



VOR's Advocacy Manual and Toolkit

for

***State Coordinators, Members
and Choice Advocates***

Rev. March 2013

VOR's Advocacy Manual and Toolkit

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Free copies of this publication are available on VOR’s website (<http://vor.net/get-help/toolkit-for-families>) or by contacting thopp@vor.net. Instructions for ordering print copies are located on page 59.



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March 2013

Dear VOR State Coordinators, Members, and Choice Advocates,

It is with great pleasure that I present to you VOR's "*Advocacy Manual and Toolkit.*"

The mission of VOR is to advocate for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). First prepared in 2005, our *Toolkit* has been refined and updated to further assist VOR advocates achieving our shared mission on behalf of people with I/DD by maximizing and harnessing our collective skills and strengths at the state and federal levels.

Even the most seasoned advocates will find something of value within the pages of the *toolkit*, and every member is invited to share the Toolkit with your members. Using this resource to reach deep into your own memberships to identify leaders and maximize participation is perhaps the greatest potential impact this toolkit can have.

As further introduction to this resource, I will turn the pages over to what could very well be called our advocacy "Dream Team." Attached is a timeless document – the cover note is authored by the late-Marty Pratt, VOR's founder and he shares "***Action Points To Use When Your Residential Facility is Threatened with Closure or Down-Sizing,***" by the late-Louise Underwood, a long time VOR Board Member and Legislative Committee Chairperson. We are indebted to these leaders for sharing their grassroots advocacy wisdom and helping VOR be the organization it is today. .

Together we will continue to advocate for high quality care and choice for our family members and friends with I/DD. Our national network requires an effective partnership with our state affiliates, leaders and members, and you have not let us down. Thank you for "*Carrying the banner, stepping up to the plate, and risen to the issues, knowing we have much work to do and many miles yet to go.*"

Respectfully,

Ann S. Knighton
President

Voice of the Retarded

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TO: ALL ORGANIZATIONAL MEMBERS
FROM: Marty Pratt - Past President
DATE: December 16, 1992
SUBJECT: ACTION POINTS WHEN RESIDENTIAL FACILITIES
ARE THREATENED WITH CLOSURE

Today, there is a strong movement being mounted, by several groups, with the objective of closing larger residential facilities.

It is most important that such action, by these closure groups, be met with strong opposition by facility parent organizations. Such positive action has been taken by Concerned Families of Hazelwood Hospital in Louisville, Kentucky. Their action has been successful in preventing the closure of the Hazelwood Hospital; a residential facility serving severely and profoundly mentally retarded persons.

Louise Underwood, VOR Legislative Chairperson, has prepared a list of "Action Points" that have been used to prevent the closure of Hazelwood Hospital. Attached is the list of these "Action Points" that can be of help to your organization should your facility be threatened with closure.

Warmest regards,


Marty Pratt
Past President

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ACTION POINTS TO USE WHEN YOUR RESIDENTIAL FACILITY IS THREATENED WITH CLOSURE OR DOWN-SIZING

1. If your facility does not have a parents' organization, form one immediately and elect officers.
2. Schedule a meeting of all the families of the residents of the facility.
IMPORTANT: Where names and addresses can't be secured, be sure to have a "sign-up sheet" and make certain all parents sign, giving name, address and phone number.
3. Make sure that each member knows their own Senator and Representative in their District (also the Senators and Representatives at the Federal level).
 - Have each member call or personally contact these elected officials and let them know what is happening to their facility; let these officials know that the member is in their district and that their help is needed. These officials know that votes are needed for re-election.
4. Members should contact local newspapers and T.V. stations.
 - A good idea is to have a group of families visit each T.V. station with details and information regarding threatened facility closure.
 - Present the same story to newspapers. The media - both print and T.V. - is always looking for a good news story. Louise Underwood says, "Believe me! This approach to the media will work!"
5. Your organization must get the names of all Senators and Legislators in your state.
 - Write a letter to each Senator and Legislator.
 - Phone calls to Senators and Legislators are also most important. Follow-up letters with phone calls.
 - Set up a phone committee for instant action!
 - Get the support of your U.S. Senators and Representatives with letters/phone calls.
6. Take your story to local elected officials in your own town. Most effective, in making contacts with elected officials is to have 2 parents make the contacts together.

11/18/92

An Association of Individuals and Parent Groups for the Developmentally Disabled
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ACTION POINTS

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7. Run an ad and get news articles in your local papers telling the community of attempts to close or downsize your facility. Ask for help from the community in protesting this action. People will read these ads and news articles; you will receive a lot of sympathy and support.
 8. Each member should write a letter to their Governor. Hand written letters "from the heart" get more attention and support. Make your letter short "and to the point".
 9. Members should attend political meetings and other meetings attended by elected officials where there is discussion of local issues. Make your voice heard!
 10. Most effective is to organize groups for a trip to the State Capitol. Be sure to wear identifying badges. Ask legislators for support in opposing the closure of your facility; also for support for the passing of any bill that will benefit your facility. If your organization wishes to draft legislation, VOR will be glad to assist in the effort.
- Stand outside the chambers of the elected officials (if you do not have an appointment). Wait for them to come out. Talk to them. (They will listen if you will "work at it").

REMEMBER! PARENT POWER IS THE STRONGEST POWER ALIVE!! But parents can only make a change if they "work" for the change. Parents must not "stand around and do nothing." The future of our handicapped family members depends on us, the parents!

Remember to let all, whom you contact, know that you are members of VOR, the national organization advocating for your interests. If materials are needed to strengthen your "story", request them from VOR. And don't forget to -----

KEEP VOR INFORMED ON YOUR SITUATION AND PROGRESS!

SECTION 1:
Organization Background and Leadership
Structure



VOR's Mission

VOR is a national organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities.

VOR's Elevator Speech

An "elevator speech" is a short, 15-20 second statement about an organization that is easy to say and quickly informs the listener, keeps their attention, and leaves them wanting to learn more.

VOR's Marketing and Communications Committee put together the following "elevator speech" for VOR members' use when talking with public officials, prospective members, advocates and others about VOR. The first sentence is our actual mission statement. The points that follow sum up what VOR is all about.

As Hugo Dwyer, Chairman of the Committee, stated, "This elevator speech contains our mission and main talking points. Members, however, should feel free to use their own words to get across these main points if they feel comfortable doing so; the 'speech' should. We hope this "elevator speech" assists our dedicated members in their outreach and awareness on VOR's behalf.

VOR's Elevator Speech:

VOR is a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities.

As the only national advocacy organization supporting a spectrum of care options, we offer hope and support for people with intellectual and developmental disabilities, and their families, who are working to protect or secure necessary services.

We advocate for appropriate care at all levels of government.

VOR members are in a unique position to promote VOR and our mission on behalf of people with intellectual and developmental disabilities with others. We hope this "elevator speech" assists our dedicated members in their outreach and awareness on VOR's behalf.

VOR State Coordinator Roles and Responsibilities

VOR State Coordinators are experienced advocates who provide VOR with volunteer leadership in many states. State Coordinators are selected for their effective advocacy in their respective states, as well as their level of involvement with VOR and a commitment to VOR's mission on behalf of individuals with intellectual disabilities.

VOR's Board, staff, members and others count on State Coordinators to help enhance VOR's overall advocacy effectiveness and assist in VOR awareness and growth. Specifically, the role of State Coordinator encompasses two broad objectives:

1. VOR Advocacy Leadership

- **Family/Individual Advocacy:** VOR hears from individuals (often non-members) who are seeking information or assistance in accessing services in a particular state. State Coordinators, who are familiar with their states' service system and policies, provide unmatched knowledge and insights for families in need. VOR State Coordinators, who provide VOR with the ability to be responsive to individuals in need, are a critical part of VOR's overall advocacy program.
- **Legislative Advocacy:** A critical role of State Coordinators is to more widely circulate VOR's Action Alerts – calls to action regarding legislative and government affairs developments that require a strong grassroots response. State Coordinators' reach goes well beyond VOR members. Their assistance in "getting the word" out is invaluable to VOR's grassroots impact.

2. VOR Awareness

As informed and involved advocates, VOR State Coordinators are visible leaders and members in their own states. For this reason, State Coordinators are uniquely positioned to raise awareness among families, advocates, and the general public about the urgency of VOR's Mission, VOR's activities and programs. Awareness opportunities will arise in the media (press releases, opinion editorials, letters to the editor, and interviews); at meetings and conferences; through visits to their family members' care providers; and other locations and opportunities where sharing VOR's information about the organization and our issues will advance awareness of the urgency of VOR's mission.

2. VOR Membership Recruitment

As with the advocacy and awareness role our State Coordinators can play, VOR Coordinators can also leverage their access to families and advocates in their states - people beyond VOR's membership – who would benefit from and be willing to support, VOR.

To help reach these potential members, VOR counts on our State Coordinators to make VOR membership information available at regularly scheduled family group meetings, encourage VOR

membership in newsletters, and otherwise identify opportunities to enhance VOR awareness and increase VOR's membership.

Coordinators are asked to reach lapsed VOR members in their own state or region. Contact lists are provided by VOR staff on a quarterly basis. To maintain accurate records, we ask that each Coordinator send a written report back to staff within 30 days.

Co-Coordinator arrangements are encouraged to help meet the Advocacy, Membership Recruitment and Awareness objective, and we welcome all input.

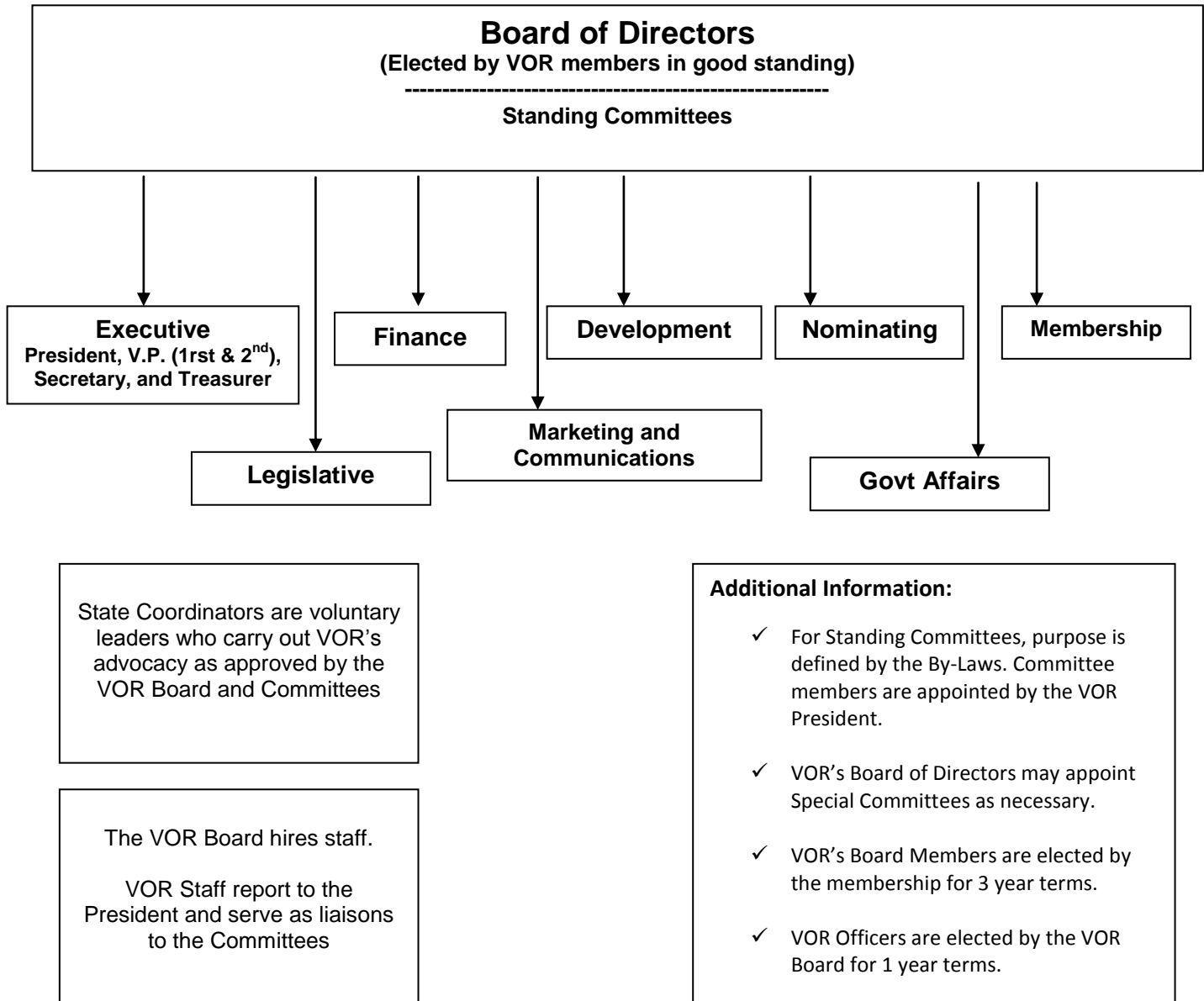
Support and tools provided by VOR for State Coordinators

VOR is here to help State Coordinators be successful. To support VOR State Coordinators, VOR provides our Coordinators with the following tools to assist in their representation of VOR:

- ✓ Regular communication by e-mail sharing news of interest, lessons learned in other states, scheduled stakeholder meetings, and more. Communication between Coordinators is encouraged.
- ✓ The VOR State Coordinator Advocacy Manual and Toolkit (rev. March 2013) will be given to every Coordinator. This will be reviewed quarterly, with Coordinators and staff working together.
- ✓ To assist with membership renewals, a list of current and lapsed VOR members from your State is provided on a quarterly basis, or as needed.
- ✓ **New:** *Quarterly Coordinator Meet-Ups* will be offered by phone or webinar to ensure ongoing communication and networking between VOR and Coordinators. Coordinators will be invited to present at *Meet-Ups* to share success stories and lessons learned.
- ✓ VOR offers State Coordinator “mentoring” between new and veteran Coordinators, upon request.
- ✓ Personal assistance when a VOR staff member or representative is visiting your state.
- ✓ **New:** VOR will assign a State Coordinator Liaison to the VOR Board who will provide a quarterly report to the Board on the State Coordinator program and activities.
- ✓ **New:** Annual awards recognizing outstanding VOR State Coordinators in the areas of Awareness, Membership Growth, and Awareness.
- ✓ Other tools on request that you need to promote VOR.

