schooling for disabled children, is the belief that all children, regardless of the severity or nature of their disabilities, can and should be educated in regular classrooms with their non-disabled peers.*** Inclusion was promoted by many disability advocates as a “right” for every child. Most discussions of the idea did not include an examination of whether the premise on which the belief is based is true for every child or whether it is required by the federal Individuals with Disabilities Education Act (it is not). In the face of any disagreement with the idea, promoters of inclusion encouraged families to take sides: “Are you for ‘Inclusion’ or against it?” Or as many advocates would have it, “Do you want disabled children isolated and segregated from the rest of society or do you want them to be fully integrated into and embraced by ‘the community’”? This continues to this day.

The Inclusion Delusion began with a false and unprovable assertion based on wishful thinking and a willful misinterpretation of federal law. In 1990, there were many disabled children who were unjustly and illegally prevented from participating in classrooms with their non-disabled peers and there still are. Many of their parents understandably leapt at the idea that by proclaiming a faith in Inclusion, their children’s needs might finally be recognized and fulfilled.

***But the uncritical acceptance of the Inclusion Delusion disregarded a number of moral and ethical questions:*** Is it right to make judgments about “all children with disabilities” without considering their individuality and acknowledging the full range of their diverse needs? Do advocacy organizations or government agencies have a right to impose on children and their parents an all-encompassing doctrine when the parents and others who know the child best have good reason to disagree? Is Inclusion the ultimate goal of educating children with disabilities or are the needs of the individual child paramount in determining educational services and placement? Is Inclusion a cause that must be served, whether or not it is appropriate for a specific child?

In the early 1990’s, the indoctrination for inclusion in schools was intense, an obvious sign that the project was well-funded and a great opportunity for organizations and local agencies to tap into a new funding stream. I attended a meeting sponsored by our local ARC (formerly the Association for Retarded Citizens) featuring a speaker from another state. She gave a rousing speech citing success stories of even the most profoundly disabled children blossoming in the presence of their non-disabled peers. Non-disabled children, she said, were learning acceptance, tolerance, and the value of people with disabilities to society and their fellow citizens.

***As I listened, I pondered how Danny would be accommodated in a regular middle school classroom?*** How would they deal with his bouts of vomiting after meals, the necessity for frequent diaper changes, and his need for floor space for his favorite activity - rolling over? Would other students and staff tolerate his occasional blood-curdling screams when things weren't going well for him? Was it wise to remove him from an environment



that had every accommodation that he needed and place him where virtually nothing was geared toward his needs? Could anything prevent him from becoming the chief source of disruption for almost every activity that normally occurs in a typical classroom?

I started to pay more attention to the speaker when she offered up some good advice:

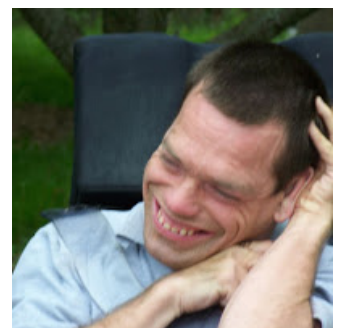
**“Give people with disabilities what they need and want! If you want to *know* what they need and want, ASK THEM! “**

Now, that made sense to me and I became more optimistic that I would get something out of the evening beyond a welcome break from caregiving. My optimism was soon crushed, however. The speaker followed her initial advice with a list, *her* list, of all the things people with disabilities are supposed to need and want. She did not ask if the audience agreed with her. “They all want to be treated like everybody else,” she said, apparently oblivious to the fact that Danny would die if he were “treated like everybody else”. She went on: “...they want to live independently and make their own decisions; they want to go to regular schools and work at regular jobs; they want to be included in their communities in every aspect of life,” and so on. Some of the items on her list made sense to me, but most did not considering the complexity of Danny’s severe disabilities.

On another occasion, I saw a film of children's responses to having disabled students in their classrooms. One boy said he had learned that, “Disabled people can do everything that everyone else can do. They just have to try harder.” I can understand a child coming to such a simplistic view of disability, but for the adults to include it in a film promoting Inclusion raises questions about their judgment. Poor Danny, I thought. With that kind of “learning”, what would ignorance look like?

