

*(Continued from previous page)*

In order for Angie to attend the workshop program each day, she would have to move into a group home. The transition was hard on the entire family. She was involved in a group home van accident in which she was seriously injured and required a metal plate in her face and plastic surgery. Angie's behaviors worsened when our mom was hospitalized and the group home could not take her to the hospital to see her mom. She had a melt down and was taken to the psychiatric ward at a St Louis hospital.

After her release, we were told that she couldn't go back to her community home. They told us they could not accommodate her behaviors and medical needs. She had recently been diagnosed with endometrial cancer. She was turned down at multiple community homes due to her behaviors and challenging health.

Angie's second community home proved to be even worse. They never followed up on her cancer diagnosis and upon our visit, she had bruises and burns. We took her to the hospital and again, received a letter from the community placement that they were no longer able to care for her after her discharge from the hospital.

Stuck in an emergency situation, we contacted Murray Center, she was evaluated, accepted and Murray became her home with her own room. Angie's care is a challenge but Murray saw to it that she was nursed back to health after cancer surgery and treatment. Over her 18 years at Murray they have handled her health, medications, development, training and provided her a life my Mom and Dad just couldn't give her on their own. Angie enjoys, clothes, purses, jewelry, visits from her mom and family, shopping, going out to eat and all the various events Murray staff organize.



***Angie at Murray on Easter***



***Our family will always be grateful to Murray Developmental Center for the love and care they have given Donna and Angie.***

## **Guardianship vs. Supported Decision Making**



The VOR Issues Oversight Committee recently responded to a report by the National Council on Disability (NCD) entitled “Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities”. Our complete response can be found at [www.vor.net](http://www.vor.net). The NCD report is available online at [https://ncd.gov/sites/default/files/NCD\\_Guardianship\\_Report\\_Accessible.pdf](https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf)

**An abbreviated version of the VOR comments on the seven NCD report findings are as follows:**

**Finding 1:** *“There is a lack of data on existing guardianships and newly filed guardianships.”*

**VOR agrees** with this finding and the recommendation to “develop initiatives to produce effective and comprehensive data on guardianship”.

**Finding 2:** *“People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions...”* **VOR disagrees** with the above statement. It may be true that some people are incorrectly assumed to be unable to make autonomous decisions. Others, especially those with profound and severe intellectual disabilities and other complex medical and behavioral conditions are indeed incapable of making decisions for themselves in some or all aspects of their lives. When necessary, they should be afforded the due process protections of guardianship to ensure that their interests and rights are protected.

**Finding 3:** *“People with disabilities are often denied due process in guardianship proceedings.”*

**VOR believes** that the vast majority of Probate Courts and state guardianship laws assure due process when properly enforced.

**Finding 4:** *“Capacity determinations often lack a sufficient scientific or evidentiary basis.”*

**VOR believes** that this finding is a broad generalization and is not accurate. Requests for guardianship usually include statements from qualified physicians along with other information on the functioning abilities of the individual and recommendations on the need for guardianship.

**Finding 5:** *“Guardianship is considered protective, but courts often fail to protect individuals.”*

**VOR believes** this statement is overly broad and subjective. Most states require reports from guardians on the condition of the person under guardianship, and many require additional oversight of guardianship cases.

**Finding 6:** *“Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often do little to enforce this requirement.”*

**VOR believes** that for people who can make decisions for themselves, less restrictive alternatives to guardianship should be available, based on the needs and desires of the individual. The recommendation to “use SDM (supported decision making) and the court systems to restore people’s rights”, even for people with severe intellectual disabilities, is questionable. Restoration of rights must consider the capacity of the individual to make decisions in some or all aspects of the person’s life.

**Finding 7:** *“Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.”*

**VOR believes** that this finding may or may not be true, given that, “Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship...”. There must be recognition that ending guardianship for some people may be fraught with unintended and harmful consequences.

***We hope to have an ongoing conversation with NCD about the needs of our severely disabled family members.***



## Danny's Story

By Terry Johnson (Danny's Dad)

How can anyone write a few words and accurately reflect a lifetime of attention to the care and wellbeing of their child with a disability? Harder still, if you are blessed and fortunate enough to never have had to deal with this challenge, how can you possibly understand and absorb what it means?

In spite of all the challenges and tough decisions that have been made along the way, I wouldn't trade my life with my son Danny for anything else in the world. Most parents probably feel the same way. Sure, the bad times were pretty brutal, but the good times... oh man.... provide us with the best feelings this planet can dish up.