VOR Organization Leadership Chart

VOR State Coordinators are urged to consider a similar leadership structure to help assist in their state level and local advocacy. Board and Committee involvement help involve more volunteer advocates in carrying out our important mission.



“VOR exists to speak for the voiceless”

VOR Case Statement for Support

VOR is a national, 501(c)(3) organization. Our mission is to advocate for high quality care and human rights for people with intellectual and developmental disabilities (I/DD).

Founded in 1983, VOR has championed individual and family decision-making with regard to all care decisions. We view the right of decision-making and the provision of person-centered services a basic human right and central to ensuring high quality care in appropriate settings.

VOR is distinguished from *all* other national advocacy organizations for people with I/DD as the *only* organization advocating in support of a full array of residential options, including home, community-based and large settings. For 30 years, VOR has been the *only* voice for families whose loved ones with profound I/DD require the Medicaid-licensed, specialized care settings that have been the target of deinstitutionalization for decades.

Aaron, Lauren, Roger, Ian, Danny, and their peers count on VOR’s voice

What if seniors in a picturesque retirement community were forced to relocate into scattered homes across a city because advocates successfully closed the retirement community on the grounds that the seniors’ congregate, specialized services and amenities were too “institutional?” Seniors protested, but their voice didn’t matter.

What if parents of elementary school students read in the newspaper that their children were plaintiffs in a lawsuit involving the closing of their school? The parents protested, but their voice didn’t matter.

What if hospitals closed intensive care units (ICU) in favor of home-based health care, despite the fact that medically-fragile people would be isolated from the specialized care they required and health care costs would skyrocket? Patients and their families protested, but their voice didn’t matter.

If these examples were true, citizens would be outraged and come to the support of these seniors, parents, and patients.

Yet, this same scenario, through aggressive “deinstitutionalization,” is impacting individuals with intellectual and developmental disabilities (I/DD), removing these fragile individuals from their homes, without regard to choice, need, or input from them or their families:

“Was there any consideration for what is best for the residents of [the center to be closed]? My daughter is 44 years old and has lived in [the center’s] cottages since she was about 8 years old.

She is comfortable there, is used to the hubbub, and loves the staff that care for her. She is non-ambulatory, has a mental age of about 2-3 years old, and has seizures. [The center] is about 53 miles from where I live. I am almost 70 years old and never dreamed that they'd pull the rug out from under my daughter's home. I don't think a group home is right for my daughter and surely hope they don't want to move her to a facility that is 3-4 hours away from me. What to do? I am scared." (E-Mail to VOR, August 2012).

Parent and family fear is understandable. There are widespread, well- documented tragedies following closures. These tragedies are predictable because needs are remarkably profound:

Aaron is 32 years old, but has the cognitive ability of a 2 month old infant. He receives 24/7, compassionate support in care facility chosen by his parents. In their words: "Aaron was born 8 weeks premature. While he survived the birth, the lifelong effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. His functional abilities are in the 2-3 month range. Seizures, respiratory insufficiency, frequent pneumonias, cortical blindness, spastic tetraplegia with ever increasing spasticity are just a few of the daily challenges for his caregivers." ~ Aaron's parents and VOR Wisconsin State Coordinators (2012)

Brian is 42 years old, but has the cognitive ability of a young child. He also experiences dangerous behaviors which are well-managed to keep him and other safe in a care facility chosen by his parent. In his mother's words: "Brian was expelled from four homes in two states because of dangerous aggression - he was sent HOME where we had little children. He injured everyone in the family except the baby who was locked away from him and broke hundreds of windows (we repaired them every weekend). Finally, in 1990, a state-operated facility for people like Brian in yet another state provided him the care he needs and continues to serve him well. What apartment building would be right for Brian and which McDonald's has an application with his name on it?" ~ Brian's mother and VOR Illinois State Coordinator (2012)

"Lauren's disabilities and needs are significant. She has severe intellectual disabilities due to corticocerebellar damage and prenatal hyposia, fibrocystic breast disease-bilateral, a seizure disorder, degenerative osteoarthritis of the spine, spastic quadriplegia, and more. Lauren is non-communicative and non-ambulatory. Once, when her bedroom moved from one room to another, she stopped eating." ~ Lauren's sister and VOR Member (2011).

Roger is 50 years old, but has the cognitive ability of an infant. He is medically-fragile and receives high quality, specialized supports in a care facility chosen by his mother. In her words: "Roger suffers from brain damage due to an oxygen deficiency at birth, epilepsy with uncontrolled mixed seizures, profound swallowing problems, brittle bones, optic atrophy with myopia, incontinence, stenosis of his neck and back, peripheral neuropathy and hyper-salivation. Roger is non-verbal and completely non-ambulatory. He gets all nutrition, hydration and medication via a gastrostomy tube." ~ Roger's mother and VOR member from Virginia (2012)

"Danny and Ian are brothers who live in a group home in Ypsilanti, Michigan. They have severe cerebral palsy and profound intellectual disabilities. Facility care was never offered as an option, but services have been cobbled together by their parents and the local community mental health agency. Still, their parents pay for a day program and a private dentist and monitor care at the group home constantly. Many families are not able or cannot afford to fill in the gaps in services.

Now that all the larger facilities for people with developmental disabilities in Michigan have closed, the advocacy groups are trying to close the only licensed facilities left – the group homes.” ~ Danny and Ian’s mother and VOR member from Michigan (2012)

Equally tragic is the fact that more than two hundred thousand (200,000) people are languishing without adequate services across the country. There are so many people waiting for services, we believe, due to deinstitutionalization, which removes people who are receiving services from their homes and adds them to an over-stressed, under capacity system of community-based care, to the direct neglect of those going without services.

“VOR exists to speak for the voiceless” (VOR Membership Survey, 2012). For 30 years, VOR has been the only national voice for affected individuals. For nearly 3 decades, VOR’s advocacy has helped connect countless families to the services their profoundly disabled loved ones require, no matter the setting they choose, and provided many more with advocacy support in an effort to prevent the closure of specialized homes.

It is a classic David and Goliath struggle. It is VOR up against the seemingly unlimited resources of the United States Department of Justice, other federally-funded entities, and many State governments. Their actions are driven by ideology – a blind belief that people are better served in smaller, home-like settings – and by cost-conscious public officials who believe money will be saved. Both notions – increased quality and cost savings – have been shown time-and-time again to be false notions, but ideologues and budget hawks persist.

The stories of abuse, suffering and unexplained deaths among those sent to homes for the disabled in New York State are horrifying. A worker sits on an autistic boy and crushes him to death. Another worker sexually abuses a 54-year-old disabled woman. A quadriplegic drowns as an aide leaves him in a tub of water. As reported in *The Times* over the last year, there have been numerous cases of abuse and at least 1,200 deaths attributed to unnatural or unknown causes in publicly financed homes for the disabled in the last decade. Many cases have barely been investigated, with incompetent workers often being moved to a different facility, without being prosecuted. (“Monitoring Care for the Disabled,” *New York Times*, May 8, 2012).

If not for VOR, the individual and family voice would be missing from all these actions. Through our current national programs – Legislative/Government Affairs, Legal, Family, State Coordinator, Awareness and Outreach, and Annual Conference programs – VOR has combatted deinstitutionalization and embraced true choice with success.

Solutions: VOR Goals

According to the U.S. Census, about 1.2 million adults and 1.7 million children have an intellectual disability. Another 944,000 adults have other developmental disabilities, including autism and cerebral palsy. Other sources estimate that 3% (about 87,000) of all citizens with intellectual disabilities have severe or profound intellectual disabilities. These individuals are most at risk due to the prevailing ideology in support of aggressive deinstitutionalization which eliminates access to specialized care and health care services, as well as constant pressure in many states to limit or eliminate specialized services in the community.

Without VOR, there would be no effective voice for these individuals.

VOR's voice must be loud and effective for these citizens. To this end, VOR is launching a public awareness campaign designed to educate the general public regarding the tragic injustice befalling individuals with I/DD around the country, especially in those areas where a center is threatened (see section on Marketing and Public Relations).

- Increase our membership and donor base so that we can remain a leader in the voice for choice in each state across the nation. Growth in all areas is projected; new sibling members will be one target audience.
- Continue our long-standing Legislative/Government Affairs, Legal, State Coordinator, and Family Advocacy national programs.
- Continue our support for guardianship relationships when in the best interest of the individual, as determined by a court of a law. Counter attacks on guardianship.
- Expand the effectiveness of our Legislative/Government Affairs program by adding an e-advocacy component to allow for enhanced grassroots participation.
- Expand the effectiveness of our State Coordinator program to assist in regionally-targeted membership and financial growth objectives.
- Expand outreach to families whose disabled family members live in community settings without adequate services. Support efforts to assure a full range of community and institutional options appropriate to the individual needs of all people with severe and profound I/DD.
- In 2013, VOR will launch an initiative to identify and pursue uniform, humane quality standards in community settings across all states, with an emphasis on staff competency and access to specialized health care and supports. Although proponents of deinstitutionalization promise a better life in the "community," the promise is far from well-documented reality, resulting in tragedy for thousands of impacted citizens.

Why You Should Care and Invest in VOR

VOR has the good fortune of having families of individuals with I/DD as our leaders, members and donors. The family connection results in an understandably unmatched commitment to our advocacy. As one reporter observed:

"Seeing Terry and Glenda and how they are with Jamie, I also feel a sense of gratitude for people like the LaFleurs. I cannot remember the last time I met people so kind, selfless and genuinely good. Jamie is a beautiful spirit - an 'angel,' as Terry calls her - who still has that sense of wonder that we all, at some time or another, wish we still had. She may not have wings, but Jamie, like her mother and father, are all angels of the same feather." ~ "Angels of a Feather," by Nancy Duplechain (*Bonnes Nouvelles Evangeline*, July 2012, featuring Terry LaFleur, VOR Board Member, and daughter Jamie).

Thanks to VOR, the LaFleurs and families like theirs across the country do not have to advocate alone. VOR has always been there for individuals with I/DD and their families, no matter where they reside. With VOR's help and its expansion goals, many more families will gain awareness and appreciation for VOR, including the general public. "VOR is the *only* organization that truly listens." (Membership Survey, 2012).

Whether you are a family member of an individual with I/DD, a friend, advocate or average citizen, we should all care about the least of our brethren.

Thank you for your support.

For More Information, Please Contact:

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Three Steps to Take the Fear of Fundraising to “Friend-Raising” and Enthusiasm

(Adapted for VOR from an [article](#) by Gail Perry, *Fired Up Fundraising*)

It won't surprise readers, that we want VOR leaders and members to be fully active in fundraising.

We know what how this sounds, but with this article, we would like you to consider approaching fundraising with a completely new perspective.

The bottom-line is this:

**The act of raising money is an effort to make the world a better place.
It is some of the most important work we can all do on the front lines causing change for the good.**

Granted, most people don't think of it that way. Many people are stuck in the “tin cup” attitude - equating fundraising with begging. Instead of the highest form of human activity - helping our fellow man – many of us turn it into one of the lowest.

So, here are four steps that will help take many of you, on VOR's behalf, from a fear of fundraising to understanding and willingness. These steps will help give you a whole new perspective about raising money that is far more empowering and inspirational.

Step One: Re-think Fundraising - Fundraising Is Not about Money

It's about changing the world.

Consider this question: “How do you feel when you write a check to your favorite organization?” Most people respond like this: I feel proud ... joyous ... glad I could do it ... wish I could do more ... happy ... giving back ... part of something important ... powerful.

These same emotions, which many of you experience when donating to your favorite organizations, are the very emotions other donors feel when they give money. When a donor makes a gift, he or she becomes a partner in a cause that is bigger than just one person's life. That donor's life and legacy are enhanced. To work for important purposes, to take part in solving problems of great magnitude gives deeper meaning even to daily routines. People want to be involved in something with meaning.

So instead of being embarrassed, nervous, or anxious about fundraising, members can shift their perspective and realize that donors are also happy and joyful when they are giving. Here's the disconnect: too often people get stuck in fear - all focused on themselves – instead of focusing on the donor and their shared experience of wanting to change the world.

We hope that this shift in focus helps put you at ease and gives you fresh inspiration and energy to take action!

Step Two: Seek Friends, Not Donors – It is all about relationships

Friend-raising, not fundraising. Friends are better for organizations than donors.

After all, what will your friends do for you? They will be interested in what you are up to, they will stick with you, they will help you out, they will spread the word, and, when the going gets tough, they will be there with you.

Of course, most friends are also donors – donors who want to be drawn into the real work of the organization. They want to be treated like real people and not wallets. What better job for VOR members than to make current and potential donors into true friends of the organization?

The more friends our members can make for our cause, the stronger and more successful our work will be. The larger the number of people who have been personally introduced to the work we do, the better we fare.

It is easy to assume that the real work is the direct solicitation of funds, but “the talking up” part of the job is equally important. If a nonprofit is a bright spot on its community’s radar screen, so to speak, then that visibility will make the fundraising so much easier and more successful.

Community buzz is so important. Members to be active in the community on behalf of VOR. “Active” can mean lots of things: talking up the organization; introducing new people to its work; bringing in friends and volunteers to help in different ways; and, yes, helping to acquire money and resources.

Friend-raising is something all members like to do and are proud to do - and it is a most valuable and needed fundraising function.

