

Welcome to the Spring Edition of the VOR Voice!

Just as the birds are starting to fly back north, VOR members are preparing for their annual trip to D.C. for **VOR's Annual Meeting and Legislative Initiative** and visits to their legislators' offices on Capitol Hill. This issue features information about the conference and how you, as a member and supporter of VOR can be part of the Initiative or help out if you can't make the trip.



We are proud to feature an article by Rita Hoover and Rita Winkeler and their accomplishments with VOR's State Coordinator program. "Team Rita", as they are affectionately known, have enlisted additional state and regional advocates from across the country to promote our message and share information with the families in their states. They are also editing and rewriting VOR's State Coordinator's Handbook, a compendium of information

and resources to enable our teams to help families understand how to navigate the DD system and stand up to the challenges they encounter.



Special thanks to Terry Lafleur for sharing his daughter Jaime's story and for his portrait of Pinecrest, Louisiana's last remaining state-operated ICF/IID. Terry is a long-time member of our Board of Directors and has served as our Secretary for the last two years.

In preparation for our Legislative Initiative, we have filled these pages with information on some of the activities in which our elected officials and government agencies have been engaged. There is an extensive report on Rep. Bob Goodlatte's hearings about the harmful effects of class action lawsuits aimed at closing Intermediate Care Facilities, and the need to protect the rights of families of people with Intellectual and Developmental Disabilities. There is an article on the Joint Report issued by HHS' Office of the Inspector General, Office of Civil Rights, and Administration for Community Living that admits the failure to report critical incidents of abuse and neglect by group home providers. We also have our "Eye on Congress" reports about legislation regarding disability issues that have been put forth in the current session of congress. We urge you to read up on these issues, and to follow the links to the information on line. What happens in D.C. reaches all across the country, and touches the lives of our VOR families and their loved ones with I/DD.

Whether or not you can attend, there are many other ways you can contribute to the success of our conference. You can organize your family group to sponsor a member to participate. You can consult with others in your state to write a short report on available residential and employment DD services where you live, or the legislative issues in your state's capitol, and submit it for our State Reports Forum on Saturday, June 9th. You can organize your family group



to sponsor a member to participate. You can make appointments with your state legislators to bring our issues to their attention, and you can make appointments with your members of congress to bring our materials to their offices in-state or in district during their summer hiatus.

Please join us if you can, or help us by donating or sponsor our efforts if you can't make it. As always, we thank you for your ongoing support of our families.



Joanne St. Amand

Joanne St. Amand, President

Hugo Dwyer

Hugo Dwyer, Executive Director

House of Representatives - Judiciary Committee, Subcommittee on Constitution and Civil Justice Hearings: Examining Class Action Lawsuits Against Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)

On March 6th, 2018, the House Judiciary's Subcommittee on Constitution and Civil Justice convened to examine the harmful effects of class action lawsuits aimed at closing Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF's/IID). The hearing came at the request of Judiciary Committee Chairman Bob Goodlatte (R-VA). and was chaired by Rep. Steve King (R-IA).

Martha Bryant, Mother, RN, BSN & VOR member, Caroline Lahrmann, Mother, VOR State Coordinator for Ohio & past president, and Peter Kinzler, Father, longtime VOR Member, Director & Legislative Committee Chair testified against class action lawsuits. Alison Barkoff of the Center for Public Representation and the Consortium for Citizens with Disabilities, spoke on behalf of those in favor of using class action lawsuits against ICF's/IID and opposed having to provide notification to families and guardians of individuals residing in these homes who would become part of the class.



First to testify was Martha Bryant, a constituent of Congressman Goodlatte who spoke about her son Tyler. Tyler and his brother Taylor were the two surviving brothers of a triplet pregnancy and were born prematurely at 29 weeks. Tyler had severe physical and intellectual disabilities, functioning at the level of a 15-20 month old baby. He was non-verbal and non-ambulatory. His condition required ICF-level care which he had received at Central Virginia Training Center (CVTC) for most of his life.

With complete disregard for his needs, Tyler was forced from his home at CVTC on Jan 17, 2017 as the result of a class action lawsuit from initiated by the Department of Justice (DOJ). Tyler was moved to an inadequate and inappropriate non-ICF facility 139 miles away without his mother's consent, and with no regard for her objections or guidance about the needs of her sons. Tyler could not tolerate the transfer. He was sent to the hospital where he spent 49 days, most of those in the ICU. Less than two months after his transfer, Tyler died in the Richmond hospital alone, more than 100 miles away from his mother who was not present at the time. She was notified of his passing by phone.



