



Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice

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“The Heart of Participation”

By Ann Knighton, President

We are mothers, fathers, sisters and brothers.

We are grandfathers, grandmothers, grandsons and cousins.

We are teachers, accountants, lawyers, doctors and mechanics.

We are volunteers.

We are advocates.

We are human.

We give all we can of ourselves to family members (disabled and not), bosses, employees, and organizations. There are never enough hours in the day, yet we always seem to find the time to give more when it comes to matters of the heart.

That is the heart of participation and what makes VOR so strong. Our members, donors, subscribers and volunteers are moved by a passion that seems to transcend time and energy limitations. Don't get me wrong: We must say “no” at times, but those times are few and

dictated by the recognition that saying “no” now will allow for more time, energy or money later.

This is also the essence of teamwork – the meaning behind “we are stronger together, than apart.”

Russell Wilson gets this. For those of you, like me, who know little about football, Wilson is the quarterback for the Seattle Seahawks who won the 2014 Super Bowl. In a post-game interview, he was asked (again) about his height (5'11”, short by NFL standards). His response was simple: “My height doesn't define my skill set,” said Wilson. “I think to be a great quarterback, you have to have great leadership, great attention to detail, and a relentless competitive nature.”

That sounds a lot like VOR. We are not the largest organization by number, or the wealthiest. Yet, our size does not define our skill set, our determination, our influence, and our passion.

We are a team and are motivated by matters of the heart. We must continue to leverage our collective skills and strengths to change the world as we know it for our loved ones with intellectual and developmental disabilities.

Join Us!

We would be honored if you would participate in our Annual Conference and Washington Initiative. Leveraging our collective voices, we will carry our message of individual choice, civil rights and human rights to every Congressional office this June. Details on how you can be a part of this exciting event are on pages 6-7, and a registration form is on page 11.

Participate and help us change the world.



VOR Is Family

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VOR MISSION STATEMENT

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

Teamwork and Time

By Julie Huso, VOR Executive Director



True teamwork is a level of motivation. The more people involved the more motivated we become.

VOR members are spread throughout the US and it is clear those individuals do not have to be in the same location to be part of a team.

This team is made up of people who are unique in their talent, experience and education. As Ann Knighton, VOR's President, stated, "The very essence of 'teamwork' is the meaning behind 'We are stronger together, than apart.'"

Teamwork can also save time and time is measured in many ways. In addition to clocks and calendars, I believe VOR members define their time as "what can I do now – today - to make a difference for my loved one and for everyone facing concerns and needs in the I/DD field."

VOR recently invested in a product that allows members and others to save time while taking important action. This product, called Salsa, allows VOR to prepare action alerts that our members and others can use to very easily communicate with Members of Congress or state elected officials. We like to call it "one click advocacy" because all you have to do is provide your zip code and the system will match you with your elected official and, with just one click, send your personalized letter directly to the targeted official(s).

Bringing it all together

On a recent trip to a facility in Wyoming, I was able to give a presentation on grassroots advocacy, speak of the importance of VOR and participate in a state committee hearing regarding the future of the Wyoming Life Resource Center.

I was so impressed with the Center and grateful to Senator Case, the staff and volunteers that took the time to give me a tour. Shortly after my visit a news article was in the Lander paper and the article quoted a family member stating, "I just cannot believe VOR, this national organization took the time to help us and visit in little Lander, Wyoming."

"The strength of the team is each individual member. The strength of each member is the team." ~ Phil Jackson

While I appreciate these kind words, this is what VOR is all about. Bringing our grassroots together and letting them know they are part of a national team, even from Lander, Wyoming.

Please join us!

It is my privilege to invite each of you to join us in Washington, D.C. for our Annual Conference and Washington Initiative where we are taking the time to join together as one team to be educated, network and walk the Halls of Congress in numbers. It is very motivating and such a wonderful feeling to know that the VOR team is making a difference. You are making a difference by taking the time to attend this outstanding event!

Matching Gift Opportunity!

Thanks to a **\$5,000 challenge gift from longtime VOR members, we can now match donations, dollar for dollar, up to \$5,000**, to fund research by the Developmental Disabilities Nurses Association (DDNA), into nursing outcomes and costs in small and large residential settings serving people with intellectual and developmental disabilities (I/DD).