Step Three: You Don’t Have to Solicit

Let us focus our leaders and members on friend-raising and many other jobs in the fundraising process. I say we take soliciting out of the picture and get our leaders and members hard at work developing friendly relationships for our organization all over the community, state, region, world - wherever our mission takes us.

There are so many activities related to fundraising (outside of soliciting) in which we need their help. For those in an organization who are not ready to take on solicitation, we can ask them to do everything else in the fundraising cycle: help create new friends and supporters, help thank and involve current donors.

Our fundraising cycle starts with identifying potential donors, then cultivating, engaging, and involving them. When they are ready, we ask for their support, and finally we thank, thank, and thank them again so they will join our bandwagon and be our friends for the long run.

Smart staff members can show leaders and members all the other ways they can contribute in fundraising without “asking.” They will begin to see just how little time is spent in the “asking” phase of the cycle, compared with all the many other activities we undertake with our donors.

They need to understand that fundraising is very much more than simply soliciting. Developing a relationship with a donor, particularly for a major gift, is a lengthy process with many delicate steps.

VOR leaders and members can help in the other myriad activities of the process, when we are simply making friends and building relationships, which of course leads to giving - and long-term giving, at that. Members can host tours, throw parties for their friends, patio parties, create community buzz, ask everyone they know for help, and personally thank donors.

As experienced fundraisers will tell you, the more emphasis we put on cultivating, thanking, and informing donors, the easier, and more natural, the “asking” will be. The more one is involved in actually helping to cultivate a donor, then they will be much more willing to help – eventually - with a solicitation.

We hope this article leaves you thinking about fundraising in a brand new way. It’s about supporting VOR’s cause and encouraging others to share your excitement and support the cause too!

Thank you!



VOR's National Family Advocacy Program

Family-to-Family Advocacy: **An important role for VOR State Coordinators**

Family empowerment is central to carrying out VOR's Mission on behalf of people with intellectual and developmental disabilities. In addition to equipping families with information and grassroots advocacy tools, VOR leverages its network of state and local leaders when one-on-one assistance is needed. VOR's Board Members, State Coordinators, key members and staff can often provide to families the personal assistance they need to effectively navigating their states' systems and access critical services. The systems serving people with intellectual and developmental disabilities in each state are complex. For a family in crisis, a helping hand from a seasoned advocate is warmly welcomed and critically necessary to ensure vulnerable individuals don't fall through the cracks.

SECTION 2: LEGISLATIVE ACTION

VOR's Legislative and Government Affairs Program

VOR's Legislative Advocacy at Work:

VOR Washington Office

Larry Innis
Washington Representative
529 Bay Dale Ct.
Arnold, MD 21012-2312
410-757-1VOR (1867)
<http://www.vor.net>

Director of Government Relations and Advocacy

Tamie Hopp - VOR
P.O. Box 1208
Rapid City, SD 57709
877-399-4VOR toll free
605-399-1624 direct
605-399-1631 fax
thopp@vor.net

VOR Legislative and Government Affairs Committees

vor.net/contact-us/committees

The Mission

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

"Never doubt that a small group of thoughtful, committed people can change the world; indeed, it's the only thing that ever has." –

Margaret Meade

Effective legislative and government affairs advocacy in support of choice and family empowerment has been a hallmark VOR program for 30 years.

VOR, independently and in coalition with other organizations, regularly initiates Action Alerts, informational updates, and personal meetings to federally advance its Mission on behalf of people with intellectual disabilities and developmental disabilities (I/DD). Issues include, but are not limited to –

- ✓ Developmental Disabilities Assistance and Bill of Rights Act reform, including legislation to restore individual and family/guardian rights in Protection & Advocacy and Department of Justice federally-funded lawsuits involving Medicaid-licensed facilities (ICFs/ID).
- ✓ Preservation of choice
- ✓ Access to quality community living, including adequate oversight and staff training
- ✓ Medicaid, Medicare, and Social Security

VOR's year-round legislative advocacy is complimented by its pinnacle event, the **Annual Meeting and Washington Initiative**. In Washington, D.C., event attendees hear from speakers of national prominence, receive training and information from VOR's legislative and government affairs leaders, network with each other, and collectively meet with every member of Congress to share VOR's written presentation.

VOR leaders are also in regular communication, including personal meetings, with officials representing the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, the Administration on Developmental Disabilities, and the Department of Justice, in addition to Members of Congress.

VOR's Legislative and Government Affairs advocacy program also includes state level advocacy. VOR supports its state organizational affiliates by drafting legislative proposals, position papers, action alerts, and media communication. VOR representatives also communicate in writing, by phone and in person with state legislators and their staff, as well as the media.

VOR's advocacy on behalf of people with I/DD is unfettered by profit motive and is loaded with common sense. By focusing its message on choice and family empowerment, VOR has developed a positive relationship with legislators and other policymakers on behalf of people with I/DD.

What is lobbying?

Under IRS regulations, "lobbying" is defined as:

***a communication**

***to legislators** (or urging the public to contact legislators)

***intended to influence specific legislation**

Under IRS rules lobbying does not include:

***Making available the results of nonpartisan analysis, study, or research;**

***Discussing broad social issues, without mentioning specific legislation;**

***Communicating with a government official or employee, other than for the purpose of influencing legislation;**

***Communicating with members of your organization with respect to legislation and expressing a view about the legislation so long as the communication does not encourage members to take action regarding the legislation;**

***Providing technical advice or assistance to a government body, or to its committee or other subdivision, in response to a *written request from the chair* of that body; and**

***Self-defense communications with a governmental body regarding legislation which would affect your existence, your powers or duties, your tax-exempt status, or the deductibility of contributions to your group (Note: fighting cuts in government funding for your cause is not self-defense) (Source: Center for Nonprofit Management).**

Lobbying by Nonprofits is Legitimate, Encouraged and Protected

There are two standards by which nonprofits' compliance with the IRS Code is measured.

The oldest and best known is the "**insubstantial part test**," which, since 1934, has required that "no substantial part of a charity's activities . . . be carrying on propaganda or otherwise attempting to influence legislation." "Substantial" is not further defined and, since charities which exceeded this vague standard risked losing their exemptions, many arbitrarily limited themselves to a tiny amount of lobbying. And many still do.

The other standard is the "**section 501(h) expenditure test**." In 1976, Congress made lobbying more worry-free by passing legislation that gave public charities the right to lobby up to 20% of their annual overall expenditures, without any risk to their exempt status (Source: "Worry-Free Lobbying for Nonprofits," Alliance for Justice, 2000). **A nonprofit may make a 501(h) election by filing a simple 1-page form that only requires a nonprofit to give its name, EIN, address and date (see, Form 5768, <http://www.irs.gov/pub/irs-pdf/f5768.pdf>).**

TIP: It's the money you spend on LOBBYING that counts

With or without a Section 501(h) election, the IRS is concerned about how much money an organization spends on lobbying – not necessarily how much time and energy. When volunteer, grassroots efforts drive a lobbying event, only the cost of the event to the organization counts towards IRS limits. The cost to participants and any donated supplies (e.g., stamps, phone calls, etc.) do not count toward lobbying expenditure limits.

TIP: A donation to an organization that lobbies is not lobbying

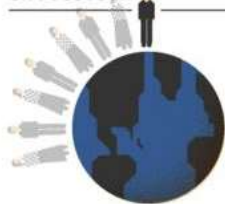
Nothing under IRS rules prohibits an organization or foundation from giving to a nonprofit that lobbies. If the donor is also a nonprofit (e.g., a family organization or foundation), and is concerned about its own lobby limits, the donor simply should not earmark the donation for lobbying purposes. A general donation, or one that is earmarked for a specific, non-lobbying project, is not spending money on "lobbying" as the IRS defines it.

What nonprofits CAN'T do

Supporting or opposing any candidate for elected office, even in nonpartisan races, is strictly prohibited and can result in loss of your tax exemption.

For More Information: "Frequently Asked Questions about Lobbying and Advocacy by Nonprofits," Center for Nonprofit Management, <http://www.cnmsocal.org/resources/leadership-and-governance/faq-lobbying-and-advocacy.html>

1 out of every 8 people on earth are on Facebook



9 out of 10 US internet users are on a social network



Social Media: An Advocate's New Frontier

Social media, such as Facebook and Twitter, offers advocates a low cost, highly efficient way reach like-minded advocates beyond your core list of supporters with call to actions, compelling news, events, and requests for membership and financial support.

It is the potential exponential outreach – beyond those advocates with whom you communicate directly – that makes Social Media so effective. “It only takes a few clicks from a number of our members to help increase our internet presence, resulting in a wider circulation of our message, greater awareness of our shared mission, more advocacy, and increased members and donations,” wrote Hugo and Cristy Dwyer, co-chairs for VOR’s Marketing and Communications Committee.

Congress and Social Media

More and more, organizations are turning to social media to “keep the volume turned up” to bolster their efforts on behalf of their causes. “Members of Congress are increasingly using these outlets to gauge constituents' concerns,” said one expert, Michael Cowden, the American Health Care Association’s (AHCA) Manager for Grassroots and Member Advocacy. “AHCA is turning to Facebook and Twitter for its Saving Our Seniors initiative to be sure we share our message on all fronts and start 2013 right.”

A [2011 study by the Congressional Management Foundation](#), confirms that most Members of Congress have thoroughly integrated Facebook into their communications operations, and are using the technology to gauge public opinion, communicate with constituents, and reach new people. More than 500 members of Congress have an official Facebook page and many maintain a separate campaign page, findings show.

A [2012 study](#) confirms this trend: “As social media popularity has increased in the United States, so has the use of social media by Members of Congress. Communication technology developments of the 20th century, such as email, changed the way Members interact with their constituents, the media, and other interested parties. Common social media platforms including Facebook, Twitter, and YouTube are now routine communication tools for Members and their staffs, and the rapid pace of development in social media will continue to shape interactions between Members of Congress and the public.”

Get Connected with VOR!



www.vor.net



/VOR



@VOR_NET



info@vor.net

On the Web

VOR's Social Media 101's

To encourage more social media use to advance VOR's mission, VOR has published a series of “101s” on social media favorites – Twitter, Facebook and LinkedIn.

For copies of our Social Media 101's, see “[Social Media: Connecting Choice Advocates](#)” on VOR's website (www.vor.net), under “Get Involved, VOR Initiatives.”

Effective Grassroots Lobbying: How to approach your legislators

The following pages are intended to provide simple but effective guidelines on how to influence state or federal elected officials who represent you and your family member with intellectual disabilities.

Whether by letter or in person, your goal is to always provide reliable, honest information based on personal experience and knowledge as a parent, guardian, family member and/or advocate.

Lobbying Tip:

Get to know your legislator on a personal basis. Volunteer in his/her office. Help with mailings or answering phones. Go to the "town hall meetings."

You should provide legislators and their staff with written information that will help them arrive at a logical and responsible decision that will be in keeping with the outcome you are seeking. The more they hear from you and others, the more their awareness level on that subject increases, and the greater is your opportunity to prevail.

Remember, like all of us, legislators have a learning curve. It is our job to help an elected official become more educated and more comfortable with an issue that is vital to you, their constituent. They need and want your help in telling them how legislation would affect people in their district.

The following tip sheets are enclosed:

- 1.** Tips for Calling Your Legislator
- 2.** Tips for Writing Your Legislator
- 3.** Tips for Meeting Your Legislator
- 4.** Events to Connect Elected-Officials and Constituents:
Legislative Days and Legislative Fly-Ins
- 5.** Tips for E-Mailing Your Legislator

**EFFECTIVE LOBBYING IS BASED ON FRIENDLY, INFORMATIVE,
RESPECTFUL, LONG-TERM RELATIONSHIPS.**

Tips for Calling Your Legislators

Plan: Before you make the call, plan what you are going to say. Your phone call will be very brief, so keep your message simple and to-the-point. Take a moment to think about it—you might even want to make some notes—and you'll find that your call goes more smoothly than if you were to call "off the cuff." **Know your request in as few words as possible, for example, "Please support Senate Bill 5."**

Message: After identifying (and writing down) your request, think about a key point or personal story that supports your position.

Call: Make the call. If your legislator is in your home district on specific days or on weekends, call them when they are in your home district. There is more time and less distraction, and your position as a constituent will be enhanced if you are talking on "home turf."

Staff or Message: You may not be able to reach your legislator at the Capitol. Be prepared to talk to one of the legislator's staff or to leave a message instead. Make sure you get the staff person's full name, and treat them with respect.

Constituent: Begin by stating that you are a constituent or that you are calling on behalf of a constituent. Legislators are most responsive to the people who can keep them in office—their constituents. If you voted for the legislator, mention that as well.

Persuade: Get to the point. State the reason for the call.

Thank You: **Regardless of their position, thank the legislator for his or her time.**

Recruit: Recruit a like-minded friend, family member, or colleague to make a call as well. Particularly with phone calls, **quantity is critical. Legislators pay attention to issues when they believe that many of their constituents care about that issue.**

Report: Report your call. When you're part of a grassroots lobbying effort, your participation is helpful only if the people mobilizing the effort know about it. Let your grassroots organization know that you made the call, and report anything of importance that the legislator said.

Call Back: Call more than once and get your family, friends, neighbors, co-workers and others to call. Quantity is as important, if not more important, than quality in grassroots advocacy, because a high number of calls indicates to a legislator that many people in their district care about an issue. As you monitor the issue, call back to ask for specific support or action as is appropriate to the process.

Source: Wisconsin Energy Cooperative

Tips for Writing Your Legislators

Begin by stating that you are a constituent or are writing on behalf of a constituent. Make sure you write your return address on the envelope, so that the legislator's office staff knows immediately that you are a constituent. If you are sending an e-mail, state that you are a constituent in the subject line.