The committee then heard from VOR's Caroline Lahrmann, the mother of severely intellectually and physically disabled twins who reside in a private ICF in Ohio. Mrs. Lahrmann gave testimony about the class action suit initiated by her state's Protection and Advocacy agency (P&A) - Disability Rights Ohio (DRO) - aimed at closing all of the state's public and private ICF's and uprooting 5,900 people with I/DD from their homes and forcing them into HCBS-waiver settings. The suit would treat all of these 5,900 individuals as if they were one and the same, with the same needs and levels of disability as the six people chosen by DRO to be named parties in the suit. Mrs. Lahrmann quoted from *Olmstead* to describe the manner in which DRO's lawsuit violates the spirit and letter of that decision. DRO's lawsuit has cost the families who oppose it over \$100,000 to date. These families are forced to fight against being named as participants in a class action suit that is the antithesis of their wishes for their loved ones. She went on to say that the ability to opt out of these suits is not sufficient, that this type of class action suit should be prohibited on the grounds that, "P&A's bring class actions against Medicaid accommodations that are needed and chosen by their own clients."



Opposition testimony was then provided by Alison Barkoff, a long-time professional advocate for the waiver system who favors closing all ICF's. Ms. Barkoff told of her family's refusal to put her brother into an ICF forty years ago, and their struggle to provide for him for years before he was able to receive supplemental at-home services. Her testimony contended that she has seen people leave ICF's and thrive in the community. She praised the class action



suit that resulted in the death of Tyler Bryant for having given community services to the son of a woman named Brenda Booth, who refused the care offered by the state of Virginia in an ICF in favor of waiting for community placement. Ms. Barkoff spoke of “expansion of services” without acknowledging that this expansion in one sector, waiver-based care came at the cost of ICF level care within the system. She did not mention the people who have suffered trauma and death by being displaced from their homes – only of those who have received services as a result of these actions. Rather than advocate for more funds and more services, her approach is to take from one group of people and give to others, and to use expensive class action suits as the way to enact that redistribution of services.

VOR’s Peter Kinzler was the last to testify. He is the father of Jason, 42, who functions at the intellectual level of a 6-month old and requires 24/7 care for all aspects of living. For 37 years, Jason received excellent care at North Virginia Training Center. In 2016, NVTC was closed by a class action suit by DOJ, in

accordance with their policy, “Community Integration for Everyone”. They did this under Federal Rule 23(b)(2), which swept all individuals residing in ICF’s into the suit, with neither advance notice nor the right to opt out. DOJ claimed to have consulted with “a whole laundry list of people in the system. The only people not consulted were the families of the residents of the ICF.” Despite near unanimous opposition by the families, DOJ went on with their case. They opposed the families motion to intervene in the case, forcing them to spend over \$125,000 in legal fees. The judge then ignored the families’ opposition and accepted a settlement between the DOJ and the State of Virginia. Mr. Kinzler’s family was forced to choose between putting Jason in a group home forty minutes from his home or into an ICF 160 miles away. To make things worse, the closure timetable was not tied to the creation of resources sufficient to handle the displaced individuals. Such displacements have resulted in considerably higher rates of mortality among this fragile population.



After testimony, Rep. Goodlatte, Rep. Cohen (D-TN), and Chairman King asked the participants a number of questions to illustrate the issues brought up in their testimony. Mr. Cohen asked Ms. Barkoff if there were protections for people who oppose class action suits. She insisted that these protections exist, making a bill that would allow families to opt-out unnecessary. Her response was in direct conflict with the experiences and testimony of Ms. Bryant, Mrs. Lahrmann, and Mr. Kinzler. Rep. Goodlatte asked Ms. Bryant if others who had been forced out of the CVTC had suffered or died as a result of their displacement. She stated that of the 42 people transferred into the community, Tyler was the tenth death that she knew about. When asked by Rep. Goodlatte about the importance of being able to intervene in these class action suits, Mrs. Lahrmann replied that the judge in her case told her that without the ability to intervene, she would have had no rights in the case in which her children were unwilling participants.

Toward the end of the hearing, Rep. Goodlatte asked several questions of Ms. Barkoff that highlighted the inconsistencies in testimony. He asked if she was aware of any class actions P&A’s conducted against group homes. She skirted the question several times and never gave a direct answer. He went on to ask her if the P&A’s had an anti-institution agenda. She replied that in her opinion, they did not. He went on to say that the process as it exists, is inflexible and that it does not recognize the needs of people in ICF’s or their families, and that more protections were needed.

We urge all of our members to read the written testimony and to watch the full video of the hearings.

