VOR the Voice
news and Views of VOR Supporters

Summer, 2017

President's Message *By Caroline Lahrmann*

As we enjoy the dog days of summer, we want to thank everyone who attended the VOR Conference and Washington Initiative in June. It was fantastic seeing longstanding members, meeting new members, sharing news from our states, and advocating for our loved ones with legislators. In this issue of the Voice, we share with you two of the materials we presented at the conference:

- "A picture is worth a thousand words" was the inspiration for our chart which depicts the out of control growth of the Home and Community Based Services waiting list vs. the decline in the number of individuals served through ICFs nationwide. De-institutionalization advocates believe that if they could just close all ICFs, the wait list will clear. Our graph shows that's not the case. In fact, the opposite is true because significant resources are spent moving happily placed ICF residents to small waiver settings. Meanwhile, the needs of the people on wait lists go unmet. (See page 2)
- Our Right to an ICF document provides the regulatory and legal support for the ICF choice. Knowledge is power and we hope this document will be helpful to VOR members in pushing back in their home states on efforts to remove the ICF choice from their loved ones. (See Page 3)

Speaking of pushing back, VOR members in Pennsylvania and Ohio have been working hard this summer. Pennsylvania advocates are fighting House Bill 1650, which seeks to close all state developmental centers. VOR was instrumental in Pennsylvania a few years back as we helped families in their successful fight against a Protection & Advocacy lawsuit. Now, VOR is working to support families in their efforts against HB 1650. If you are a PA resident and want to help, please contact info@VOR.net!

Ohio families are fighting a Protection & Advocacy class action that threatens ICFs, sheltered workshops, and day programs. Families made significant progress this month. A ***Motion to Intervene*** in the suit filed by guardians was granted by the federal court. Families whose loved ones need and choose higher levels of care are now party to the suit and will play a role in ensuring its fair resolution. VOR was instrumental in filing an Amicus Brief in support of guardian efforts. Ohio families who want to help, please contact us!

We hope this issue of the Voice is helpful to you in your advocacy. Your continued support of VOR is deeply appreciated. Questions, comments, and your input is always welcome. Please do not hesitate to contact us!

Enjoy the rest of summer!

Caroline Lahrmann

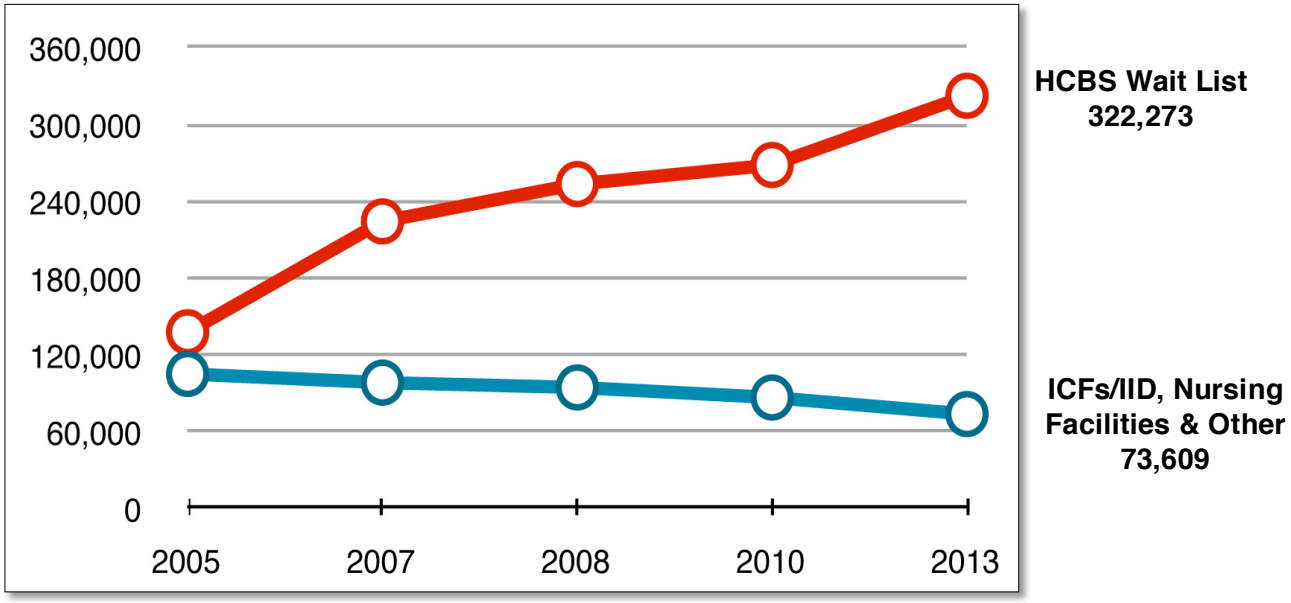
President, VOR Board of Directors

Adverse Effect of Deinstitutionalization Policy on Home & Community Based Services Wait List