I would say some of the toughest times were when Danny finally was "on his own", meaning beyond the legal age of his K-12 years in public school. Once a disabled person reaches this age, they seem to be standing on the edge of an abyss with no clear path forward. And the pressure falls onto us parents, who now have to make life altering choices for another adult person! No stress there!

It was my experience to give just about everything a try. Over about 10 years, Danny belonged to FOUR different "Community based" Medicaid Waiver programs, and we even built and ran our own Group House. Although these programs work well for some, they were nightmares for Danny and our family.

By definition, these programs assign a single care-giver to a single client, usually going through 3 shifts of care-givers every 24-hour period. This creates a one-on-one situation that produces extreme tension and responsibility for care-givers that by financial default, are not trained professionals. Most are retirees or College kids making some extra money. Again, fine for some, but a formula for disaster for many, like my son, who are complicated and demanding to say the very least. The administration of tightly controlled medicines...the proper and safe handling of extreme behavioral episodes.... not to mention the day to day personal hygiene requirements of an adult, are just too much to lay on a single care-giver, regardless of training.

**The answer?** For us it was finally finding the Jonesboro Human Development Center. There are about 100 Medicaid Waiver programs in Arkansas, but only FIVE HDC's. An HDC provides a real Community atmosphere, right there on campus. Sure, Danny takes trips all over town for special activities, dances, haircuts, McDonalds and what have you...but the HDC serves as his "College", complete with a wealth of friends, classroom learning, baseball teams and workshops. And instead of just one care-giver per client, at any time, there are at least 3-4 staff within verbal distance of Danny. He loves the structure and daily routines and faces. He has genuinely thrived in this environment. He loves his "College".



What is the future looking like? Well, none of us are sure. There are several misguided organizations who are constantly trying to defund our HDC's and redirect those funds to their "alternative" care models such as the Community based Waiver Programs. And of course, our own Federal Government has several groups preaching "least restrictive environment" laws that have little to no knowledge of the damage they would cause if they actually won what they believe they are fighting for.

I hope...and pray...that all those in authority within our society's leadership will understand and take the time to fully appreciate the human value that our HDC's provide to those of us who depend on them.

Respectfully,  
Terry Johnson (Danny's Dad)



[terry.johnson@clearpointe.com](mailto:terry.johnson@clearpointe.com)

### **Our Voice Speaks For YOU!**

*For 35 years, VOR has been the only national grassroots organization advocating for a full range of residential and employment opportunities for our loved ones with Intellectual and Developmental Disabilities.*

***Please Donate Today to Help Us Continue Our Mission!***

Members of the Parents-Relatives Organization for Oakwood Facilities (PROOF) are asking to open admissions for long term care as well as short term care, keep their loved ones there and to continue providing top-quality service to the intellectually and developmentally disabled individuals of Kentucky and their families.

Like every state, Kentucky has its own laws and bureaucratic hurdles to face when advocating for the rights of our family members with ID/DD. In addition to MAP 350 and the Michelle P. waiver, we have Chapter 202B under Kentucky's Revised Statutes. 202B governs involuntary short-term admissions into ICFs/IID and discharges of voluntary and involuntary short term residents. It also governs the discharge of long-term residents, who must be evaluated periodically in "202B Hearings", part of the ongoing effort to remove people from their long-term ICF/IID homes and to place them into HCBS waiver settings. Only short term care admissions are open. Those admitted for short term care can extend their time as long as the transition team feels they need to be there. A doctor and court can admit an individual if they meet the guidelines that are in place.



Five members of PROOF met in October with Kentucky State Senators Rick Girdler and Jimmy Higdon, and with Wendy Morris, the Commissioner of Department of Behavioral Health/ Developmental and Intellectual Disabilities, Kara Daniel, the Director of Division of Program Integrity, and Brandon Smith, the Executive Director Office of Legislative and Regulatory Affairs, to discuss ways to alleviate the burden of 202B hearings. The meeting was held in Senator Girdler's office. Senator Girdler had previously attended a PROOF meeting in September at Oakwood and toured the campus with my sister, Karen House, where he met families and saw first-hand the care our families receive at Oakwood and the range of disabilities that are at Oakwood. Senator Higdon has been to Oakwood several times and has supported the families and Oakwood in the past.