Testimony from the hearings is available at:

<https://judiciary.house.gov/hearing/examining-class-action-lawsuits-intermediate-care-facilities-individuals-intellectual-disabilities-icf-iid>

Taped testimony of the hearing is available on YouTube (Note: Video begins at 5:18):

<https://www.youtube.com/watch?v=PA9xH0PYnvA>

Please note: Your membership renewal date is listed at the bottom of the address label on the back page of this issue of The Voice.



Joint Report from U.S. Department of Health and Human Services' Office of Inspector General (OIG), Administration for Community Living (ACL), and Office for Civil Rights (OCR):

In January of 2018, three agencies operated by the U.S. Department of Health and Human Services, acknowledged systemic shortcomings in protecting residents of HCBS waiver group homes from incidents of abuse and neglect. The Office of the Inspector General (OIG) determined that **up to 99 percent of these critical incidents were not reported to the appropriate law enforcement or state agencies as required.** The report stated, **“Group Home beneficiaries are at risk of serious harm. OIG found that health and safety policies and procedures were not being followed. Failure to comply with these policies and procedures left group home beneficiaries at risk of serious harm. These are not isolated incidents but a systemic problem – 49 States had media reports of health and safety problems in group homes.”**

The report grew out of investigations into under-reporting of critical incidents by group home providers in Connecticut, Massachusetts, and Maine that had been conducted by the OIG in 2015. The reports found drastic under-reporting of incidents resulting in trips to the emergency room and/or hospitalizations by group home providers. Concurrent with those investigations, the Inspector General also looked into critical incident reporting by ICF's in NY State. That investigation determined that NY's ICF's had an excellent record of reporting incidents, and that no actions or recommendations were necessary.

OIG highlighted under-reporting critical incidents of abuse and neglect in privately operated group homes, including “deaths, physical and sexual assaults, suicide attempts, unplanned hospitalizations, near drowning, missing persons, and serious injuries. Critical incidents requiring a minor level of review generally include suspected verbal or emotional abuse, theft, and property damage. For critical incidents that involve suspected abuse or neglect, the HCBS waiver and State regulations also require mandated reporting.” It found that in the states under study, “the State agencies did not comply with Federal waiver and State requirements for reporting and monitoring critical incidents involving Medicaid beneficiaries with developmental disabilities.”

The report identified four Compliance Oversight Components that “help ensure that beneficiary health, safety, and civil rights are adequately protected, that provider and service agencies operate under appropriate accountability mechanisms, and that public services are delivered consistent with funding expectations.”

1. Reliable incident management and investigation processes;
2. Audit protocols that ensure compliance with reporting, review, and response requirements;
3. Effective mortality reviews of unexpected deaths
4. Quality assurance mechanisms that ensure the delivery and fiscal integrity of appropriate community-based services.

In conclusion, the three agencies proposed that the Center for Medicare and Medicaid Services (CMS):

1. Encourage States to implement comprehensive compliance oversight systems for group homes, such as the Model Practices, and regularly report their findings to CMS;
2. Form a “SWAT” team to address, in a timely manner, systemic problems in State implementation of and compliance with health and safety oversight systems for group homes
3. Take immediate action in response to serious health and safety findings, for group homes using the authority under 42 CFR § 441.304(g).

Comments: Most families who have signed the HCBS Waiver would have had reasonable expectations that the four oversight components listed above were in place all along. The first three of these components are mandatory licensing requirements of Intermediate Care Facilities. As for the “SWAT” teams, isn't that the job that has been expected of Protection and Advocacy agencies in each state? If not, then what *is* expected of them by HHS and CMS? And why do these agencies tell us that our loved ones can receive the same level of care in group homes that they receive in ICF's, and encourage us to leave the ICF's, when they know that these problems remain unchecked in the HCBS waiver system?

For more information on the Joint Report go to the Administration for Community Living (ACL) website at:

<https://www.acl.gov/aging-and-disability-in-america/joint-report-ensuring-beneficiary-health-and-safety-group-homes>

The report is available for download at:

<https://www.vor.net/images/stories/2017-2018/ACL-group-homes-joint-report.pdf>

EYE ON CONGRESS:

S.910 – The Disability Integration Act of 2017

Sponsor: Sen. Chuck Schumer (D-NY) Introduced April 7, 2017 Co-sponsors: 17

H.R.2472 - The Disability Integration Act of 2017

Sponsor: Jim Sensenbrenner (R-WI). Introduced May 16, 2017. Co-sponsors: 84



VOR's Concerns: S.910 and H.R.2472 which was derived from various legislative efforts introduced in congress since 1997. At that time, the Congressional Budget Office (CBO) estimated that, if the program were to cover about 2 million individuals it would cost the federal government 10-20 billion dollars per year. Those numbers were prohibitive at that time and have greatly increased even more over the past 20 years. There is no estimate as to what the costs would be to individual states and most states have been cutting budgets and services already for people with I/DD. They are not prepared to take on the costs mandated by these bills.