HHS' Administration on Community Living (ACL) and the Department of Justice (DOJ) have pursued a policy of deinstitutionalization, driving individuals with severe and profound I/DD and complex medical and behavioral needs from large Medicaid-certified residential facilities, such as Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs/IID), into small group homes.

Instead of decreasing wait lists, this policy has contributed to nearly doubling their total size nationwide, stranding over 320,000 people because (1) too many resources are spent transferring happily-placed ICF/IID residents to community settings, rather than addressing the unmet needs of those on wait lists; (2) proper care for residents with complex needs who are transferred from ICF/IID homes is more costly in small community settings, crowding out those on wait lists from services.

Total Persons in ICFs/IID, Nursing Facilities & Other Homes of 16+ Beds vs. Total Persons on Home & Community Based Services (HCBS) State Wait Lists



Sources: United Cerebral Palsy Case for Inclusion and Coleman Institute and Dept. of Psychiatry, University of Colorado

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Special Color Edition of the Summer, 2017 VOR VOICE

The Right To Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF's/IID)

Individuals who qualify for Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)[1] under Medicaid have a legal right to such facilities for as long as they remain eligible and choose to do so. Despite a deinstitutionalization effort by those opposed to congregate care, the ICF/IID program remains a legally enforceable federal entitlement under Medicaid.

Right to ICF/IID services is legally enforceable:

Participation by states in the Medicaid program is voluntary; however, once a state elects to provide services, the state's provision of those services is "mandatory upon them." 42 U.S.C. § 1396a(a)(1).

http://uscode.house.gov/view.xhtml?req=granuleid:USC-prelim-title42-section1396a&num=0&edition=prelim

If a state elects in its Medicaid State Plan to offer qualified individuals services in an ICF/IID, it must provide that "all individuals wishing to make application under the plan shall have the opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals." 42 U.S.C. § 1396a(a)(8).

http://uscode.house.gov/view.xhtml?req=granuleid:USC-prelim-title42-section1396a&num=0&edition=prelim

The right to ICF/IID services has been tested in Federal District and Appellate Courts in Florida. In Doe v. Chiles, 136 F.3d 709 (1998) the State of Florida argued that ICF/IID services are an optional Medicaid program. The Eleventh Circuit rejected the argument, noting that "even when a state elects to provide an optional service, that service becomes part of the state Medicaid plan and is subject to the requirements of federal law." Id at 721. The 11th Circuit found, "*In sum, we hold that the appellees have a federal right to reasonably prompt provision of assistance under section 1396a(a)(8) of the Medicaid Act, and that this right is enforceable under section 1983.*"

http://caselaw.findlaw.com/us-11th-circuit/1306318.html

ICF/IID as an enforceable right under 42 U.S.C. § 1983 was also acknowledged (although not actually ruled upon) in the Federal District Court and Seventh Circuit decisions in Bertrand v. Maram, (2006, 2007).

http://www.abisoft.org/opinions/2006/1_05-cv-00544_20060925.pdf

http://caselaw.findlaw.com/us-7th-circuit/1478192.html

The Home and Community Based Waiver is optional, not mandatory, and cannot be imposed on an individual who qualifies for and chooses an ICF/IID. In fact, the HCBS waiver will not be granted and may be revoked unless the state offers ICF/IID services to those who qualify.

The Medicaid Act provides that the Home and Community Based Service waiver "shall not be granted" to states unless the state provides satisfactory assurances that "such individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital, nursing facility services or services in an intermediate care facility for the mentally retarded." 42 U.S.C. § 1396n(c)(2)(C).

http://uscode.house.gov/view.xhtml?req=granuleid:USC-prelim-title42-section1396n&num=0&edition=prelim

CMS Regulations implementing this law stipulate that "CMS will not grant a waiver...and may terminate a waiver already granted" unless a state provides certain "satisfactory assurances" including assurances that "the recipient or his or her legal representative will be 1) Informed of any feasible alternatives available under the waiver, and 2) Given the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d).

http://162.140.57.127/cgi-bin/text-idx?SID=42049c80e5fc366349391435bb959f15&mc=true&node=pt42.4.441&rgn=div5 - se42.4.441_1302

The right to ICF/IID services as a valid service offering was affirmed – NOT struck down – by the Supreme Court decision in Olmstead v. L.C.