Danny continued at High Point school for another 13 years. As the Inclusion movement took hold, many children were moved out to local schools, some with the approval and support of their parents and some without. There were threats that the school would close and it almost did. Finally, a charter school and other programs sponsored by the County school district moved in to the empty classrooms and eventually filled the space left by special ed students who had moved out. The integration of High Point and the charter school proceeded at a relaxed pace and was not forced where it was not appropriate for the students involved. At the same time the integrity and the usefulness of the High Point program continued to function to the benefit of the most severely disabled children in Washtenaw County.

***Was this an example of the success of Inclusive education?*** I don’t believe so and it certainly did not meet the criteria set by advocacy organizations that demanded that disabled children be seen to hobnob with their non-disabled peers to prove to the world they were just like everybody else. The purpose of High Point was never to isolate and segregate its students from the broader community, but to give them an environment and specialized care that was not likely to be achieved anywhere else.



The Inclusion Movement in education was an ideological undertaking, more enshrined in the imagination of zealots than in the laws and policies governing the education of actual children with disabilities. The 1975 Education for All Handicapped Children Act was in full swing by the late 1970’s and early 1980’s, with the majority of children in special education, those with learning disabilities and speech and language problems, attending their neighborhood schools and spending most of their time with children who were not disabled. It was true that schools still ignored the needs of children who caused them inconvenience or were difficult to accommodate or educate, but parents were getting the idea that with a lot of hard work and belief in themselves and what they knew about their children, it was possible to make headway with the new protections and rights afforded their children.

***The Inclusion Delusion, that all children could be accommodated in regular classrooms, signaled a dramatic shift in thinking.*** Rather than determining the education that each child received based on his or her unique needs, it made the assumption that every child could succeed in placement in regular classrooms. If that

*(Continued on page 10)*

*(Danny at 40, continued from page 9)*

did not work, the parents, the schools, and the professionals must have done something wrong. Or, as one parent said in another short documentary promoting Inclusion, “Even if it doesn’t work, you should do it anyway. It’s the right thing to do”.

For years, the proponents of Inclusion in schools have pitted parents against parents, demonized teachers and staff who work with children in specialized classrooms and special schools and set the stage for years to come for disability movements based on over broad generalizations about people with disabilities.

In the mad dash to close institutions and many other specialized programs for people with disabilities, the people directly affected by these closures were rarely asked their opinion early enough in the process to make a difference. Instead, advocacy groups, especially those that receive federal funding to promote their causes,

*claimed to represent people with disabilities and swooped in with all the answers: No one would choose to live in an institution or group home, work at a sheltered workshop, attend a day program with other people with disabilities, or live anywhere but in their own home or at home with their family. All people with disabilities can and should live independently, make all their own decisions, and work in integrated, competitive work settings.*

The truth is that there are people with disabilities who can do only some of these things, some who can do none of them, and some who choose to do things differently than other people with similar disabilities. They have been marginalized. The closure of programs and services that meet their needs has been justified with the promise that closing

programs that no one wants, according to the advocates, will pay for more services to more people, “in the community”. This is unlikely to ever be realized as states see “savings” as opportunities to fund more popular government- supported programs (such as fixing potholes), to reduce taxes, and to continue to ignore many of the needs of people with disabilities. Attempts to develop innovative family-initiated projects to serve and house people with disabilities that may actually save money in the long run are also being thwarted by advocates who fear any incursions into the territory they have claimed for themselves as the representatives of all people with disabilities.

Thanks to Danny (and Ian who came along eight years later), my blog has been an attempt to set the record straight, give a voice to people who are rarely heard, and attempt to restore some balance in the stories that are told about people with disabilities. This is an unbelievably frustrating time for families who see their judgment questioned at every turn as they attempt to salvage necessary services for their loved ones and hope for a truly inclusive future that acknowledges differences in abilities and needs and honors the choices that families and their loved-ones must make.