The Disability Integration Act of 2017 ignores the needs and levels of disability of the individuals involved. It treats the very diverse I/DD population as a single group with common needs, the primary one being inclusion in the community. It marginalizes those who benefit from the level of care provided in the ICF environment and whose needs are best met by a larger staff of well-trained professionals. It refuses to recognize that large congregate care facilities are homes to those who choose them and those who thrive there. A home offers safety, comfort, and care. A home is not defined by the number of people who reside there or the physical size of the structure. A small facility with a high turnover of underqualified staff that fails to meet the physical and psychological needs of an individual is *not* a home. No law should ever mandate where any person must live.

The D.I.A. neglects to insure the safety of those who would be forced out of their homes and put into environments with fewer services and protections. It conforms to the dangerous assertion made by opponents of ICF's that everyone receives the same services in the community that are offered in an ICF. This is patently false.

The bill also calls on the Department of Justice (DOJ) for enforcement of its regulations. In the past, DOJ has brought over 30 class action lawsuits, leading to closure of ICF's in several states including Virginia, Nebraska, and Georgia. In Georgia, it is well documented that the DOJ forced the closure of facilities so quickly and without proper concern for successful transitions into the community that an estimated 500 individuals died as a result of this careless "enforcement".

VOR would expect Congress to support diversity, choice, and a full continuum of care as protected under *Olmstead*. We respect the value of integration into the community and the labor force for those who seek it. However, we strongly believe that those individuals whose needs are met in congregate care facilities such as ICFs, and whose families and guardians choose those facilities should never be forced by law to leave.

<https://www.congress.gov/bill/115th-congress/senate-bill/910>

<https://www.congress.gov/bill/115th-congress/house-bill/2472>

S.2227 – Empower Care Act (To Reauthorize Money Follows the Person)

Sponsor: Sen. Rob Portman (R-OH) Introduced 12/13/17 Cosponsors: 4

H.R.5306 – Empower Care Act (Companion Bill)

Sponsor: Rep. Brett Guthrie (R-K) Introduced 03/15/18 Cosponsors: 3



The Money Follows the Person Demonstration Program (MFP) expired in 2016, though some states have funding through 2020. This bill would renew the program. MFP is intended to move individuals from ICF's and place them into waiver settings. Over 75,000 people have received waiver services as a result of MFP.

VOR's Concerns: MFP has been used as one of many platforms to weaken the role of ICF's in what should be a full continuum of care. As people move from ICF to HCBS settings, the money that follows them leaves the ICF, reducing the economy of scale in costs, ultimately resulting in cuts to staffing and professional services. In most states, the money that followed the person into the HCBS system reverts to the state's general fund when the individual passes on, reducing the amount of money in the state's DD system.

Another concern is that not all of the services follow the individual into the community. Additionally, the Enhanced Federal Medical Assistance Rate expires after one year, further reducing services in the HCBS setting.

The Senate bill may be read at: <https://www.congress.gov/bill/115th-congress/senate-bill/2227>

The House bill may be read at: <https://www.congress.gov/bill/115th-congress/house-bill/5306>

Our youngest daughter Jamie is a resident at Pinecrest. My wife, Glenda and I have two older children, son Steve and oldest daughter Patti. Jamie functions at the level of a 3-year old. She lived at home with us until age 5, we could see she needed more that we could offer. She was first admitted to a private facility in Alexandria, La. until age 19, then to a community home, where their way of dealing with her behavior was with drugs. She aspirated one night and was rushed to local hospital where she stayed in ICU for 2 weeks. At that time the home called to inform us she would not allowed to go back there, so she came home until Pinecrest called about 2 months later to let us know they had room for her if we wanted to visit. Over the years, we had heard very bad stories about Pinecrest and didn't want to see her there. We decided to go visit and were very surprised at what we saw, caring staff, clean homes, on grounds outpatient care unit and qualified medical staff.