"*We emphasize that* nothing in the ADA...condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Olmstead v L.C. 527 U.S. 581, 601-02 (1999)

https://www.law.cornell.edu/supct/search/display.html?terms=98-536&url=/supct/html/98-536.ZO.html

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[1] Note: ICF/IID is now used in federal regulations. Federal statute still uses the original term – Intermediate Care Facility for Mentally Retarded (ICF/MR).

VOR's Quality of Care Committee: Pursuing Solutions to Inadequate Dental Care In Community Settings

By Jill Barker and Brad Whitehead

Finding adequate dental care in community settings for people with severe and profound intellectual and developmental disabilities (IDD) is a daunting problem. For residents of Intermediate Care Facilities for individuals with intellectual disabilities (ICF/IID), dental care is part of the comprehensive set of services routinely available and is usually provided by people with training and experience in working with the IDD population. People in community settings who have been moved out of ICFs or who have never received an ICF level of care have a much more difficult time accessing adequate services. While many community providers do have access to quality dental care professionals who are trained in working with people with people with IDD and behavioral problems, there are many other providers who do not have such professionals available in their community. This problem appears to be pervasive throughout the country.

The VOR Quality of Care Committee is looking into the lack of access to quality dental care, especially for people with IDD who have complex medical issues or severe behavioral impairments. There have been some successes in treating this population using VOR's Community Resource Model that expands services provided at existing ICFs/IID to the greater community. This is part of the solution to maintaining these facilities for the people who need them and assuring that similar services are available to the community at large. Beyond that, specialty clinics that treat Medicaid patients and regional service agencies that are set up to provide a range of services to people with IDD should be encouraged to include medical and dental services for people with severe and profound IDD.

One example of the Community Resource Model was featured in a New York Times article "An Oasis of Care for People with Intellectual Disabilities" by Dan Barry, 12/30/2014. The Lee Specialty Clinic in Louisville, Kentucky, originally opened as a dental clinic associated with the Hazelwood ICF in Louisville. Its founders included Louise Underwood, a passionate advocate for people with the most severe disabilities and a long-time VOR member who passed away in 2008. Others involved in this effort included a state legislator, Jimmy Lee, and two dentists specializing in care for this unique population, Dr. Henry Hood and Dr. Matt Holder. The New York Times article includes a compelling video about the clinic that shows how it has affected people from all over the state who rely on it to provide services generally unavailable to this special population. https://www.nytimes.com/2014/12/31/us/in-louisville-an-oasis-of-care-for-the-disabled.html?_r=0

Doctors Matt Holder and Henry Hood of the Lee Specialty Clinic

Another obstacle to obtaining quality dental care in the community has been the lack of dentists trained and willing to work with the IDD population. Special Care Dentistry at Tufts University School of Dental Medicine has provided dental care to thousands of patients with severe disabilities in clinics in the Boston area as well as training to dentists. The George Mavridis Foundation, which has been supported and promoted by VOR member George Mavridis' Foundation, provides funding for the program's work for patients with special needs. ["Dental program for developmentally disabled patients marks 40 years" by Gerry Tuoti, 12/2/16

http://www.tauntongazette.com/news/20161202/dental-program-for-developmentally-disabled-patients-marks-40-years

In June, speaking to the Administration for Community Living (ACL), VOR pointed out the lack of IDD-appropriate professionals in the community, and presented the idea of their using their considerable resources and influence to create programs that could help to increase the number of dentists available to the IDD community. We encouraged them to provide funding for Dental Schools across the country to train dentists to work with the IDD population, and to offer tuition reimbursements to those students who participate. The result would be a win-win-win, where the dental schools profit from creating the program and facilities, the dental students profit from extra training and reduction in their student loans, and the IDD community benefits from an increased number of professionals trained to meet their unique needs and challenges.

The Quality of Care Committee has accumulated resources and information on dental care on the VOR Website. http://www.vor.net/get-help/medical-help/item/find-a-doctor-or-dentist?category_id=23 The committee has some data on the costs and benefits of providing dental care to people with IDD and the consequences to individuals and their families when the specialized care is not available or accessible to them, but we need more. Our goal is to promote solutions to these problems for people who are especially hard to serve and appreciate any help or information that our members have to share.