Kathy Brown, the President of DDNA, will also be a featured speaker at VOR's Annual Conference. She will discuss DDNA's findings and its use in our shared advocacy on behalf of people with I/DD in community and facility-based settings.

We know that there are added costs and challenges to delivering nursing to individuals in scattered community homes - additional costs and logistics (especially time and transportation costs) which are not often considered by state policymakers when making closure decisions. As a result, adequate access to nursing is often sacrificed. Having in hand credible research will be of great advocacy value to our membership that is either **seeking adequate care in community settings or attempting to protect facility homes from closing.**

There has been no better time to turn your \$50 donation into a \$100 donation through this matching gift opportunity to help fund this much needed and meaningful project.

We will be seeking funding for this project until April 15, 2014, so **please take a minute and make a contribution. You can use the form on page 12.** This is a great time to stretch your dollars. Remember, every dollar you give will be matched. **THANK YOU!**

VOR joins other housing choice advocates to form Coalition for Community Choice

The Coalition for Community Choice (CCC) is a national grassroots collaboration of persons with disabilities, their families and friends, disability rights advocates, professionals, educators, and housing and services providers to advance the principle that *community can be experienced in all residential settings*.

CCC was created to 1) promote and defend the rights of people with intellectual and developmental disabilities (I/DD) and autism to choose their residential settings from the broadest range of options; 2) educate federal and state governments on innovative *Olmstead*-compliant housing alternatives instead of “one-size-fits-all” approaches; and 3) preserve access to essential, publicly-funded services and supports in these settings.

The founding and current members of CCC, including VOR, came together as a unified voice for increasing options and decreasing barriers to housing choices. The impetus for our coalition was a proposed federal regulation (“rule”) that included changes on how “community” was defined for the purpose of eligibility for Medicaid Home & Community-Based Services (HCBS) funding (see related article, this page). CCC participants, individually and as a unified group, strongly opposed the proposed regulation, along with other advocates, organizations, states and others. At the heart of our opposition was the effect an artificially narrow definition of “community” would have on individuals receiving HCBS-funded supports in settings that, upon implementation, federal law would no longer consider “community enough” to warrant HCBS-funded supports. The rule has since been finalized and our unified advocacy resulted in some important changes and ongoing opportunities for stakeholder input, although challenges remain.

Final Regulation Defining “Community” released by the Centers for Medicare & Medicaid Services (CMS)

On January 10, 2014, CMS released its final regulation (“rule”) that defines what CMS considers to be characteristics of “community” for people with developmental disabilities for the purpose of receiving Medicaid HCBS 1915(c),(i), and (k) funding in qualified residential and vocational settings.

Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) are not directly affected by this rule.

Under the new rule, an individual may receive Medicaid HCBS funding in settings that are integrated in, and support full access to, the greater community, as determined by CMS. Specifically, CMS will consider whether the setting • Is selected by the individual from among setting options; • Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint; • Optimizes autonomy and independence in making life choices; and • Facilitates choice regarding services and who provides them.

The final rule also includes requirements for provider-owned or controlled home and community-based residential settings, including • Individuals have a lease or other legally enforceable agreement; • the home is physically accessible; • has a private, locking room with choice of roommates and decor; • the right to visitors at any time; and • the right to food at any time.

Individuals who reside in settings that do not directly meet these criteria may still be eligible for HCBS funding in that setting if a State argues that the setting meets the criteria and does not “have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS.” Such exceptions will be approved only after “heightened [federal] scrutiny.”

The rule also requires person-centered plans to ensure individualized health, support and long-term services for HCBS recipients. A person-centered plan must support any modifications to HCBS criteria (e.g., locked food; locked home to prevent dangerous elopement, etc.) with documentation that less restrictive solutions have first been tried.



Graphic Courtesy of Shannon Doty, Madison House Autism Foundation

VOR Is Teamwork

For more information:

The final Home and Community-Based Services regulations set forth new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports.

Links to the new regulation, fact sheets and more are available at www.medicaid.gov/HCBS.
Questions: hcbs@cms.hhs.gov



Llamas in Space and the View from 13% By Tamie Hopp, VOR Director of Government Relations & Advocacy

Recently, a VOR member asked if the National Council on Disability, an “independent federal agency,” was independent from even Congressional review. It’s a fair question given the little attention Congress has paid to our issues in recent years.