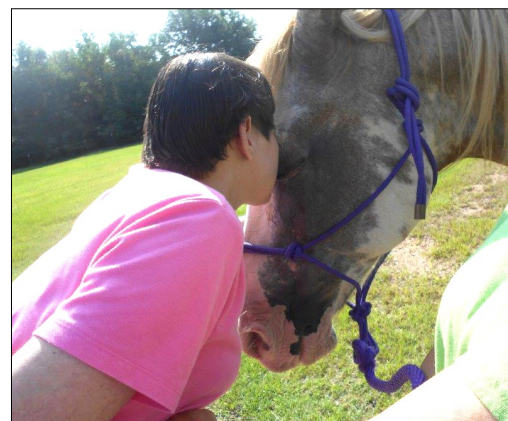


Jamie has been at Pinecrest since 2001. She still has some behavioral issues but now, through hard work from dedicated Pinecrest staff, her behavior has improved very much. Jamie is able to walk. Her communication is not too good and although she can't carry on a conversation she does let us know when she needs the bathroom or when she is cold, hot, thirsty, hungry or has enough to eat. She enjoys our weekly visits as well as home visits with family and home cooking. Her eyesight is failing but she still likes to cook (stir in the pot with assistance) at her day program, going eat out, shopping, going to church on campus and visiting the Horse Ranch also located on the grounds. The Ranch has a goat named Duck, a horse named Foxy, two cats and several chickens. When Jamie visits the ranch, she gets to pet the cats, Duck, and Foxy, and pick eggs from the laying hens. Pinecrest will soon be home for another horse, donated by a close friend of mine and we are

looking at getting a miniature horse as well.

Pinecrest is a beautiful facility with well-kept grounds where residents enjoy the freedom and safety of walking, riding their bikes or electric scooters, those who can, and always have the right of way. Pinecrest offers our residents many other activities they look forward to; such as cookouts, off campus trips, a Christmas pageant, beautiful Christmas decorations with a Christmas lights tour, enjoyed by families from Alexandria and Pineville, dances (sock hops), basketball court, swimming pool, Mardi Gras and Christmas parades with local organizations volunteering to help. Also for Christmas, each home has their own Christmas parties where families attend.

Jaime loves her home at Pinecrest. Glenda and I are grateful for all they have given her, and the support they have given our family over the years.



EYE ON CONGRESS

H.R.620 – ADA Education and Reform Act of 2017 - Sponsor: Rep. Ted Poe (R-TX)

Introduced 1/24/17. Passed in the House 225-192 on 2/15/18. Received in the Senate 2/26/18

H.R. 620 proposes to alter the Americans with Disabilities Act (ADA) (1990) to protect businesses from lawsuits due to their failure to comply with directives to make their facilities accessible to persons with disabilities. Proponents of the bill claim that frivolous lawsuits hurt businesses, benefiting only trial attorneys. Opponents claim that businesses have had over twenty-five years to come into compliance with the ADA, and have chosen not to follow the law. They feel that the rights of people with disabilities have been violated and need to be protected through enforcement of the existing law.

VOR's Concern: This bill pits the rights of businesses against the rights of individuals with disabilities, supporting businesses as the injured parties in this matter. Disability rights organizations fear that this bill would set disability rights back three decades, and oppose any changes to the ADA that might weaken the law and the rights of the disabled. Businesses would have the right not to comply by making their facilities accessible to persons with disabilities until legally notified, and would then be given extended periods of time to come into compliance.

The bill may be read at: <https://www.congress.gov/bill/115th-congress/house-bill/620>

For more information, see: <https://www.govtrack.us/congress/bills/115/hr620/summary>



A BRIEF HISTORY OF PINECREST

Pinecrest Supports and Services Center in Pineville, Louisiana received legal authorization from the Legislative Act. No. 141 of 1918 and began providing services for individuals with intellectual disabilities in 1921. It is the only facility left in Louisiana for the DD population. Historically the facility supported over 2000 residents and at one time was completely self-sufficient with a working vegetable farm, dairy operation, livestock such as chickens, hogs, and cattle. This was during a time when the only way the facility could operate was through self-sufficiency due to budget constraints. Years later more funding was given to the agency so they could purchase instead of produce.



Pinecrest consists of 947 total acres with 163 acres leased to Ward 9 recreational facility, giving the facility 784 acres to care for. There are 335 total buildings on campus with 158 heated and cooled buildings utilized, 7.5 miles of paved road, onsite sewage treatment, a million-gallon potable water tank with two water towers with backup generators for pumps, an emergency evacuation shelter for DD individuals, emergency power generators across grounds and full generator power with HVAC capacity in the most medically fragile area of campus.

Currently thirty-six buildings are used as residential homes, three buildings for intensive treatment units and an area for an observation unit for the individuals supported. There are twelve day-service buildings for day program training, active treatment and vocational learning opportunities. Pinecrest has various work training options including many contracts with agencies in the community, including wildlife and fisheries, The State Office Building, England Air Park, Prince of Peace Church, and contracts with various agencies for paper shredding and janitorial duties. Pinecrest has an on-grounds bakery, and also subcontracts with Cleco Electric to produce shop rags for the mechanic shops. The greenhouse provides training in landscaping and lawn care with opportunities to be part of work crews both on-grounds and in the community. The Department of Education offers a school for individuals 12 through 26 with curricula focusing on their specific needs. Pinecrest now offers a GED program and a specific GED teacher for the folks who can benefit from that.