Gratitude to the Voice in Congress

By Mary L. Reese, Member of the VOR Board of Directors

Donna Edwards

The Washington Post newspaper July 9, 2017, Sunday Opinion, lead article was an open letter from Donna Edwards to her colleagues in Congress. "I have a preexisting condition" details Ms. Edwards diagnosis of multiple sclerosis in June 2015 while she was a member of Congress representing Maryland's 4th District. She writes ***" Last year, I found out I have multiple sclerosis. I didn't know anything about MS but I knew I was fortunate to have a great health care coverage. A year later, I am no longer in Congress, and my future health care is uncertain."***

Our family has been deeply affected by Congresswoman Edwards' work to bring justice to all, regardless of station in life or medical status. We are assured that Ms. Edwards, wherever she may shine, will be about her life work to bringing justice to our citizens. Representative Edwards' staff, led by her constituent advocate Katrina Owens, were relentless in championing my ward, Virginia "Ginger" Massa's struggle to gain residential admission into a Maryland (MD) Intermediate Care Facility for Intellectual/Developmental Disabled (ICF/IDD), the Holly Center, Salisbury.

In far too many states, when a person with disabilities, their families or guardians choose to seek ICF/IDD care, they "lock horns" with government and bureaucrats with a philosophy of a "no admission policy" which denies admissions to ICF's in their states. Therefore, powerful Friends and Advocates of individual choice and the full continuum of care are not only warmly welcome by families, they are essential to our efforts.

This was the situation Ginger's Dad and I, her legal guardians, found ourselves in 2003 in our attempt to obtain her care in a federally regulated ICF which was so necessary to life sustaining care, medical needs and quality of life.

After Mr. Massa's death at age 92 in 2005, as Ginger's sole guardian, the effort to seek ICF care for Ginger reached a critical point as her daily life declined while she resided in a community agency house and her medical needs increased. One a sunny Saturday I visited Ginger and found her still in her nightgown at 2 pm on a lovely October day. I wrote an appeal letter to Governor Robert Erlich requesting his intervention to our request for ICF care on Maryland's Eastern Shore.

In an effort to inform other powerful decision makers of Ginger's plight, copies of this letter to the Governor were sent to the MD's Secretary of Health and Mental Hygiene and Director of the Developmental Disabilities Administration, also to; chairs of key committees of the Maryland General Assembly and to our members of Congress. At that time, Ginger's community house was in Representative Edwards' district. My cell phone ran early one morning in February 2012. A staffer from Representative Edwards' office was calling after having read my letter to the Governor. After a conversation with the staffer, now known as Katrina Owens, more information was provided about Ginger and why her admission to Holly Center was important to her health and quality of life. Ms. Owens said the Congresswoman's office would make some phone calls to Maryland officials and get back to me.

What followed were a series of consistent contacts and inquiries by Rep Edwards staff with the office of MD's Governor, the state's DHMH Secretary's office, and the office of the DDA Director. One is never privy to such discussions or the content of the conversations, however, the momentum of our appeal for ICF admission accelerated.

On August 22nd and 23rd of 2012, a Mediation was conducted by the MD Office of Administrative Hearings, at which the state government and I tried to negotiate the guardians' request for ICF care. Since this was a "closed" preceding (no evidence presented could be used in any future court cases) the state admitted that Ginger's condition required ICF care and she was not adequately served in her community agency house where she had lived for 16 years.

Mary and Ginger at the beach in Ocean City, MD

On December 17, 2012, I drove Ginger from the agency house in Laurel, MD over the Bay Bridge to Salisbury, MD to be admitted to the Holly Center. Holly is her home where she receives all the care and medical support she needs (plus a lot of love from her caregivers and family).

(Continued on next page)

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In the Spring of 2013, Larry Innes, VOR Board member and Treasurer, and I were invited to the office of Rep Edwards in the Rayburn House Office Building. We shared with photos of Ginger in her new home and personally thanked the Representative and her staff for their support and efforts in making Ginger's move to Holly happen.

Rep. Donna Edwards, Mary Reese, and Larry Innis

The Congresswoman ran unsuccessfully in the 2016 senatorial primary leading to the election to replace the long serving retiring Senator Barbara Mikulski. This resulted in Rep. Edwards leaving Congress at the end of her term as Representative from Maryland from 2008 to 2017, after nine years of distinguished service. Former Congresswoman Edwards' July 9th letter to Congress tells of her struggles after leaving Congress to obtain necessary health care coverage for treatment of her MS.