Personalize your letter. Research consistently shows that handwritten letters have the most impact. In making your case on the issue, use personal examples to further distinguish your letter and briefly describe your family member's situation – level of intellectual and developmental disability and the supports he/she requires. Include with your letter a fact sheet on intellectual disabilities that defines and describes the different levels of intellectual disabilities.

If the legislator has supported your issues in the past, acknowledge this. Give reasons why the legislator must continue or intensify his or her support.

Show restraint. Keep your letter brief—one to one-and-a-half pages at the most.

Quantity Counts. Persuade a like-minded friend, family member, or colleague to write a letter as well. Again, quantity is critical. Legislators pay attention to issues when they believe that many of their constituents care about that issue.

Follow up. In the letter, ask your legislator for a response. To get a better picture of your legislator's position, consider following your letter with a phone call or visit.

Report your letter. When you're part of a grassroots lobbying effort, your participation is helpful only if the people mobilizing the effort know about it. Let your grassroots organization know you wrote the letter, copy the President and/or the Legislative Committee Chairperson, and what you intend to do to follow up.

Communicate more than once. Again, **quantity is important.** As you monitor the issue, communicate with the legislator through phone calls, additional letters, e-mail, or visits to ask for specific support or action as appropriate to the process.

Source: Wisconsin Energy Cooperative

SAMPLE LETTER

Dear Senator/Representative Doe,

My name is Mary Louise and I am a constituent. I had the pleasure of meeting you during your visit to Peabody, KY. I am writing to urge you to strongly oppose any proposal to cut or cap (block grant) the Medicaid program.

Medicaid provides the crucial services such as long-term supports and services and therapy that people with disabilities need – people like my SON/DAUGHTER/COUSIN/FRIEND/ETC with intellectual disabilities. HE/SHE receives crucial, life-sustaining supports from the Medicaid program (DESCRIBE YOUR FAMILY MEMBER/FRIEND AND THE SERVICES THEY NEED).

Cuts or caps to Medicaid will create enormous hardship for Floridians with intellectual disabilities who, like my family member, rely on Medicaid for their essential health care services.

We urge you and your colleagues to oppose any Medicaid cuts and/or caps. Thousands of constituents in our state, including my family, and around the country, are counting on you to do the right thing. Thank you in advance for your support.

Sincerely, NAME, ADDRESS, PHONE, FAX, E-MAIL

Tips for Meeting Your Legislators

Plan your meeting. Decide whether you are going alone or with others. If you go as a group, decide who is going to lead the meeting and what each person is going to contribute to the discussion. This will help eliminate awkward silence or repetitive messages and will ensure that you hit all the key points you want to cover. You will likely have only 15-20 minutes for your meeting, so plan accordingly.

Make an appointment ... but don't be surprised if it changes. Legislators often have last-minute hearings or committee meetings. **Be flexible.**

Know your audience. Do a little research about your legislator if you don't know him or her. Once you're in the door, begin by finding something personal that you have in common with the legislator. Engage in a little "small talk" to break the ice—but keep it brief. If at all possible, find out his or her position on the issues you're focusing on.

Define your message. Tell your legislator that you are visiting to ask for his or her support for your issue. Plan two or three observations that get at the heart of your position. Describe your loved one!

Meet in your home district. Meetings in the home district are often less hurried than meetings at the Capitol, and they provide the "home turf" advantage. Find out when your legislator is in his or her home district and schedule your appointment then, or if your workplace illustrates your position, invite them to visit you. If that's not possible, travel to the Capitol.

Lobbying Tip:

When meeting with your legislator, don't be tempted to overstate your case, fudge the facts, exaggerate, or guess. If you do, you'll never be trusted again.

Invite comments and questions. Engage your legislator in dialogue.

Don't worry if they ask you something you don't know the answer to—simply tell them you don't know, but that you'll find out and get back to him/her.

Prepare written "leave-behind" information and pictures: It helps to provide your legislator with brief, written information and pictures of your family member for further reflection. Make sure it contains the local angle for your district, if at all possible.

Ask for a commitment. If you don't ask your legislator for action, you won't see any. If they decline, encourage them to think about it, and let them know you'll keep in touch. Follow up. Send a handwritten thank-you note to your legislator. Let them know that you appreciate their time. If you promised to get them additional information, provide it or let them know how and when they can expect to receive it.

Visit more than once. Over time, visit with your legislator to continue to discuss issues and make requests as you have them. **Be sure to be a reliable source of information for them on your issue by delivering what you promise, avoiding overstatement, and communicating clearly.**

Events to Connect Constituents with Elected-Officials: Legislative Days and Legislative Fly-Ins

Seeing is believing:

Invite your legislators to visit your family members' facility

Family organizations across the country have organized Legislative Days, Legislative Breakfasts/Lunches, Legislator Appreciation Days, and Receptions. **Held on the facility's grounds**, all such events **include a tour of the facility**. These events are a great way to introduce your elected officials to their constituents with intellectual disabilities and the publicly-supported services they require. These events also provide families with the opportunity to build positive relationships with legislators.

To organize a legislative event at your facility, begin your planning by communicating with your most influential legislative contact.

Lobbying Tip:

You can link to your state legislature's website by going to the NCLS website (www.ncsl.org/public/leglinks.cfm)

At your state legislature's site, you'll find contact information for state legislators, days the legislature is in session, parking logistics at your state capitol building and more.

Grassroots organizations are encouraged to obtain and distribute legislative contact information to their members.

Legislative "Fly-In" Initiative: Visiting your state capitol

An Initiative or "Fly-In" is when as many families and advocates as possible visit your state capital on a single day, carrying a single, prepared message.

Key Points:

- ✓ Schedule meetings with legislators and/or their aides in advance. Get to know the legislative aides personally through regular, respectful, communication.
- ✓ Sponsor a bus or vans to make transportation easier for participants.
- ✓ **Prepare "leave-behind" documents that are hand-delivered to every state legislator to achieve a consistent message.**
- ✓ Plan a participant briefing to prepare everyone. This may occur on the bus or at the Capitol. A supportive legislator may reserve a conference where you can convene, have refreshments and plan for the day(s).
- ✓ Pictures of your family members are a very effective way to convey your message and introduce legislators and aide to the population with intellectual disabilities.
- ✓ **Send thank you notes to legislators and their aides following the Initiative.**

***A Summary: Cost Comparisons of Community and Institutional Residential Settings:
Historical Review of Selected Research***

**Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green
Mental Retardation, Volume 41, Number 2: 103-122, April 2003**

By Kevin K. Walsh (January 23, 2009)

In the 2003 article noted above a review of selected literature was undertaken to determine the validity of institutional vs. community cost comparisons. A number of methodological problems were identified in the literature reviewed that compromised much of the earlier research on the topic. Additionally, a number of considerations were outlined – source of funds, cost shifting, cost variation, staffing, and case mix – that need to be taken into account when such comparisons are undertaken.

The question has arisen whether the conclusion of this 2003 review, that large savings are not possible within the field of developmental disabilities by shifting from institutional to community settings, remains current.

For the reasons explained below, we find that the 2003 article continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers.

As such, the study will continue to be useful in policy discussions in states. Several factors point to why the study's conclusions remain valid in 2009:

Review Article. As a review article, the 2003 publication does not generate new data; that is, it reviews previous research. Because of this, the article is more resistant to becoming outdated. Those reading the article, however, would do well to keep in mind that the studies reviewed in the article employ cost figures that existed at the time the original research articles were published. Therefore, while the findings and conclusions drawn in Walsh, et al. (2003) will continue to be timely, the actual cost figures may need to be adjusted to current levels.

Stability of the Components. Because the service and support landscape remains, in large part, similar in 2009 to 2003 and before, the conclusions of Walsh, et al. are likely to hold. For the most part comparisons reviewed generally compared congregate ICF/ID settings and community-based residential settings (typically group homes) funded under the Medicaid HCBS waiver. Although many states have been moving toward personal budgets and fee-for-service models, group homes continue to be a primary community residential service setting. In this way also the conclusions of the 2003 article continue to be applicable.

Stability of the Issues. As noted, the 2003 article presented descriptions of various considerations that affect cost comparisons across states. Because the structural components of the issue have remained unchanged (e.g., institutional settings, group homes) and the funding models have remained largely intact (i.e., Medicaid ICF/ID and HCBS waivers), the various factors affecting them, for the most part, remain as presented in Walsh, et al.

That is, there remains a great deal of cost variation from institutional to community settings as described in the article; cost shifting, as described in Walsh, et al., is to some extent likely to be structurally fixed in most states owing to the nature of state governments. That is, when certain costs disappear, when individuals are transferred from ICF/ID settings, it is highly likely that these costs will reappear in other state budgets (such as Medicaid). In nearly all instances, this is almost unavoidable. In short, costs don't just disappear when individuals are moved.

Based on the forgoing, it appears that the conclusions drawn in the 2003 article continue to be valid. – KKW (Jan. 23, 2009)

Intermediate Care Facilities for People with Intellectual Disabilities Provide Life Sustaining Quality of Care to Residents

Intermediate Care Facilities for People with Intellectual Disabilities (ICFs/ID) provide the least restrictive, cost effective, comfortable, and safe homes for the most needy, the most fragile, the most disabled citizens of our country. ICF/ID residents have multiple disabilities, extreme functional limitations, chronic medical conditions and/or behavioral challenges. Residents benefit from federal assurances that certain quality of care standards will be met, including access to health care, appropriate staffing ratios, and attention to therapeutic needs.

The United States Supreme Court recognized the need for ICFs/MR when it stated, “We emphasize that nothing in the ADA or its implementing regulations 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., 119 S. Ct. at 2187). Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” 119 S. Ct. at 2191

ICFs/ID residents are participating members of the community.

ICFs/ID routinely involve the residents in community life through participation in community events, such as the theatre, parks, restaurants, church, and other activities. Most large ICFs/ID also invite community neighbors to participate at center activities through regular volunteer opportunities and events.

ICFs/ID are a good state investment.

The lifeline services in facilities are provided cost effectively due to the extensive and specialized needs of the residents – needs that must be provided for regardless of setting – as well as tenured and fairly compensated staff. Peer-reviewed research has shown that transferring individuals from large settings to smaller settings will not necessarily save money, if all services are provided and adequately funded (Walsh, et al., *Mental Retardation*, Vol. 41, Number 2, April 2003).

A Future Vision for all Large ICFs/ID.

Large private and state-operated ICFs/ID are ideally situated to be Community Resource Centers by providing out-patient health care services to community-based individuals with intellectual and developmental disabilities, as well as to coordinate developmental disability curriculum for students and staff at nearby vocational schools, colleges, and universities. This proven model, established in several states, is a solution to providing access to health care where it is often lacking, making community placements more successful and happy, while maintaining the high quality services to residents.

The services people receive in Medicaid-licensed Intermediate Care Facilities for People with Intellectual Disabilities (ICFs/ID)

This comprehensive assortment of federally-certified professional therapeutic, dietary, health care, recreational, and residential services is required by the neediest, most fragile, and most disabled members of our society. Group homes – even those homes that are certified by the Centers for Medicare and Medicaid Services (CMS) – do not provide the same level of programming, with the same assortment of onsite, specialized services, as ICFs/ID. For some ICF/ID residents the provision of professional support and health care is required for their very survival.

Medical	Dental	Behavioral psychology	Clinical social work	Dermatology
ENT	Gastroenterology	Gynecology	Neurology	Nursing
Nutrition	Occupational therapy	Physical therapy	Orthopedics	Ophthalmology
Pharmacology	Psychiatric	Podiatry	Pulmonology	Lab work
Speech/ language therapy	Therapeutic recreation (e.g, swimming, equestrians, etc.)	Vocational assessment, training and opportunities (on and off campus)	Wheelchair clinics/Rehab engineering	Assistive technology/ communication augments/ switch activation
Audiology	Respite Services	Habilitation	Staff and Student Training (classroom/on-the-job).	Residential, including dormitory, group homes, private rooms, cottages, apartments.
Direct care for activities of daily living (eating, dressing, bathing/hygiene, toileting, mobility, etc.)	Sensory integration/ Stimulation Room	Pet therapy	Respiratory therapist	QMRPs
Family Support and Advocacy Organizations	Active Treatment Services	Transportation	Library	Nutritionist/ Dieticians
Religious services/ chapel	Human Rights Committee	Cafeteria, private kitchens, Canteens	Restaurants and stores open to public	Other services not noted here

For more information:

Background and Milestones – ICFs/MR (http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/downloads/ICFMR_Background.pdf)

Characteristics of Residents of Large Facilities (Chart, page 39). (<http://rtc.umn.edu/docs/risp2010.pdf>)

An invitation to visit an ICF/ID (<http://vor.net/legislative-voice/37-additional-dd-act-reauthorization-resources/103-an-invitation-to-visit-an-icfmr?q=visit>)

Model State Legislation in Support of Choice of Residential Settings for Persons with Intellectual and Developmental Disabilities

VOR is a national nonprofit advocacy organization supporting the right of individuals with intellectual and developmental disabilities (I/DD) to receive high quality care and support in residential settings based on individual need and choice, whether that is a family home, own home, community living arrangement, or facility-based care.

Most states opt, as part of their Medicaid plan, to provide services to some people with I/DD the option to receive services in Medicaid funded and certified Intermediate Care Facility for Persons with Intellectual disabilities (ICFs/ID). ICF/ID residents are the neediest, most fragile, and most disabled citizens of in your state. ICFs/ID provide cost effective, comfortable and safe living for them. A vast majority of the families and guardians of ICF/ID residents are very satisfied with the care their loved ones receive.

Yet, the very existence of ICFs/ID is threatened in many states. Often, the decision to downsize or close an ICF/ID is made unilaterally by a State's Governor or his/her designee (hereafter, "State's Administration"), without any involvement of the state's legislature.

Legislative Proposal in Support of Choice

The decision to downsize or close an ICFs/ID should not be made unilaterally by a State's Administration. When an ICF/ID is closed, a state's most fragile citizens are removed from their long-time home and often separated from life-sustaining specialized services. Furthermore, nearly every state has thousands of people waiting for services. The decision to eliminate any service option must rest in the hands of one governmental entity.