In 2010 Pinecrest had 1635 staff and 489 residents of whom roughly 7% had behavioral or psychiatric issues and challenges. Currently, Pinecrest has 1233 staff and 430 residents of whom over 40% have behavioral and/psychiatric issues and challenges. Layoffs and budget cuts in 2011 and 2012 forced the following programs to be eliminated; the x-ray dept., EEG dept., art therapy, music therapy and foster grandparent program.

Pinecrest continues to serve ID and DD residents with psychiatric and mental health issues, geriatric/dementia care, and autism and is a safety net for La. Dept. of Health's intellectual and developmental disabilities system. Pinecrest is available for individuals in need of services for whom there are no services available, current services are no longer adequate and /or an individual status change requiring more intensive assessment, intervention and treatment planning.

Eye on Congress: H.R.4547 - Strengthening Protections for Social Security Beneficiaries Act

Sponsor: Rep. Sam Johnson (R-TX) Introduced 12/05/17

Passed in the House 396-0. Passed in Senate without amendment by Unanimous Consent.

Signed into law by President Trump, 04/13/18.

VOR's Concerns: While this Act ostensibly purports to protect the Social Security system from misuse of finances by representative payees who oversee funds for a beneficiary, and while this bill does have several laudable ideals, it also raises concerns for VOR families. Of greatest concern is the provision in Section 101, in which the Social Security Administration will provide a minimum of \$25,000,000 annually, to be divided among the various state Protection and Advocacy agencies. The P&A's are given the authority to identify representative payees and investigate their use, or misuse, of funds. We are concerned by P&A's history of abusing their mandate by discriminating against ICF's while overlooking abuses in the HCBS waiver system they are charged with protecting.

<https://www.congress.gov/bill/115th-congress/house-bill/4547>



The VOR State Coordinator Program

by Rita Winkeler and Rita Hoover

VOR will often hear from individuals, including non-members, who are seeking information or assistance for services in their state. This is where the VOR State Coordinators provide unmatched knowledge and insights for families in need regarding their state's agencies, facilities, and providers. VOR's State Coordinators are an important part of VOR's overall advocacy program. Rita Hoover, Arkansas State Coordinator, and Rita Winkeler, Illinois State Coordinator are working to revitalize the VOR State Coordinator Program.



Part of the revitalizing efforts are creating ten regions. Rita Winkeler will assist Regions 1-5 and Rita Hoover will assist Regions 6-10. Each region will be a team of five states. The State Coordinators will form a team and communicate among themselves. Each region team will conduct a quarterly telephone conference with each other. The team will bring to the table their concerns in their states, ideas and assistance to make a stronger VOR organization to advocate nationally and locally for a full range of quality residential options and services and unite families in other states with shared experiences. Each team will bring forth a report that would be combined with the other five regions



in their group and provide their reports to VOR. Our strength is in our State Coordinator Teams.

Besides providing knowledge to individuals seeking help, VOR State Coordinators also play an important role in helping to widely circulate VOR's Action Alerts - calls to action regarding legislative and government affair developments that require a strong grassroots response. These alerts can be sent out to VOR advocates on the state level or nationally.

VOR State Coordinators also help make VOR membership information available at family group meetings, encourage VOR membership in newsletters and identify opportunities to enhance VOR awareness and increase VOR's membership. They often provide advocacy campaigns and materials for families to circulate at their meetings.

VOR assists State Coordinators by regular communication by email -sharing news of interest, lessons learned in other states, and more. VOR offers State Coordinators "mentoring" and new State coordinators can work with veteran state coordinators in learning their role.

As "Team Rita" works to revitalize the State Coordinator Program they welcome VOR members to volunteer to be a State Coordinator. "Team Rita" is ready to answer questions regarding this role, and look forward to helping our new group of State Coordinators. For more information on VOR's State Coordinators, call our toll-free number 877-399-4867 (877-399-4VOR) or email to info@vor.net.

EYE ON CONGRESS

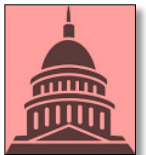
H.R.1377 – Transitioning To Integrated and Meaningful Employment Act of 2017

Sponsor: Rep. Greg Harper (R-MS)

Introduced 03/07/17

Committees: House Education and the Workforce

Co-sponsors: 28



VOR's Concerns: This bill would amend the Fair Labor Standards Act of 1938 to: (1) prohibit the Department of Labor from issuing new special wage certificates [Section 14(c)] for individuals whose earning or productive capacity is impaired by age, physical or mental deficiency, or injury, and (2) repeal the authority for issuing such certificates six years after the enactment of this bill, at which time any outstanding special wage certificates shall be revoked.