PROOF members attending to represent individuals and families of developmental & intellectual disabilities were Nora Putnam, Charlotte and Gayle Rees, Lillian Bassett and Cheri Ellis-Reeves.

Several of the residents remaining in Oakwood's long-term care have lived there 35-40 plus years, some since it was opened in 1972, it is the only home they know. Most have existing health issues, are nonverbal, unable to dress, feed themselves, need bathing and toileting assistance, hand over hand with 100% guidance and have no sense of danger to themselves or others. Moving these vulnerable individuals from their homes, away from staff who have become part of their family, and who know their needs by their actions, could have a cruel and heartbreaking result.

Our goal was to see if there were additional steps or guidelines that could be implemented to keep our families from starting transitions out of Intermediate Care Facilities. I asked why families' choice was not being respected when Olmstead, the Empower Act, the Michelle P. Waiver and MAP 350 all state that the individuals/guardians have the right to choose Intermediate Care Facilities. Nora Putnam asked Wendy Morris how open the Cabinet might be to relaxing the criteria for long term care in going before the judge for 202B hearings? Could the state not allow five years maximum so families won't have the physical and emotional toll and financial cost? Ms. Morris responded that some residents are put into Intermediate Care Facilities that may no longer need the services and could benefit the person that could benefit into Supported Community Living homes and that families may say that they need an Intermediate Care Facility put transition team feels that the family may not have the residents best interest. Cheri said that she found that statement offensive, and that the families that are going to court want the best for their child or siblings. They are not just dropped off or an inconvenience. Cheri said that going to court, hiring a lawyer to represent your family and hire an independent psychologist cost her family around \$12,000.00.

Little was resolved at the meeting, but the families of Oakwood thanked everyone again and asked that Senator Girdler and Senator Higdon to reach out to us if any help is needed and to continue to work on helping the families who choose Intermediate Care Facilities. They are as vital to the community as well and we need them to be our voices.

It is a constant struggle to stand up for the rights that we are supposed to have under law.

### **PREPARE TO MEET THE 116<sup>TH</sup> CONGRESS**

It's a New Year, and a new Congress will be sworn in on January 3, 2019. There will be some old faces  
Committee Chairs will change in the House as the Democrats now hold the majority.

We urge our members to contact your senators, representatives, and the elected officials in your statehouse.  
They need to know who we are and what we stand for.



## **SAVE THE DATE!**



### **VOR 2019 Annual Conference and Washington Initiative June 7 - 12, 2019**

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

#### **START PLANNING NOW!**

- **Speak with your Family and Friends Association about support for your trip, and encourage other members to attend**
- **Start a “GoFundMe” campaign to help cover your stay**
- **Take pictures and videos of your loved ones to bring to Congressional Offices**

**MORE INFORMATION WILL BE COMING SOON!**

#### **THE POWER OF IMAGERY**

We are not self-advocates. Very few of our families are capable of bringing their loved ones to D.C. or to their statehouse. That puts us at a disadvantage, because our legislators have seen many people with I/DD who are not as severely disabled or behaviorally challenged as our family members.

Many of our members bring photographs of their loved ones to their meetings with legislators and aides. This has proven to be an effective way of personalizing the need for choice and for supporting a full continuum of care.

Last year, I went with Karen House and Cheri Ellis-Reeves to the office of one of their legislative aides. They pulled out a cell phone and handed it to the aide, playing him a 10-second video of their sister Patti. I was amazed by how effective this action was! By handing over your smart phone, you are literally handing a stranger a very personal and powerful piece of your modern identity. You are saying, “I trust you.” The person who watches the video and hands back your phone now relates to you in an entirely different manner. There is a more personal connection now than existed before, both from the video and from the trust they feel from having been handed your phone.



836 S. Arlington Heights Rd., #351  
Elk Grove Village, IL 60007  
877-399-4867 toll free  
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**A national, non-profit 501(c)(3) volunteer organization  
speaking out for people with intellectual and developmental disabilities**



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## **Membership / Contribution Form**

VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007 Fax:  
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☐ **MY CONTACT INFORMATION HAS CHANGED**

☐ **\$45 per year per individual;**

☐ **\$200 per year per family organization**

☐ **\$250 per year per provider / professional org.**

☐ **I would like to make monthly donations to VOR. Please charge my credit card each month for: \$ \_\_\_\_\_**

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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](mailto:hdwyer@vor.net).

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