The following outlines a model legislative proposal that takes the best of several state laws where the legislature has regained control and is in charge of any closure decision that may be proposed. This model also includes ample opportunity for the legislature to hear from all stakeholders and consider all potential ramifications of a proposed closure.

Summary of the Model State Legislation

This proposed bill is modeled after Kentucky Revised Statutes –

- Chapter 210.045, Additional duties – Requirements as to closure of certain state owned or state operated facilities: <http://www.lrc.ky.gov/KRS/210-00/045.PDF>
- Chapter 210.047, Facility Closure Hearing – Required considerations: <http://www.lrc.ky.gov/KRS/210-00/047.PDF>
- Chapter 210.049, Applicability of notice provisions to pre-existing closure announcements -- Delay of hearings. <http://www.lrc.ky.gov/KRS/210-00/049.PDF>

The proposed bill contains the following components:

- (1) Gives the legislature ultimate discretion regarding the closure of ICFs/ID;
- (2) Requires that the Administration give 60 days notice to the legislature and immediate family members/guardians of any intent to propose downsizing or closure; and

- (3) Requires a public hearing to give all stakeholders an opportunity to be heard as well as to provide an opportunity for consideration of all aspects of the closure including but not limited to: resident health and welfare, community capacity (residential and healthcare), oversight, and the ultimate projected cost of closure (including the cost of serving the residents in the community).

Similar laws have also been passed in **Illinois** ([State Facilities Closure Act](#), the legislature, through the budget process, gets the final word on facility closures, after filing with the legislative Commission on Government Forecasting and Accountability which holds public hearings and reviews the fiscal impact of the closure.), **South Carolina** (SC Code, 44-20-365, "Closing regional centers to be authorized by law. No regional center of the department may be closed except as authorized by the General Assembly by law in an enactment that specifies by name the regional center to be closed"); and **Oklahoma** (OK Statutes, 56-3050, "The Department of Human Services shall not close state-administered resources centers . . . until authorized by the Legislature . . ."). In addition, SB 402 was introduced in **Florida** (see, SB 402 (2006), <http://www.flsenate.gov/data/session/2007/Senate/bills/billtext/pdf/s0402.pdf>).

Detailed Provisions of the Model Legislation

LEGISLATIVE CONTROL

Subject to certain notice of intent requirements, and only after the passage of a state law by the legislature, may a state Administration close any state-owned and operated ICFs/ID.

In the case of a demonstrated health and/or safety emergency that necessitates the gradual or immediate closure of an ICF/ID, the State Administration may seek relief from the requirements of this section in the Circuit Court of the county where the facility is located.

NOTICE

The State Administration shall --

- (a) At least sixty (60) days prior to the next legislative session, provide written notice to the Legislature of its intent to propose legislation or in any manner permit or encourage immediate or gradual closure of any state-owned and operated ICFs/ID, except in the case where there is a demonstrated health or safety emergency in which ten (10) days notice of intent to file an emergency petition in Circuit Court is required; and
- (b) At least sixty (60) days prior to the next legislative session, provide written notice by registered mail to each resident, his or her immediate family, if known, **and** his or her guardian, of its intent to propose legislation to permit immediate or gradual closure of any state-owned and operated ICFs/ID, except in the case where there is a demonstrated health or safety emergency in which ten (10) days notice of intent to file an emergency petition in Circuit Court is required; and
- (c) Include in the written notice that the resident, the resident's immediate family, his or her guardian, or any other interested party with standing to act on behalf of the resident has the right to pursue legal action relating to the notice provision of this paragraph and relating to the closure of the facility.

The State Administration shall be subject to the notice of provisions of this Act within ten (10) days of passage of this proposed legislation (and/or the effective date within), for any ICF/ID that the State Administration has announced plans for closure prior to passage of this legislation.

PUBLIC HEARING

If the State Administration proposes the immediate or gradual closure of any state-owned and operated ICF/ID, the State Administration shall –

(1) Hold a public hearing and provide all stakeholders, including residents and their immediate family members and guardians, and each member of the legislature, notice of the hearing by registered mail.

(2) The hearing shall be held at least 30 days prior to the beginning of the legislative session. Notice shall be provided 60 days in advance of the hearing.

To ensure the health and welfare of the affected residents, the hearing shall at minimum include testimony on the following –

- (1) Community capacity, including adequate staffing, health care, and experienced community providers.
- (2) Total cost of downsizing and closure.
- (3) Effect of the downsizing on facility residents.
- (4) Individual and community monitoring and safeguards to protect health and safety.
- (5) The process used to develop a community living plan.
- (6) Assurances of family/guardian involvement in the development of the plan.
- (7) Responsibilities of state and local governments.
- (8) The process used to transfer ownership or the state's plan to reuse the property.
- (9) Plan for reemployment of state workers.
- (10) Other issues identified by the legislature, the resident, family member or guardian, or other interested parties.

For more information, please contact: Tamie Hopp, VOR Director of Government Relations and Advocacy, 605-399-1624, thopp@vor.net.

SECTION 3: PUBLIC RELATIONS

VOR National Awareness and Outreach Program

Public Relations Update:

In addition to educating the general public to garner broader support for VOR's Mission, ***reaching the media*** is one important ***public relations*** tool that helps enhance awareness of the good work that VOR does.

VOR's Board of Directors, in June 2010, agreed to expand VOR's public relations program. In furtherance of this objective, in 2012, its Marketing / Communications Committee was made as a VOR Standing Committee.

Media placement of VOR's perspective via letters to the editor, opinion editorials, and quotes in newspaper articles can be a powerful vehicle for educating the public, and influencing legislative and legal policy.

An important VOR priority is reaching the media and raising VOR awareness among families, professionals and policymakers. Efforts include press releases, social media outreach, media interviews with VOR board members and staff, VOR letters to the editors and opinion editorials. VOR also accomplishes its mission on behalf of people with intellectual and developmental disabilities (I/DD) by providing drafting support for letters to the editor and opinion editorials for our state affiliates and members.

VOR has enjoyed success reaching the media and raising VOR awareness:

- ✓ VOR regularly issues [press releases](#) on important issues and we share [VOR updates and other news](#) with thousands of advocates each week via email.
- ✓ VOR's Facebook (/VOR) and Twitter (@VOR_NET) help promote VOR awareness, as well as disseminate news and issues of relevance to our members and followers.
- ✓ VOR has been quoted in the *Washington Post* on an issue relating to the use of "mental retardation." VOR was also quoted in a Connecticut newspaper regarding tragic events involving two individuals with I/DD and their parents, events that received national media attention. Recently, VOR's Director of Government Affairs has been quoted by the *Associated Press*, the *Oklahoman*, the *Tulsa World*, and other newspapers.
- ✓ Opinion Editorials (Op/Eds) written by VOR staff for state leaders appeared in the *St. Petersburg Times* (Florida), *The Baltimore Sun* (Maryland), and the *Sun Times* (Chicago).
- ✓ VOR letters to the editor have appeared many papers, including in the *Christian Science Monitor* (national), *the Daily News Tribune* (Massachusetts), *the Sacramento Bee* (California), and *the News-Press* (Florida). VOR letters were submitted to the *Herald-Leader* (Kentucky), the *Des Moines Register* (Iowa), and more. VOR State Coordinator letters also have been printed in newspapers throughout the country.
- ✓ VOR staff and board members regularly grant interviews with reporters from across the country who seek a national perspective relating to a local issue impacting people with I/DD.

Reaching the Media: Tips for Writing Printable Letters to the Editor

Opinion Editorials ("Op-Eds")

On the opinion page of most newspapers you will see long editorials written by guest columnists. Often these columnists are community leaders or individuals with a particular expertise about a timely issue. These are called "Op-Eds" and, if accepted by the newspaper for print, allow for more space to express your views than the standard letter to the editor.

To secure approval for an Op-Ed, call and/or meet with editorial boards. The editorial boards on newspapers often meet with community members, and sometimes will either accept an Op-Ed or write an editorial based on information they receive from these meetings.

Ask for a meeting with your local paper's editorial board, make a case for your issue.

An example Op-Ed follows on page 34.

Letters to the editor can be powerful vehicles for influencing or inspiring public debate, making the case for your issue, or responding to related events. In addition, elected officials always read the opinion pages of their local paper, because it gives them an idea of what their constituents think. The trick is to write a letter that the editors find compelling enough to print. Use these tips to write a letter that is more likely to get printed.

Capitalize on the hot stories. Find ways to tie recent news stories in with your issue. Open your letter to a reference to the recent event, and then quickly build a logical bridge to your issue.

Keep it brief. Most Letters to the Editor should be under 250 words. Edit your letter aggressively.

Be clear. Avoid jargon, use common vocabulary, and let a few friends or colleagues review the letter before you send it.

Use word cues to underscore your point. For instance, preface your major conclusion with "The important thing is ..." If you have research that makes your case, preface the facts with "Research shows that ..."

Don't overlook neighborhood weeklies and smaller papers. Often these publications have more room for letters, and community papers have very large readerships.

Include a call to action or solution. If you are illustrating a need or making a case for a specific action, include a line about what people can do to help.

Don't be afraid to toot your own horn. If you or your organization is involved in work that addresses the issue, include that in your letter.

Be passionate, but not poisonous. There is a difference between "fire in the belly" and righteous indignation. Avoid sarcasm, and if you're very angry, cool off a bit before sending a final version.

Use local or personal angles. All grassroots strategies rely on the "local" angles and the "personal" angles in an issue. Include this perspective to illustrate why readers should care about the issue

Source: Wisconsin Energy Cooperative

SAMPLE LETTERS TO THE EDITOR

Best Place Scenario
Philadelphia City Paper
November 8, 2012

There simply can be no comparison between a White Haven Center resident, whose cognitive ability equals an infant, and Jean Searle, who was *inappropriately* institutionalized 30 years ago and has since received supports and has been working as a receptionist. ("[A bitter battle over how PA serves people with disabilities](#)," October 25, 2012). Would society demand that an infant has the right to live in an apartment and work in an office? **Of course not.** Yet that is what closure advocates and the State call for in a legal settlement that will displace hundreds of fragile people. Citizens are encouraged to trust that dedicated families – not advocates or government lawyers – know best. **(Letter stats: 112 words)**.

Julie Huso, *VOR Executive Director*

(VOR is a national organization supporting a full range of residential options for people with disabilities. VOR participated as *amicus curiae* in the Benjamin appeal discussed in this article).

LETTER: Applauds Murphy's Call For Group Homes Probe
The Harford Courant
March 6, 2013

U.S. Senator Chris Murphy seems like the only person who is being proactive about a serious issue that is getting attention around Connecticut and other states [March 5, Page 1, "Murphy Calls For Federal Investigation"].

I not only agree with Sen. Murphy's call for an investigation of these awful conditions for the developmentally disabled, but I believe that mandatory inspections of these privately run homes and government-financed facilities should be required by the state.

There is clear evidence that this issue merits immediate action, for we do not know when an act of neglect will happen again that results in a death for one of these citizens. I hold Connecticut to a high standard, and for the state to brush off this type of serious situation in which the lives of citizens are being pushed to the side not only makes me disgusted, it makes me question whether the Department of Developmental Services has citizens' best interests at heart. **(Letter stats: 112 words)**

Molly Martin, *Ellington*

Wall Street Journal
October 10, 2005

I hope your paper will continue to educate readers about our nation's citizens with severe disabilities and the insidious elimination of the very public service systems upon which they and their exhausted families rely. States are closing and downsizing their institutions – not because they aren't doing a good job with the limited funds they receive (they are) and not because families don't choose and support the facilities (they do) and not because they aren't cost effective (they are). Litigation and intense lobbying by group opposed to "congregate" care are the cause of the closures and downsizing of the safety net for persons with intellectual disabilities. **(Letter stats: 105 words)**

Carole Sherman, *Little Rock, Ark.*

(Mrs. Sherman is the mother of John, age 36, a long-time resident of Arkadelphia Human Development Center, a licensed intermediate care facility for the mentally retarded).

Example of Opinion Editorial (Op/Ed)

Op/Ed Tip:

To secure approval for an Op/Ed, call, e-mail and/or meet with the opinion editor of your paper and “pitch” your idea. Editors and editorial boards often meet with community members, and sometimes will either accept an Op-Ed or write an editorial based on information they receive from these meetings.

Don't play politics with the future of Wyoming's most disabled citizens

Casper Star-Tribune * February 3, 2013 by Connie Howard, VOR State Coordinator

Residents of the Wyoming Life Resource Center, and their families and friends are facing an uncertain future.

My son, Mark, has profound intellectual disabilities. For his entire life, I have been a disability advocate, seeking adequate care for him and his peers. My interest is truly making sure my son and others with disabilities have the care they need, whether they are living with family, in a small community setting (like my son), or at WLRC.

Unfortunately, time and again on my advocacy journey, I find myself dismayed that politics so often factor into decisions which should transcend politics. After all, we are talking about care for the least of our brethren. They deserve our support, not our threats.

The present threat involves the future of our most fragile of our Wyoming citizens – residents of WLRC. WLRC, located in Lander, is a specialized-care facility providing exceptional, highly specialized care to 90 individuals with profound intellectual, developmental disabilities, and traumatic brain injuries. These individuals require help in all aspects of daily care and most are also medically fragile or experience severe behavioral challenges.

WLRC residents and their families have weathered past threats. In 1990, the Wyoming Protection & Advocacy filed a class action lawsuit that sought improvements at the facility and more community living options for residents. Standing alone, these objectives are ones I readily support. In fact, the lawsuit can be credited for the exemplary facility that WLRC is today. However, P&A has not stopped there and continues to press lawmakers to move all residents out of a care setting that they call home and that serves them very well.