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*Jill is a member of VOR, a national non-profit organization that advocates for a full range of services and settings to meet the diverse needs of people with intellectual and developmental disabilities. Standing up for choice and access to community and facility-based homes, VOR is dedicated to maintaining individual and family choice, offering advocacy support for access to community, legal, medical and educational resources for individuals with special needs and their families.*



## Of Great Service

*By Carole Sherman, in response to Arkansas Democrat-Gazette, October 24, 2016*

On Sunday, Sept. 4, I made the familiar trip to Arkadelphia to visit our son John, a longtime resident of the state-operated human development center (HDC) located there. These events unfolded:

The middle-aged man with the mind of a young toddler impatiently watches me cut up his evening meal in bite-size pieces. In less than 7 minutes, he finishes off a beef filet, spaghetti with sauce, spinach salad with tomatoes, and a perfect Arkansas peach, the size of a large softball. I am careful not to turn my back or to leave the peach pit where he can see it: he would eat that too. "Slow down," I say, "Chew ... chew." "Take little bites," demonstrating chewing as I have done all his long life.



After the meal, we are of two minds: I am turning away, thinking the meal is over and ready to move on to the next in-room activities (flossing and brushing his teeth, then nail trimming) but our son wants to leave the B&B guestroom and return to the inn's galley kitchen. John is non-verbal; he simply gets up and heads toward the door. I am arm's-length away: "No, John," I say, and I instinctively try to pull him back in the room. Startled, he bellows.

Our son avoids being touched. I know this but I also know that hotel guests are just outside our door visiting in a common sitting area. My 47-year-old son bellows. In a blur, he brushes me aside and he is out of the room, across the hall and then he turns back to me: I see his left arm go up to his ear and then to his mouth in a familiar gesture of the beginning of self-abusive behavior. This time he does not spiral into ripping his skin with his teeth. He bellows.

John moves across the sitting area, which presently has four - perhaps more - hotel guests who sit, now frozen. My eyes are on John. "Sorry, guys," I say to these strangers, without looking at them but pulling them into the scenario. John goes to the narrow kitchen galley, which is stocked with snacks. He looks back to me. I stand outside, speaking to him, not crossing the common room.

"Choose one," I say, hoping against hope his body will tell him that he is not hungry, that really he doesn't need more food. I am also hoping that he will not escalate into more and louder bellows. Miraculously, he picks up a package of peanut-butter crackers and I say, "Come," and he comes, and we walk through the close space of hotel guests to our room. "Sorry," I say, as my tall son and I brush by. An older woman—perhaps my age—says, "No ... no problem."

### **My heart is pounding.**

After I take John to his home at the HDC, I walk the quiet streets of Arkadelphia. I think about the visit and how I might have avoided the incident at the B&B. I hope the guests will not complain to the innkeeper who has been our understanding hostess for many years. I say prayers for John, for the staff members who have worked a weekend shift, and for the other 16 guys in his home.

In the morning, I call Lake DeGray State Park Lodge restaurant to make arrangements for my son to come for lunch. "This is John Sherman's mother, have you helped me before?" I ask. She has not and I quickly describe what I will need: John's food on the table when we arrive; damp paper towels and the bill. Our son does not understand "to wait." Over time, both the lodge staff and I have grown comfortable with the routine of his lunch there: The wait staff assures that his order is ready and on the table, the bill is there, which I quickly pay. We have had successful visits here: Our son's behaviors have not spiraled out of control/there have been no meltdowns in the beautiful restaurant. Our luncheon visits at Lake DeGray Lodge last perhaps 10 minutes.

Back at the HDC, I say my thanks to the direct care staff who have worked a difficult job on the holiday. I am grateful.

It is late Monday afternoon, Sept. 5; I am on the road back to Little Rock. I stop to call a friend, another HDC mother, who describes the Democrat-Gazette Perspective article printed the day before. The article about Arkansas' human services has not described the realities of our family members who require eyes-on close care, those who have slight or no awareness of danger, individuals with lifelong profound cognitive deficits. The writer's message is that our state's facilities for people who cannot care for themselves cannot be justified.

My thoughts wheel back to the events of the last 24 hours, to our son and his housemates, and to the people I saw working on a holiday to keep grown men unable to care for themselves healthy, safe and clean; to the nurses on weekend duty who measured and dispensed each person's medications; and to the welcoming grounds where our at-risk family members with disabilities can move freely and with safety, and where routine medical, dental, training and other support services are located on-site.

### **My heart is pounding.**



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