The bill wrongly assumes that all individuals working in facility based employment (sheltered workshops) are capable of working in minimum wage settings but are being held back from the opportunity. It makes no provision for individuals who do choose facility employment or those whose skills do not meet the requirements of employers paying minimum wage – the very people for whom Section 14(c) was written. These individuals would be "retired" from the work environment they love, and put into day programs that they find less challenging and less rewarding.

VOR supports opportunities for competitive employment for those who seek them, but not at the cost of taking facility based employment from individuals who desire and thrive in that environment. VOR supports individual choice.

<https://www.congress.gov/bill/115th-congress/house-bill/1377>

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VOR 2018 Annual Conference and Washington Initiative

June 9 - 13, 2018

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

Saturday, June 9, 2018

Registration: Network with families from across the country **Noon**

VOR Board of Directors Meeting & Report to Membership **12:30 pm**

Annual meeting of the VOR Board of Directors, open to all members
 Committee Reports and Presentations
 Mentoring our next generation of advocates
 Time will be provided for member questions and comments

Installation of VOR 2017-2018 Officers and Board Members **3:30 pm**

Reports from the States **4:00 pm**

Participants report on news from their states. Session is moderated by VOR Board Members

Sunday, June 10, 2018

Registration: Network with families from across the country **11:30 am**

VOR Legislative Initiative 2018 **Noon**

Opening Remarks - Joanne St. Amand, President and Hugo Dwyer, Executive Director
 Panel Discussion on State Advocacy – Liz Belile (TX), Susan Jennings (PA), Rita Winkeler (IL)
 Guest Speakers – Kate McSweeney, Vice President on Govt. Affairs & General Counsel at ACCSES
 (Other speakers TBA)

Legislative Briefing **3:00 pm**

Panel Discussion and Issue Briefing. Folders for Congressional visits will be distributed.

Awards and Events **5:00 pm**

VOR's Sunday Dinner at The Dubliner - 7:00 pm

Sunday Dinner at The Dubliner is optional. The price is \$35 per person. Alcoholic beverages are available at an extra charge.

Monday, June 11 – Wednesday, June 13, 2018

The Washington Initiative

Visits to Capitol Hill - Personal meetings with Members and Congress and their staff are the most effective way to educate and influence federal lawmakers. Join VOR members and advocates from around the country to convey the importance of residential choice and family decision-making to Members of Congress. Be sure to plan enough time to cover your state's Congressional Delegation.

Monday, June 11 **Informal De-briefing** **6:30 - 8:00 pm**

Tuesday, June 12 **Informal De-briefing** **6:30 - 8:00 pm**

To register for the conference and legislative initiative or make a dinner reservation at the Dubliner, go to: <http://weblink.donorperfect.com/VOR2018>

If you prefer to mail in your registration, please use the form on the following page.

Note: Mail in Registration is slow. We recommend registering online

VOR 2018 Annual Conference and Legislative Initiative

Register online <http://weblink.donorperfect.com/VOR2018>

or use this form and return to:

VOR * 836 S. Arlington Heights Rd., #351 * Elk Grove Village, IL 60007

Fax: 877-866-8377; Email: hdwyer@vor.net

(Reminder: Online Registration is faster)

Name(s): _____

Address: _____

City, State, Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

Sponsoring Organization: _____

INITIATIVE REGISTRATION

I / We will attend the Washington Initiative and will make Congressional visits on:

___ Monday, June 11 ___ Tuesday, June 12 ___ Wednesday, June 13

ANNUAL CONFERENCE REGISTRATION: Fee includes all Saturday and Sunday events, debriefing sessions on Monday and Tuesday nights, and include all conference presentations and materials.

VOR Members:

___ \$110 per member if paid after May 1, 2018

Non-VOR Members: (Fee includes 1 year membership (Reg. \$45))

___ \$150 per person if paid after May 1, 2018

Donations to help defray the event's costs are appreciated

I would like to make an additional donation of \$ _____

Total Amount to Charge: _____

Credit card number _____ Expiration Date: _____ 3-Digit Code (back of card): _____

Charge card: MC ☐ Visa ☐ Discover ☐

VOR's Sunday Dinner at The Dubliner - 7:00 pm

Sunday Dinner at The Dubliner is optional. The price is \$35 per person. Alcoholic beverages are available at an extra charge.

Payment will be collected at the end of the meal, but we ask that you register now to attend.