At its core, P&A's motive is ideological. Without regard or respect for individual need and choice, P&A believes all people are better served in small settings. Some members of our Legislature seem to agree and will also suggest that closing WLRC will save the state money. Not surprisingly, any suggestion that money will be saved turns heads and tends to lead discussion to conclusions that do not have individual need and choice in mind.

This brings me to the present day threat. The Wyoming Senate is currently debating House-passed Bill 68, a proposal to determine whether WLRC residents can be transitioned into smaller settings. Understandably, families of both center residents and community-based residents have voiced concerns. Families of center residents worry that the purpose of the bill is to close the center. Families of people in the community worry that community programs which are already stretched beyond any reasonable measure will face even greater challenges if their clients have to compete with residents leaving WLRC for access to already insufficient resources. In fact, WLRC already helps some non-residents with access to professional services, an existing valued partnership that should be increased but will be lost if lawmakers support WLRC's closure.

To date, amendments have been offered to help make HB 68 more balanced. These amendments would shift the focus from transitioning WLRC residents to a consideration of the most efficient model of care, regardless of setting, and would also require study of how WLRC's specialized services could better support non-residents.

WLRC is home to its residents, in every sense of the word. Homes on the center's campus average less than six persons per home and the facility receives exemplary reviews from state and federal surveyors. Residents enjoy home-like settings with immediate access to the compassionate and professional direct care and health care supports they require.

HB 68 is the latest threat, but is a real and present one. The amendments supported by families would make the bill much better and the resulting study of greater value to Wyoming taxpayers. It is in no one's interest to close the Wyoming Life Resource Center. Wyoming has a proud history of equality and the responsibility of every state is to the health, wellness, and safety of its residents. As citizens, we have a moral obligation to care our fragile neighbors. WLRC is providing compassionate, cost effective supports. It's a state jewel worth supporting. **(670 words)**

For Immediate Release

November 6, 2012

For More Information

Julie Huso, Executive Director

Jill Barker, VOR Board Member (Michigan)

**National Disability Advocate VOR to Present at
St. Louis Center Parents' Association Event**

Julie Huso, Executive Director of VOR, a national advocacy organization for people with intellectual and developmental disabilities, will speak at the St. Louis Center in Chelsea, Michigan, on Sunday, November 11, 2012 at 5:30 pm, following a meeting of the center's Parents' Association. Jill Barker, a member of VOR's national Board of Directors and representative of Friends of DD, a Michigan-based organization, will also present.

VOR advocates for high quality care and human rights for all people with intellectual and developmental disabilities across the country. The St. Louis Center is a residential community and learning environment providing for the physical, emotional, and spiritual needs of children and adults with intellectual and developmental Disabilities.

Huso, who has served as VOR's Executive Director for nearly five years and has worked as a disability advocate for more than 25 years, will deliver a presentation titled, "Choices for a Lifetime, Options for All," relating to national disability trends impacting people with intellectual and developmental disabilities in Michigan and across the country.

"Like so many facets of our lives, the economy is impacting the care received by people with intellectual disabilities," said Huso. "Individuals in all settings, and their families, face service cuts and cost shifting. The people served by the St. Louis Center and others in Michigan and across the country who depend on the compassionate care they receive from others and face an especially uncertain future."

"In Michigan, many specialized programs for people with developmental disabilities have been cut or closed over the years," added Barker. "Yet, some programs like the St. Louis Center remain threatened because of proposed new federal rules which would redefine what constitutes 'community' and cut funding to those programs that don't measure up."

In her presentation, Huso will touch on these trends which are impacting people's lives, including an effort by advocates and governments to close places like the St. Louis Center in favor of smaller, often unlicensed home care settings.

"Ideology and budget cuts often trump common sense and result in the closure of these good programs. Families are the most informed and should be the primary decision-makers. Working together, families can be an effective voice and counter harmful trends," stated Huso.

The presentation, "Choices for a Lifetime, Options for All, will begin at 5:30 at the St. Louis Center, following a meeting of the St. Louis Parents' Association. For more information about the St. Louis Center, including the services it offers and its location, visit <http://www.stlouiscenter.org>.

About VOR: VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. Offering community, legal, medical and educational resources for families of individuals with special needs, VOR is committed to providing help for people with disabilities. Standing up for long term care facilities and community disability programs, VOR is dedicated to maintaining family choice for people with intellectual and developmental disabilities. For more information about VOR, please visit us at www.vor.net.

For Immediate Release

December 19, 2012

For More Information

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**VOR Calls for Mental Health Reform -
Extends Heartfelt Sympathy For Sandy Hook Families and Community**

VOR, a national organization advocating for high quality care and human rights for people with intellectual and developmental disabilities, joins the chorus of heartfelt sympathy expressed for the families and friends of the victims of the Sandy Hook tragedy. While many citizens and organizations are taking aim at gun control, VOR believes that systemic reform of disability and mental health policies is critically necessary to prevent future violence.

"Politics over diverse issues have divided our nation," said Julie Huso, VOR Executive Director. "There can be no justice for these senseless killings in Connecticut and elsewhere, but uniting as a nation will get us as close to healing as possible and help prevent tragedies in the future."

"We can't tolerate this anymore," stated President Barak Obama, as he addressed a grieving nation Sunday night. "These tragedies must end, and to end them, we must change." ([Transcript of President's Remarks](#), reprinted by *The Washington Post*, December 16, 2012)

For 30 years, VOR has been calling on Congress to support specialized treatment options for people with profound intellectual and developmental disabilities.

"Too many people who need help have nowhere to go, are turned away, are displaced from specialized care, or are not adequately treated and monitored," said Huso. "Patients' rights have trumped almost completely safety – to self and others -- in the name of 'deinstitutionalization' and 'integration.'"

Decades of deinstitutionalization has resulted in the depletion of an adequate safety net for people who need our help.

"Our mental health system has completely failed individuals with severe mental illness and their communities," said Doris A. Fuller, executive director for the Treatment Advocacy Center, a nonprofit organization which advocates for timely and effective treatment of severe mental illness. "We have emptied the nation's hospitals, gutted state and local mental health programs, and turned involuntary treatment into a debate point instead of using it as a viable option to prevent tragedy involving those

too ill to help themselves.” [[Treatment for Mental Illness Should be as Easy to Get as Guns](#), Treatment Advocacy Center (December 14, 2012)].

Beginning in the 1960s, closing specialized care centers for people with developmental disabilities and mental illness – “deinstitutionalization” – was meant to advance the civil liberties of those inappropriately institutionalized by offering care and supports in a less restrictive environment.

Some advocates, however, say deinstitutionalization has gone much too far. Today, people with profound developmental disabilities and health concerns, and those with severe mental illness, are being removed from highly specialized care or prevented from accessing such care in the first place.

“What began with altruistic motives – namely, better and more appropriate care for disabled people – has spawned into something very different,” remarked Huso. “Today, very fragile people are being forced from their homes under the belief that money will be saved and quality of life will improve.”

“We’re protecting civil liberties at the expense of health and safety,” says Fuller.

“Deinstitutionalization has gone way too far.” (“[Seven facts about America’s mental health-care system](#),” *The Washington Post* (quoting Fuller) (December 14, 2012))

VOR calls for reform, beginning with a moratorium on deinstitutionalization

Tragedies will continue to befall people with I/DD, children, adults, and citizens if our laws and policies continue to support deinstitutionalization, depriving people with disabilities of needed specialized, residential care and treatment.

“Over and over again, news investigations and state audits show that these very fragile individuals need comprehensive, skilled care. They are the ICU residents of the disability community. Scattering them in homes around a community only separates them from qualified staff, life-sustaining health care, oversight, and friends,” said Ann Knighton, VOR’s president.

“Prison is now the last resort for the mentally ill,” wrote Liza Long, whose son, Michael has severe mental illness. [“[I am Adam Lanza’s Mother](#),” by Liza Long (*The Blue Review*, December 14, 2012)].

President Obama vowed to use “whatever power this office holds to engage my fellow citizens, from law enforcement, to mental health professionals, to parents and educators, in an effort aimed at preventing more tragedies like this.” ([Transcript of President’s Remarks](#), reprinted by *The Washington Post*, December 16, 2012)

Yet, a significant part of the problem begins at his doorstep, says VOR.

“Significant federal funds and energies by powerful federal agencies are dedicated to deinstitutionalization,” said Tamie Hopp, Director of Government Relations and Advocacy for VOR. “The Justice Department has pursued more than 30 legal actions which at their core aim to displace individuals from specialized care options. In Georgia, a Justice Department settlement calls for moving 9,000 people with mental illness from mental health facilities by 2015.” (“[Olmstead: Community Integration for everyone](#),” U.S. Department of Justice’s Olmstead Enforcement Website); ([U.S. v. Georgia Fact Sheet](#), U.S. Department of Justice (October 19, 2012)

Likewise, in a move that VOR characterizes as “reckless,” the National Council on Disability, an independent federal agency, last month released a 300 page policy document and toolkit calling for the closure of all “institutions,” which it defines as any setting larger than 4 people. [[“Deinstitutionalization: Unfinished Business,”](#) National Council on Disability (November 2012); [“Reckless disregard shown for the needs and choices of vulnerable persons with severe and profound disabilities,”](#) VOR (December 2012)]

“As a nation, the Sandy Hook tragedies have left us heartbroken,” said Hopp. “Families of individuals with profound cognitive disabilities recognize the reform that is needed better than most. Their sons and daughters need highly specialized treatment. Instead federal agencies, some state governments and advocates, are putting energies into removing their loved ones from treatment”

We agree with the President. “This must end.” ([Transcript of President’s Remarks](#), reprinted by *The Washington Post*, December 16, 2012).

-End-

About VOR: VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. Offering community, legal, medical and educational resources for families of individuals with special needs, VOR is committed to providing help for people with disabilities. Standing up for long term care facilities and community disability programs, VOR is dedicated to maintaining family choice for people with intellectual and developmental disabilities. For more information about VOR, please visit us at www.vor.net.

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Individuals With Intellectual And Developmental Disabilities, And Their Families Seek the Gift of Choice

Some families of individuals with profound intellectual and developmental disabilities (I/DD) seek a gift that can't be wrapped.

Simply, choice.

Across the country, "deinstitutionalization" – a decades-old movement that since 1960 has resulted in the closure of 200 state-operated "institutions" – continues in earnest. With visions of sterile halls and segregated living, many Americans assume that this once well-intentioned movement is a good thing.

"History is both a lesson and curse for families like mine who family members require highly specialized care in licensed facilities," said Ann Knighton, President of VOR, a national organization advocating for high quality care and human rights for people with I/DD. It's the only national organization of its kind that supports the now reformed specialized "institutions" for people with profound intellectual disabilities, while also supporting the expansion and improvement of smaller residential settings.

"Many family advocates were on the front lines decades ago successfully transforming the institutions of old to the federally licensed, highly specialized homes they are today. Unfortunately, the old image still sticks with people," said Knighton. "Family advocates are now working hard to champion choice by fighting to save residential centers while also advocating for much higher quality standards in community programs."

Knighton's daughter, Erika, has profound intellectual disabilities and a host of medical issues, making daily survival something to celebrate.

Erika is one of more than a 100 residents of the East Central Georgia Regional Hospital in Augusta, Georgia. Also known as Gracewood, the hospital is federally licensed and provides highly specialized care and a compassionate home to its residents.

Across the country, about 160 federally-licensed, state-operated residential programs like Gracewood, and several hundred private centers, serve medically fragile or behaviorally dangerous individuals who also have profound intellectual disabilities. Stringent federal requirements are reviewed annually ensuring consistently high quality care in areas relating to staffing, onsite health care, nutrition, and "active treatment" - programming designed to help individuals gain new skills.

Big still considered bad

These very facilities, designed to serve the most disabled, however, continue to fall victim to "deinstitutionalization." However, unlike the early decades of this movement when less disabled people were inappropriately placed and conditions of care were a concern, today deinstitutionalization is motivated primarily by integration – the ability for disabled people to interact with nondisabled people more readily.

Yet, families whose loved ones receive care at facility homes will argue that their lives are far more integrated on their expansive and open campuses than they could ever hope to achieve in a four person home on a busy street.

"Along with other family members I checked out some smaller residential settings that were being pitched as an alternative to the Bellefontaine Center [in St. Louis, Missouri] where my brother lives," said Mary Vitale. "Some of the homes had no exterior devices to assist disabled residents and several were located in high crime areas with collapsing buildings and abandoned properties. The promise of 'community integration' was far from reality."

One federally funded agency, the National Council on Disabilities (NCD), is so fervent in its desire to close all federally-licensed residential homes that it recently published a 300 page policy document and toolkit arguing the "unfinished business of closing

state-run institutions and other public and private institutional settings . . . should be a top public policy priority in every state where such institutions exist.”

“Families whose individuals will be displaced from their homes if states act on NCD’s recommendations were not consulted,” remarked Julie Huso, VOR’s Executive Director. “Their voices should matter most, but they were completely ignored. NCD is not alleging that these programs are bad, only that they are too big. Remarkably, NCD feels that four people in a home is too “institutional.”

NCD is not the only threat. Family advocates find themselves up against a veritable Goliath as they desperately defend their choice of care for their loved ones. The U.S. Department of Justice, federal advocacy agencies, and some State Governments all seek closure of larger programs, arguing people can be served cheaper and better in the smaller settings.

Families strongly disagree.

“You get what you pay for,” said Knighton. “Over and over again, news investigations and state audits show that these very fragile individuals need comprehensive, skilled care. They are the ICU residents of the disability community. Scattering them in homes around a community only separates them from qualified staff, life-sustaining health care, oversight, and friends. Tragedy is predictable.”

Forgotten Families

Linda Lotzi is her sister, Lauren’s, primary advocate. As her legal guardian, she found herself challenging a lawsuit by a federally – funded agency to close Lauren’s home.