Ms. Edwards is currently a senior fellow with the Brennan Center of Justice (of course!)

The prayers of the Massa-Reese Family are for a future of good health for Donna Edwards. Her strong advocacy for justice for Ginger was there when it was greatly needed. This part of Ginger's journey is one more in many episodes of "truth is stranger than fiction" or more accurately, "you can't make this stuff up, people". We know we will always have a Friend in Ms. Edwards and we want her to know she has friends in VOR

Ginger's story is also testament to the fact that there are kind-hearted representatives and senators willing to go the distance to represent our country's most vulnerable citizens. We salute these public servants. VOR families who fight daily for our loved ones' care know what a powerful force of goodness their public service can be.

Best wishes to you, Donna Edwards!
Mary Reese and Ginger Massa

Lori Moore, a dedicated caregiver at Central Wisconsin Center, has been selected to receive the 2017 Jordy Engels Award

Lori, a veteran CWC employee, is representative of the hundreds of outstanding caregivers, known as resident care technicians (RCT), CWC employs. Whether providing for the personal care needs of the residents of her primary group or assisting another RCT, braiding a resident's hair, feeding a resident, or answering questions for a parent, Lori's love for these individuals shines through. In addition to providing for the daily care and active treatment needs of the individuals in her primary group, Lori mentors and coaches RCTs new to the living unit which is home to non-mobile and non-verbal individuals with profound intellectual disabilities and complex medical needs. CWC resident care technicians are part of a team that provides the unique, comprehensive, and synchronized care each resident requires. Working on a unit with non-verbal individuals whose medical status can change rapidly, Lori and her co-workers are knowledgeable about the quirks of each resident and their subtle signs indicating a potential change requiring intervention.

Lori Moore, recipient of the 2017 Jordy Award

Being a CWC caregiver is a second career path for Lori. Having transitioned from the retail world 14 years ago, Lori recently commented that she was not initially sure she would like CWC but admitted she now wishes she had made that transition years earlier than she did. She loves her residents and her residents (and their parents) love her. Thank you Lori for your dedication!

CWC, a state operated Intermediate Care Facility for Individuals with Intellectual Disabilities in Madison, Wisconsin, is a nationally recognized long term care organization. More than 200 people live in the residential treatment program at CWC. Over 800 staff members attend to the complex medical needs of the people who live here, including physicians, nurses, nurse's aides, therapists, social workers, nutritionists, psychologists, and more.

SHARING MY VOICE FOR OUR INTELLECTUALLY DEVELOPMENTALLY DISABLED

By Patricia Russillo, Bloomfield, NJ

I was introduced to VOR when I had first joined the AHDC (Association for Hunterdon Developmental Center). I was ever so thrilled and relieved that there is an organization that understands and advocates for the rights of all residential options for the spectrum of levels of the intellectually developmentally disabled. My brother and I have an intellectually disabled brother who resides at one of the 5 remaining ICF/IIDs in the State of New Jersey. Because of the misrepresentation of the Olmstead Act, the Governor of New Jersey decided to shut down two of the ICF/IIDs claiming that they are a restrictive environment. This initiative to shut down the two centers has caused much disheartening havoc to our intellectually disabled and their families. This, in my opinion, was an unjust assessment of what the Olmstead Act represents whereby the individual is given the option to leave his residential placement into a least restrictive environment. The ICF/IIDs, however, are a least restrictive residential environment for some individuals.

As I have come to understand that this twisted view of thinking of what the Olmsted Act purports has left our ICF/IID in a negative view and many of our intellectually developmentally disabled who were moved of out of the ICF/IID have suffered the consequences. The ICF/IID environment provides an active treatment plan to enable the individual to live up to their optional potential; opportunities for sheltered workshop employment, a greenhouse program, onsite nursing and dental care; a theatrics department to develop the appreciation of individual arts expression along with the many other social opportunities inside and outside the ICF/IID. The professionals and direct care staff also boast of a predictable low turnover rate and produce a family like atmosphere. I applaud the VOR in recognizing that one size does not fit all – all residential options should be explored and respected for our families and intellectually disabled to choose what is most comfortable for their level of disability and given the opportunity to provide that choice. It is my hope that our New Jersey legislators will realize the various residential options offered and respect the opinions and views of parents and guardians as to what residential option is most suitable for their intellectually disabled loved ones.