Please indicate the number of people who will be attending here: _____

HOTEL INFORMATION

Hyatt Regency Capitol Hill 400 New Jersey Ave, NW Washington, D.C. 20001

We have a bloc of rooms available for conference attendees.

The VOR Group rate is \$279 for single or double rooms, plus tax, per night. Larger rooms & suites are also available.

Hotel Reservations are due by May 11, 2018

To make your reservations online, go to: <https://aws.passkey.com/go/AnnualVORConference2018>

If you do not have internet access, call 1-888-421-1442 and mention "VOR's Annual Conference" when making your reservation.

Join us as we Celebrate Thirty-Five Years of Advocacy!

We invite you to join us in Washington, D. C. as we gather to advance our mission to advocate for high quality care and the human rights of ALL individuals with intellectual and developmental disabilities (I/DD). We hope you will further support our effort by becoming a 2018 Conference Sponsor.

- VOR celebrates the diversity of people with disabilities and champions the right to receive services of **their choice**, according to **their individual needs and desires**.
- Founded in 1983, **VOR** is a nonprofit advocacy organization supporting a full range of services and residential options for people with I/DD, from home and community based services to congregate care, from center-based employment and facility-based day programs to competitive employment opportunities.
- VOR empowers individuals with I/DD, their families and legal guardians with information, training, and advocacy resources. We recognize that they know best when it comes to the care of their family members with I/DD.
- VOR advocates face new opportunities and challenges in Washington, D.C. This Initiative is an important time to meet our Legislators in Washington, and to advocate for real choice for those with I/DD. This is the time for our Representatives to hear a "Voice of Reason".

VOR's Annual Conference is dedicated toward advancing these principles and creating a forum in which our members can listen, learn and share with each other. Members are empowered to visit their lawmakers on Capitol Hill and other government agencies, as well as sharing information with advocates when they return to their home states.

Sponsorship and Exhibit Opportunities

Annual Meeting Sponsor - \$1,000

- Quarter-page ad in conference program & signage recognition.
- Opportunity to share information with conference attendees as an exhibitor
- 1-year Organizational Membership in VOR
- One free registration at the VOR 2018 Conference (including one-year individual membership for the attendee)
- One prix-fixe dinner at VOR's Dinner at the Dubliner event (Sunday, June 10, 2018)

Fellowship Sponsor - \$500 (Need 5 sponsors)

- Recognition in conference program & signage recognition.
- Recognition in VOR's print and e-mail newsletters, direct email announcement, on VOR's website and in social media, reaching thousands.
- Opportunity to share information with conference attendees as an exhibitor
- One free registration at the VOR 2018 Conference

Advocacy Sponsor - \$250 (Need 5 Sponsors)

1. Recognition in conference program & signage recognition.
2. Recognition in VOR's print and e-mail newsletters, direct email announcement, on VOR's website and in social media, reaching thousands.

All sponsors will receive recognition in VOR's print and e-mail newsletters, direct email announcements, on VOR's website.

To become a sponsor of VOR's 2018 Conference, please go to

https://www.vor.net/images/stories/2017-2018/2018_VOR_Annual_Conference_Sponsorships_Final.pdf

To sponsor by mail (much slower!), please return this form to:

VOR, 836 S. Arlington Heights Road #351, Elk Grove Village, IL 60007

Sponsorship Amount \$: _____ Sponsorship Category: _____

Name of Organization: _____

Contact: _____

Mailing Address: _____

Telephone: _____ E-Mail: _____



836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4867 toll free
www.vor.net

U.S. Postage

***A national, non-profit 501(c)(3) volunteer organization
speaking out for people with intellectual and developmental disabilities***

Please note: Your membership expiration date is listed on the bottom of the address label above.

Membership / Contribution Form

**VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007 Fax:
877-866-8377 or donate online @ <http://www.vor.net/get-involved>**

Thank you for your dues and contributions!

I would like to give a gift membership to:

NAME _____

NAME _____

ADDRESS _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

CITY _____ STATE _____ ZIP _____

TELEPHONE _____ FAX _____

TELEPHONE _____ FAX _____

EMAIL _____

EMAIL _____

☐ **MY CONTACT INFORMATION HAS CHANGED**

☐ \$45 per year per individual;

☐ \$200 per year per family organization

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

**To make a memorial or honorary donation, please
visit our website at:**

<http://www.vor.net/get-involved/donate-to-vor>

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

☐ I would like to make an additional donation to support VOR. An additional gift is enclosed for:

☐ \$5,000 ☐ \$2,500 ☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$50 ☐ Other \$ _____

Make checks payable to VOR, or use your credit card: ☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____ **Expires:** _____ / _____ **CVC (3-Digit Security Code):** _____

Signature: _____

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.

April 2018 NL