“They [federal advocacy attorneys] filed this lawsuit claiming to represent Lauren. They had never met Lauren, yet these attorneys decided that Lauren would be happier and better served in a new home,” said Lotzi. “White Haven [in Pennsylvania] has been her home for 40 years. Once, when she moved just from bedroom to another, she stopped eating. I have no idea why the attorneys didn’t consult with me.”

Families like Lotzi are fighting back with the help of attorneys referred to them by VOR. A grateful Lotzi is now serving on VOR’s national Board of Directors.

“VOR listens – really listens – to the families,” says Lotzi. “My involvement with VOR has enabled me to with families all across the country who are facing similar threats. This is truly a national crisis.”

Knighton agrees. “In Georgia, we are facing the closure of all specialized residential services due to a Justice Department Settlement,” said Knighton. “Erika could lose her home.”

“Justice Department officials boast about stakeholder involvement. Yet, here I am – a mother and a state and national leader in disability advocacy. No one thought to ask my opinion. All we want is a voice and choice. It’s our right as parents.”

The concern about lack of family involvement in legal actions that seek to close licensed homes has received Congressional attention. A federal bill, with broad bipartisan support, would address this very concern. It would not prevent lawsuits, but would require that federal attorneys only file suits on behalf of informed and willing individuals. Such a change, argues VOR, would help ensure that existing federal laws requiring residential choice, are more consistently enforced.

“The law is on our side,” said Huso. “Families need help enforcing it. Help from attorneys, help from Congress, help from state. All these families seek is respect – respect for the informed choices they have made for their family members with intellectual and developmental disabilities.

-End-

About VOR: VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

Coming Soon:

Updated VOR Press Kit

SECTION 4: LEGAL ADVOCACY

VOR's Legal Advocacy Program

Choices for a Lifetime, Options For All

Recent Legal Highlights

- VOR participated twice as *Amicus Curiae* and secured for families pro bono counsel in a **Pennsylvania** P&A lawsuit that seeks to close ICFs/ID
- VOR's Past President served as an expert witness for **Arkansas** in its defense of **Conway** Human Development Center against the claims of DOJ. The DOJ case was dismissed by a federal judge.
- VOR has provided significant support to **Virginia** families who are intervenors in a DOJ lawsuit against the State of Virginia.
- VOR's *Amicus Curiae* brief is quoted in the landmark Olmstead Supreme Court decision ("Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution").
- **Tamie Hopp**, VOR's Director of Govt Relations & Advocacy, has provided legal advocacy support to Illinois families of private ICF/ID residents, including an affidavit in support of the families' motion to oppose a dangerous settlement agreement.

Justice regarding residential placement options for people with intellectual disabilities is best achieved when those most familiar with the needs of the residents are involved (see, Heller v. Doe, 509 U.S. 312, 328-30 (1993)). Yet, families are often excluded from litigation that will directly impact their loved one's care.

VOR's ***Choices for a Lifetime, Options for All*** legal advocacy program minimizes the injustice of excluding families by defending choice and empowering families in the legal system. VOR assists in various ways, as appropriate to each circumstance:

- ✓ VOR provides advocacy and education through the provision of expert witness referrals and supportive documentation (e.g., sample pleadings, precedent, and studies on cost and quality).
- ✓ With the help of VOR's volunteer Pro Bono Coordinating Counsel and staff, VOR arranges for pro bono or reduced fee expert legal representation or consultation on a case-by-case basis. To date, VOR has helped families in nationally significant legal situations in AR, CA, CT, FL, IL, MA, MD, NJ, PA, TN, VA and WA. The value of pro bono legal representation secured for families has exceeded \$800,000.
- ✓ Through *Amicus Curiae* ("friend of the court") participation. VOR has submitted *Amicus* briefs in three Supreme Court cases (Olmstead, Garrett and Heller) and five federal district Court cases (Cramer, Parsons, Ricci, Martin and Brown), with a 75% success rate on the issues briefed by VOR.
- ✓ VOR offers grassroots organization and advocacy training to help achieve positive media and legislative outcomes on issues directly impacting the outcome of the lawsuit.
- ✓ In its publications, VOR provides its membership and others with legal news and updates relating to the field of intellectual and developmental disabilities.

Often a classic David and Goliath struggle, VOR's ***Choices for a Lifetime, Options for All*** legal advocacy program has successfully empowered families to champion their family members' right to secure services in settings appropriate to their extreme needs.

Olmstead Supports Residential Choice!

The Supreme Court, in its Olmstead ruling, recognized the need for a range of services which respond to the varied and unique needs of the entire disability community:

- (1) Unjustified institutionalization is discrimination based on disability.
119 S. Ct. 2176, 2185 (1999).
- (2) The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when –
 - “(a) the State’s treatment professionals have determined that community placement is appropriate;
 - (b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
 - (c) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” 119 S. Ct. at 2181.
- (3) A majority of Justices in Olmstead recognized an ongoing role for publicly and privately-operated institutions: “We emphasize that nothing in the ADA or its implementing regulations 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.” 119 S. Ct. at 2187.
- (4) A plurality of Justices noted:

“[N]o placement outside the institution may ever be appropriate . . . ‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times-perhaps in the short run, perhaps in the long run-for the risks and exposure of the less protective environment of community settings’ for these persons, ‘institutional settings are needed and must remain available’” (quoting Amicus Curiae Brief for the American Psychiatric Association, et al). 119 S. Ct. at 2189.

“As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’[quoting VOR’s *Amici Curiae* brief].” *Id.*
- (5) Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” 119 S. Ct. at 2191.

1993

The Developmental Disabilities Assistance and Bill of Rights Act

“Individuals with developmental disabilities and their families are the **primary decisionmakers** regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(1993) (*Findings, Purposes and Policies*) (**emphasis added**).

1999

Olmstead v. L.C., 119 St. Ct. 2176

“We emphasize that nothing in the ADA [Americans with Disabilities Act] or its implementing regulations 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.” 119 S. Ct. 2176, 2187 (1999).

2000

DD Act Amendment

“Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, **including regarding choosing where the individuals live from available options**, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(2000) (**amended language**).

Residential Choice: It's The Law

Congress in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and the U.S. Supreme Court in its landmark *Olmstead* decision have confronted the same questions of community integration, individual needs and residential choice for people with severe intellectual and other disabilities. In each case, they have reached the same conclusion: *While community integration is preferred for most individuals, some individuals have needs that are so great that they require facility-based care. The ultimate decision whether to leave a facility resides with the individual and his/her family/legal guardians, not with “professionals.”*

Both the DD Act and *Olmstead* embrace individuality – recognizing that people with disabilities have very diverse needs. Yet, time and again, federally-funded organizations charged with upholding the rights of all individuals with intellectual and developmental disabilities, work in the media, legislatures and the courts to eliminate one of those choices – Medicaid-certified and funded Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/ID).

These practices have forced the transfer of thousands of individuals, against individual and family choice, from ICFs/ID that specialize in meeting their extreme needs. In far too many cases, the results have been unnecessary abuse and even death (see, <http://vor.net/resources/general/abuse-and-neglect-document>).

Reform and Reauthorization of the DD Act

The DD Act was last reauthorized in 2000. Congressional scrutiny is long overdue.

Across the country, individuals with intellectual disabilities receive highly specialized, 24/7 quality care in our nation's ICFs. Their families/legal guardians call on Congress to reauthorize the DD Act *with reforms* to ensure adherence to the Act's requirement - and *Olmstead's* mandate - to **respect family decisionmaking regarding residential choice**.

For more information about *Olmstead* and VOR, visit
<http://www.vor.net/olmstead-resources>

EXAMPLE OF VOR ADVOCACY LETTER EXPLAINING OLMSTEAD and RELATED PRECEDENT

COPY

January 15, 2010

Kareem Dale, Esq.
Special Assistant to the President for Disability Policy
Eisenhower Executive Office Building
Pennsylvania Ave., NW and 17th St.
Washington, D.C. 20500

Dear Mr. Dale,

On behalf of VOR, I am writing to express our serious concerns about statements and actions by the United States Department of Justice (DOJ) Civil Rights Division with regard to its positions and initiatives relating to "*Olmstead* enforcement." We are concerned that these actions are motivated by an ideology against federally-licensed Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) that is not in the best interests of the residents, is not supported by the residents' family members and guardians and is not supported by law, including *Olmstead*.

If the DOJ persists in its attacks against residential choice, our nation's most fragile citizens with intellectual disabilities will have their living options narrowed significantly and, if history is any guide, may suffer serious harm as well.

I. A Note About Conditions of Care

To be clear, VOR does not dispute DOJ's involvement to address allegations of poor quality of care. Indeed, the Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. § 1997a et seq., authorizes the Attorney General to conduct investigations and litigation relating to **conditions of care** in state or locally operated institutions. VOR members whose loved ones receive services in ICFs/MR cite their loved one's happiness and comfort, compassionate, high quality care, and the annual federal oversight, resulting licensing, and the daily opportunities by many people to witness and report alleged abuse as critical to their support of the ICFs/MR setting. Family members take great comfort in the knowledge that if anyone has done wrong by their loved ones, it will be quickly addressed.

Systemic concerns about **quality of care** in licensed facilities are relatively few, but when these concerns are identified, they are corrected or the facility closes. In contrast, many if not most community programs are "out of sight, out of mind." Problems are most often brought to light when industrious newspaper reporters do some digging and release alarming investigative reports about the abuse, neglect and even death found (see, e.g., <http://vor.net/get-help/toolkit-for-families/quality-of-care-abuse-and-neglect-in-community-settings>, reporting examples of systemic abuse, neglect and death in community systems of care in more than 25 states and Washington, DC).

II. Enforcing Olmstead:

Recent DOJ statements and actions indicate that ideology is motivating policy

A. Olmstead Briefs: Disregard for Personal Choice

At the 2009 Annual Convention of The Arc of the United States in November, Deputy Assistant Attorney General Samuel R. Bagenstos pledged that the Civil Rights Division has “no more important challenge than” enforcing *Olmstead*, calling the decision the *Brown v. Board of Education* of the disability rights movement for the advancement of civil rights, vowing to push the law forward in the “unsettled areas that remained after the Supreme Court’s [Olmstead] decision.”¹

Already DOJ is aggressively pursuing its interpretation of *Olmstead*. Since Mr. Bagenstos’ November 13 presentation, DOJ has filed *Olmstead*-related briefs in cases in New York (Nov. 24, 2009); Virginia (Nov. 24, 2009); Connecticut (Nov. 25, 2009); and North Carolina (Dec. 23, 2009)².

Plaintiffs in the Virginia, Connecticut and North Carolina cases did NOT raise concerns regarding conditions of care. In each of these cases, Plaintiffs and DOJ argued that the respective states violated “Olmstead’s integration mandate based on the manner it chooses to administer the services its [sic] provides to individuals with disabilities,” including the settings in which it offers services and the allocation of resources for these services. (*The Arc of Virginia v. Timothy Kaine, et. al*, DOJ Brief at 1-2).

The Virginia case is particularly illustrative of VOR’s claim that DOJ is motivated more by ideology than by law. In that case, The Arc of Virginia sued in its organizational capacity to challenge the rebuilding and downsizing of Southeastern Virginia Training Center (SEVTC), a state operated ICFs/MR, arguing that the State’s plan to commit resources to rebuild SEVTC “put all residents of SEVTC at risk for placement in the new, segregated facility.” The State filed a Motion to Dismiss. DOJ participated as *Amicus Curiae* to oppose dismissal, arguing that the State’s plan to rebuild SEVTC was a ripe ADA (*Olmstead*) violation.

The Court disagreed and, on December 17, 2009, granted the Commonwealth’s Motion to Dismiss, finding that the claims were not ripe for adjudication. Central to the Court’s decision was a finding that the State plan with regard to SEVTC included assurances that individual choice would be honored:

“Thus, ***the argument made by ARC and the United States [DOJ] regarding risk of institutionalization fails to account for a key principle in the Olmstead decision: personal choice.*** And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it.” (*Arc of Virginia* at 22, emphasis added) (*see also*,

¹ Mr. Bagenstos full presentation can found on the DOJ website at:
http://www.justice.gov/crt/speeches/bagenstos_speech_arc.pdf

² See, <http://www.ada.gov/briefs/adabrief.htm>, for DOJ’s list of American with Disabilities Act (ADA) briefs, including in ADA Title II litigation, citing *Olmstead*.

Stanley Ligas, et al. v. Barry S. Maram, et al., 05 C 4331 (N.D. Illinois, July 7, 2009) (denying proposed settlement and decertifying class on finding that the named plaintiffs failed to meet the criteria set forth in *Olmstead* because class definition was not restricted to individuals who were eligible for, and desired, community placement.).

In its argument opposing dismissal, DOJ offered a cursory, somewhat patronizing, discussion of the *Olmstead* decision's personal choice requirement:

"However, to contend that individuals with disabilities will have such a 'choice' requires that community-based services be available and that individuals are fully informed of these opportunities. Defendants attempt to reassure this Court that it will not place individuals in the new facility if they would prefer to live in the community, however, no support is offered for how the State would ensure this commitment is fulfilled." (DOJ Brief at 10, citation omitted).

In *Arc of Virginia*, the Court directly addressed the inconsistencies between the obvious ideological motives behind the action and the *Olmstead* decision:

"[Dismissing for lack of ripeness] will also avoid lending a judicial hand to the real objective behind the action which, as Arc's counsel expressed at oral argument, is to eliminate all institutional housing of persons with mental disabilities anywhere. Whether that is, or is not, a desirable goal is beyond the purview of the courts. And, the Supreme Court has held that 'nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.' [citation omitted]. Indeed throughout the remainder of the opinion, the Supreme Court acknowledged that such facilities likely would continue to be required."

B. Olmstead-Only Cases

In his presentation to The Arc in November 2009, Mr. Bagenstos also stated that it was DOJ's intent, over the next year, to use federally established CRIPA jurisdiction to investigate "*Olmstead*-only cases, in which we sue a state for violating *Olmstead* **but do not at the same time challenge the conditions** at its facility."