Membership / Contribution Form

VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007
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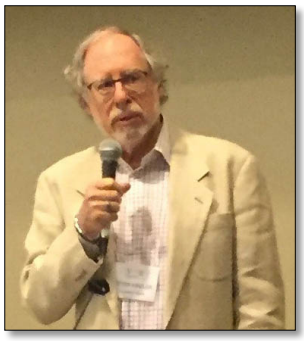
If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

August20

Report from VOR's 2017 Conference and Legislative Initiative

VOR held its Annual Meeting and Legislative Initiative again this year at the Hyatt Regency on Capitol Hill in Washington, D. C. Members came together in to share our experiences and acquired knowledge to help each other with the challenges that face our families with loved ones with intellectual and developmental disabilities.

The open meeting of the Board of Directors on Saturday confirmed that VOR remains strong both financially and in terms of its commitment to our principles and our advocacy. This was followed by the States Reports Session, which once again proved to be an informative and evocative forum for exchanging information and strategies in our ongoing fight with P&A's, DD Councils, and the Department of Justice in their pursuit to close larger congregate care facilities, cut back on sheltered workshops, and day programs, and diminish the rights of families and guardians in caring for our loved ones.



Sunday's session began with an opening statement from President Caroline Lahrmann, who then gave a strong presentation of the Rights to ICF care under Medicaid Law, the ADA, and Olmstead. This was followed by a presentation by Jill Barker and Brad Whitehead of the Quality of Care Committee regarding the difficulties families experience in finding good dental care in the community. There was a short film on the Lee Specialty Clinic in Kentucky, as well as a discussion of the Tufts University dental program. Mary Vitale spoke on the work accomplished by the Issues and Oversight Committee on Guardianship. This was followed by Peter Kinzler's presentation detailing the materials in the folders that members would bring to Capitol Hill over the next few days.

Monday, Tuesday and Wednesday our members met with staffers and members of congress to discuss our issues, gain support for our principles, and to try to find new champions in congress to help us to enact legislation to protect the rights of individuals with intellectual disabilities, as well as our rights as family members and guardians.

During this week, Peter Kinzler, Hugo Dwyer, Caroline Lahrmann, accompanied by Jill Barker, Irene Welch, Joan Kelley, Rita Winkeler, and Laurie Stengler, met with members of the Department of Justice, Health and Human Services, The Administration for Community Living, the Republican Study Group, Congressman John Shimkus, and other agencies and decision makers in hopes that the new administration might cut back on activities that close ICF's and to encourage them to use their resources to improve services in the community instead. A month later, Caroline and Hugo returned to the area to meet with members of the Center for Medicaid Services in Baltimore.

Sending love to all our members, from VOR's 2017 Annual Conference!

VOR 2017 VOICE AWARDS

This year, VOR presented four VOICE Award was presented to members who have long and distinguished histories of service to their loved ones, their facilities, their states, those with issues outside of their states, national issues, and to VOR itself.

Bill and Carole Sherman of Little Rock, Arkansas, have been active members for years, advocating on behalf of their son John who lives at the Arkadelphia Human Developmental Center. Bill has provided legal guidance on behalf of families in Arkansas and has written extensively for VOR. Carole has served on VOR's Board of Directors, and maintains a network of advocates to augment her VOR activities.

Carole, John, and Bill Sherman

Steve and Mary Vitale

Mary Vitale of St. Louis, Missouri has been with VOR for over 20 years. She currently serves as our 2nd Vice President, and has long served on the Board of Directors and on a number of our committees. Mary chairs the *Issues and Oversight Committee.* Mary serves as guardian for her brother Jim, and has been instrumental in leading VOR's most recent work on guardianship rights.

George Mavridis lives in Peabody, Massachusetts, but for years has covered most or all of the New England states at VOR's Washington Initiative. The George Mavridis Foundation has supported the work of the Tufts Dental clinic in training dentists to work with the IDD population for over two decades. George is currently a member of VOR's Board of Directors and the Finance Committee. George came to VOR as guardian for his niece, Joanna Bezubka, who passed away in 2012.

George and Joanna on Joanna's 60th birthday.

Mary Reese and Ginger Massa on Ginger's Birthday

Mary Reese of Ocean City, Maryland is a VOR dynamo, having persisted for sixteen years, working with VOR and her legal team, to get her daughter/ward Ginger into ICF care at Holly Center. A longtime board member and chair or participant in several of VOR's committees, Mary has testified before Congress on our behalf, and continues to travel the halls of Capitol Hill each year. If that's not enough, Mary sews a VOR Bear for our conference each year.

Congratulations to all of our 2017 VOICE Award Recipients
And thank you all for your years of service!