In further support for deinstitutionalization actions that have nothing to do with conditions of care, DOJ has also expressed support for Protection & Advocacy's (P&A) deinstitutionalization litigation, arguing in one case support for P&A's associational standing:

"The standing of the protection and advocacy organization to bring this case is of considerable importance for enforcement of ADA. The Department of Justice has limited resources and cannot address every violation of title II of the ADA; private litigation is an integral component of effective enforcement of the ADA. (*State of Connecticut Office of Protection and Advocacy for Persons with Disabilities, et al. v. State of Connecticut, et al.*, DOJ Brief at 13).

VOR takes no comfort in DOJ's support of P&A to "carry the ball" in these cases. As a federally-funded organization itself, P&A has evidenced itself to be as ideologically driven as DOJ with regard to *Olmstead* interpretation. In a report evaluating the progress of *Olmstead* implementation, the

national association for P&As – the National Disability Rights Network -- expressed renewed hope that the new DOJ leadership would make good on stated commitments to use *Olmstead* to transition more people from facilities rather than “fix[ing] up those crumbling old institutions.”³ Additionally, the failure of P&A to routinely notify residents (or where appointed, their legal guardians) of class action lawsuits against ICFs/MR is the subject of a pending federal bill, which, if passed, would require notification and an opportunity to opt out of these lawsuits. H.R. 1255 was introduced by Rep. Barney Frank (D-MA) and enjoys the support of 74 Representatives (34 Democrats; 40 Republicans).

III. CONCLUSION

VOR seeks your assistance in reigning in DOJ actions which appear to be purely ideologically motivated.

Statements by high ranking DOJ Civil Rights Division officials and actual DOJ *amicus* filings since October illustrate an ingrained bias against federally-created, funded and certified ICFs/MR and total disregard for personal choice. Federal Judge Robert Payne, who dismissed the case against Southeastern Virginia Training Center despite DOJ’s argument to the contrary, got it right: ***Personal choice is a fundamental principle in the Olmstead decision, and one that DOJ failed to account for in its brief to the court.***

Like DOJ, VOR has a “strong interest in ensuring the proper and consistent application of its ADA regulations.”⁴ DOJ’s CRIPA investigations should be conducted pursuant to written policies and procedures setting forth expectations for *conditions* of care, including, but not limited to, *unjustified* institutionalization. DOJ policies to determine whether someone is unjustifiably institutionalized must include consideration of personal choice, as specifically required by *Olmstead*, and not solely DOJ’s notion of what people would choose.

To date, it seems DOJ’s interpretation has gone well beyond the boundaries of established ADA law. Its attempted use of *Olmstead* as a sword to achieve the displacement of individuals from licensed ICF/MR settings, in disregard of personal choice, is not only contrary to *Olmstead*, but also discriminatory against individuals who need and choose ICF/MR care.⁵ The tragedies that flow from this “one-size-fits-all” philosophy are well-documented around the country. If DOJ persists in its version of *Olmstead* enforcement, many very fragile Americans – our family members – will suffer.

Sincerely,
/S/ Robin Sims, VOR President

³December 2009 cover letter from Curt Decker, Executive Director, National Disability Rights Network (enclosure: “A Decade of ‘Little Progress’ Implementing Olmstead: Evaluating Federal Agency Impact After 10 Years,” September 2009).

⁴October 16, 2009 letter to Judge Nicholas G. Garaufus confirming a pre-motion conference on DOJ’s Motion to Intervene in *DAI. v. Patterson, et al.*

⁵Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794, which prohibits discrimination on the basis of disability in federally conducted programs in all of the operations of public entities that receive federal funding, would seem to prohibit DOJ from anti-choice, anti-ICF/MR actions.

ILLINOIS: A BLUEPRINT FOR HOW TO “WIN” *The Voice* * Spring 2011

A five year legal battle is finally wrapping up in Illinois where families with loved ones in larger facilities fought the state, the “advocates,” and even the Court – and won. The *Ligas* case is a good lesson on how to win these battles.

The *Ligas* federal class action lawsuit was brought in 2005 by Equip for Equality (P&A), Access Living, and the ACLU against Illinois on behalf of about 6,000 severely disabled residents who live in the 240 privately-operated ICFs/ID with more than 9 residents, as well as those living at home with elderly parents awaiting placements. Included in the lawsuit was Misericordia in Chicago where President Obama’s chief advisor – David Axelrod – has a daughter.

The plaintiffs alleged that ICF/ID residents were “warehoused, segregated, and deprived of their civil liberties.” Instead, plaintiffs wanted the state to fund more placements in homes with less than 8 residents (called “CILAs” in Illinois).

In the first four years of the case, families, on behalf of their loved ones, unsuccessfully tried to intervene. As feared, in 2009, after four years of litigation, the parties reached a proposed settlement and submitted it to the court for approval. The settlement was troubling in that it would have required the state to reduce private “institutional” beds for each community bed it added.

In response, more than 2,000 families throughout the state for whom the settlement was supposed to help objected to the settlement. Teams of lawyers organized them and helped them file objections. At least 200 “objectors” attended the Fairness Hearing. In response, on July 1, 2009, Chief Judge Holderman rejected the parties’ proposed settlement **and** decertified the class, effectively sending the case back to the beginning. Parties, however, persisted and in April 2010 tried to get a similar settlement approved and recertification of the class. Judge Holderman rejected their efforts and this time ordered the parties to instead negotiate directly with the family objectors, approving intervention.

Parties and objectors recently agreed to a settlement that require Illinois to fund at least 3,000 new community placements over five years, but also preserve the right of individuals to live in large facilities and the state’s obligation to fund that choice.

“Though we always thought our legal arguments were correct, what turned the case was grassroots organizing, which in this case meant organizing thousands of families who knew their loved ones were not living dehumanizing, segregated lives as the complaint alleged,” said William Choslovsky, counsel for Misericordia families and whose sister is a resident. “What makes these cases so dangerous is that they are brought by supposed ‘advocates’ who claim to speak for all disabled people. Viewed in this light, they are a Trojan Horse of sorts.” He adds, “Let me be clear. We are not against CILAs. CILAs are wonderful . . . for some people. But just the same, so are large ‘institutions.’ True choice is a two way street, and when it comes for caring for the disabled, one size does not fit all. Why the ‘advocates’ use size as a proxy for quality is the real, underlying problem here.”

Sister Rosemary Connelly who has run Misericordia for over 40 years sums it up this way: “Big can be bad. Small can be bad. Both can be good.”



On the Web

VOR's website includes a Legal Resources link that offers articles, legal filings, and decisions in support of residential choice.

You are encouraged to visit and share these resources with advocates and attorneys defending the right of residential choice in state and federal courts.

<http://vor.net/get-help/legal-resources>

SECTION 5: JOIN VOR!



Toll free
877-399-4867
www.vor.net

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WHO IS VOR?

We speak up **for families/guardians** when results of legal precedents in other states will affect their family members and friends with intellectual and developmental disabilities (ID/DD).

We speak up **for individuals with ID/DD** to make sure that the quality of care in all settings meets the individual needs of each resident.

We speak up **for right of individuals with ID/DD and their families/guardians** to defend the spectrum of residential choices, including large or small, state or private, or home.

We speak up for individuals with ID/DD and their families on national issues (like Medicaid) that affect funding and quality of life for people with intellectual.

We speak up for the needed specialized care by doctors, dentists, nurses, dieticians, therapists, and loving employees who care about people with ID/DD.

We are an information resource for families, advocates, professionals, the media and legislative staff. We provide a **weekly email publication**, a **tri-annual newsletter**, and **action alerts**. We connect families with information about critical services, and policymakers with the information needed to forge responsible policy.

We speak up for the future of people with intellectual and developmental disabilities.

To join VOR, or for more information about on how to be part of VOR's advocacy and information network please return the form below to: VOR, 836 S. Arlington Heights Rd., #351, Elk Grove Village, IL 60007, 605-399-1631 fax

To join VOR, please enclose dues payment: ☐ Individual \$40 ☐ Family Organization \$200 ☐ Professional Assn. \$250
An extra donation is enclosed. \$1000__ \$500__ \$100__ \$50__ Other _____

Name _____ Home Phone _____

Street Address _____ Work Phone _____

City, State, Zip _____ Fax _____

Facility/Organization Affiliation _____ Title _____

E-mail _____

Mail Checks (payable to VOR) or Charge MC ☐ Visa ☐ Card number _____

Expiration date _____ Signature _____

The Value of VOR Membership!

VOR is a national, nonprofit 501(c)(3) organization advocating for high quality care and human rights for all persons with intellectual and developmental disabilities (I/DD). VOR is the only national advocacy organization supporting a full continuum of care options for people with intellectual disabilities and developmental disabilities, and their families.

VOR is 100% privately funded and receives more than 95% of its financial support from families of individuals with intellectual and developmental disabilities.

Individuals investing in VOR through membership dues and donations will receive the *Weekly E-Mail News Update*, a print newsletter (*The Voice*) three times a year, an invitation to an Annual Conference and Initiative in Washington, D.C., Action Alerts, individual advocacy, and legislative and legal advocacy. Members and supporters also enjoy the intangible benefit of supporting the **only** national organization We recognize and champion the right of individuals and their families to be the primary decision-makers regarding care and policy decisions, regardless of service setting.

Thousands of individuals, families, professionals and organizations across the country support VOR through annual membership dues and additional contributions. The membership's ongoing financial and advocacy support speaks directly to the grassroots' confidence in VOR's ability to succeed in its mission on behalf of people with intellectual disabilities and developmental disabilities.

Supporting VOR is a good investment!

Thank you for your membership and financial support!

+++++

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

jhuso@vor.net ; 605-271-0445 fax; 877-399-4867

<http://www.vor.net/online-membership-form>

To join VOR, please enclose dues payment: ☐ Individual \$40 ☐ Family Organization \$200 ☐ Professional Assn. \$250
An extra donation is enclosed. \$1000__ \$500__ \$100__ \$50__ Other _____

Name _____ Home Phone _____

Street Address _____ Work Phone _____

City, State, Zip _____

E-Mail _____ Fax _____

Facility/Organization Affiliation _____ Title: _____

Please Charge my: MC ☐ Visa ☐ Discover ☐ Card number: _____

Expiration Date : _____ Three Digit Security Code: _____ Signature: _____

Location your loved one calls home: _____ State: _____

Thank you for supporting VOR. Gifts to VOR are tax-deductible to the fullest extent of the law, as no goods or services are provided in consideration of a gift.

VOR MEMBERSHIP BENEFITS

TANGIBLE BENEFITS TO MEMBERS:

- ✓ **VOR's Weekly E-Mail Update**, that provides members with "real time" national news.
- ✓ VOR's print newsletter, **The Voice**, that includes legislative, legal and state news, along with VOR organizational updates, published three times per year.
- ✓ Regular **Action Alerts** with background information, template messages and contact information enabling members to respond to legislative and other policy proposals impacting people with intellectual and developmental disabilities.
- ✓ An annual **VOR's Conference** and related events which feature prominent speakers and timely topics in Washington, D.C.
- ✓ **Individual advocacy assistance** via access to VOR's Board Members, State Coordinators, staff and key leaders.
- ✓ A vibrant **Legislative Advocacy** program, including an annual **Washington Initiative** and a year-round Washington Representative who attends legislative meetings, hearings, and conferences on VOR's behalf, ensuring a regular presence in our nation's capitol.
- ✓ A vibrant **Legal Advocacy** program which includes legal advocacy and, when available, pro bono legal representation for nationally significant litigation. VOR has had a presence and impact in cases in Florida, Illinois, Maryland, Pennsylvania, New Jersey; Washington State, California, Massachusetts, and Virginia.
- ✓ An **informative website** (www.vor.net) which some members regard as a "one-stop advocacy shop."
- ✓ Access to VOR speakers and grassroots training opportunities.
- ✓ The right to select VOR's Board of Directors through an annual vote.

THE INTANGIBLE BENEFITS TO MEMBERS:

- ✓ VOR speaks up for families and gets involved **when results of legal precedents in other states will affect your loved ones.**
- ✓ VOR speaks up for individuals **to make sure that the quality of care in all settings meets the individual needs of each resident.**
- ✓ VOR speaks up for families and individuals **to choose from a spectrum of residential choices, including large or small, state or private, or home.**
- ✓ Only VOR speaks up for families **on federal issues that affect funding and quality of life for people with intellectual and developmental disabilities, like Olmstead, DD Act reform and Medicaid.**

EXPANDING YOUR VOICE

Who you know that would be glad to help

- Family members
- Friends
- Neighbors
- Teachers
- Bankers
- Unions
- Judges
- Lawyers
- Physicians
- Corporations
- Small businesses
- Insurance carriers
- Businesses that provide services to your family member (*e.g.*, adaptive equipment providers)
- Others

**All you have to do is ask and
our collective voices will be heard.**

Numbers Count!!

On the Web!

Membership and Donation Opportunities

VOR's website includes resources to assist with Membership Recruitment and Donation opportunities, including online giving options.

- ✓ **Join Now. Great Mission. Great Benefits**
<http://vor.net/join-now>
- ✓ **Donation Opportunities**
<http://vor.net/donate-now>
- ✓ **Joining, renewing and donating online**
https://fs9.formsite.com/VORIllinois/form404301208/secure_index.html



ORDERING INFORMATION

You are encouraged to reproduce all or part of this *VOR Advocacy Manual and Toolkit* for use with your members and advocates.

- ✓ Free electronic copies are available on VOR's website (<http://vor.net/get-help/toolkit-for-families>) or by e-mail (contact thopp@vor.net) upon request.
- ✓ Bulk print copies may also be purchased. Contact VOR at 605-399-1624 or 605-399-4867 (toll free) for details.



If not us, then who?

Thank you!