I responded that Congress provides appropriations for federal agencies, even “independent” ones, so the buck ultimately stops there. To make the point, I offered an absurd example. “If the National Council on Disability started using its appropriations to fund a ‘Llamas in Space’ program, Congress would (probably) notice.” The point being that the absurd (e.g., “The bridge to nowhere”) often gets more attention than the tragic.

Without question our issues are compelling and urgent; the challenge for advocates is convincing Congress of that.

Which brings me to the 13%.

That’s the percentage of Americans who think Congress is doing a good job (Gallup, January 2014). Why is Congress’ approval rating so low? One writer remarked, “I believe Americans are completely fed up with this do-nothing Congress, which is unwilling or unable to put aside partisan bickering and put the good of the country first.”

I agree, but we must not let up or give up. VOR’s Annual Washington Initiative provides advocates an opportunity to educate Congress about the tragic, compelling, urgent and absurd relative to issues that impact your family members with I/DD. Members of Congress are beginning, slowly, to dislike the view from 13%. They must change or they will lose their jobs (appropriately).

Please Join us in D.C. and Think Local

In addition to our Washington Initiative, there is another real opportunity for advocacy: **Think local.**

More than ever, the issues impacting people with I/DD are shifting to the states. According to Salsa Labs, Inc., which recently published a White Paper on the virtues of state and local level advocacy, there is real potential in the local touch. Every U.S Representative has about 710,000 constituents, even more for the average Senator, while the number of constituents per representative drops dramatically on the state level and is even lower on the local level, meaning that “there’s less clutter to break through and each voter has more impact on their elected officials.” (Salsa)

Federal AND local advocacy is necessary

There are some issues necessarily federal (Medicaid, NCD, etc.), but many other issues can and must be addressed locally (e.g., state budgets for publicly-funded ICFs/IID operations and capital improvements). The Constitution after all gives the federal government certain powers, but anything not granted to the federal government is reserved for the states.

VOR Is Vision

Awareness Donation Helps VOR Grow

Thanks to long-time VOR member Sally Dubrowsky, VOR was granted the opportunity to run articles online in Age of Autism. Her sponsorship of advertising space and the right to post VOR-developed content has helped reach tens of thousands of families of individuals with severe I/DD and autism. Our initial article, which shared information about VOR and what distinguishes us from other national disability organizations, resulted in a noticeable jump in Facebook likes, Twitter follows, and emails expressing an interest in learning more about VOR.

VOR is grateful to Mrs. Dubrowsky for this opportunity. Our Age of Autism posts are being cross-posted on other websites and blogs for broader awareness. Such outreach allows us to reach many more families of individuals with profound disabilities who are desperately seeking quality services for their families. We remain independent from these other organizations, just as they are independent from VOR.

VOR holds a special place in Mrs. Dubrowsky’s heart. She has three grandchildren with autism. Her son, Geoff, is currently serving as a VOR Officer and board member; and her late-daughter, the beloved Robin Sims, served two terms as VOR’s President. We are grateful for her generosity and her vision to give a donation that keeps on giving as it helps VOR grow.

VOR Can Now Launch State-Level Action Alerts

VOR’s new “Salsa” system allows for “one-click” advocacy at the state level. VOR’s staff can work with you on developing a template letter and a personalized “Action Page” link for your members to click and send. Personalized letters from constituents will then be sent directly to state legislators. Contact Tamie Hopp at thopp@vor.net; or 605-399-1624 for more details.

VOR's 2014 Annual Conference and Washington Initiative: Making it Happen- Reforming Policy and Law in Support of Person-Centered Quality and Choice

VOR's Conference (Sunday, June 8, 2014) and Washington Initiative (beginning Monday, June 9, 2014), are our pinnacle annual event bringing together choice advocates from around the country and featuring presentations that will inform and inspire. This year's conference features several speakers and presentations which together will help participants advance legitimate person-centered planning to achieve quality and choice – down to the individual.



William Choslovsky, Esq.

Bill is a partner at Neal, Gerber & Eisenberg, LLP, a Chicago law firm, where he specializes in financial restructuring and litigation. A Harvard Law School graduate (1994), Bill also clerked for two judges before starting his legal career.

Perhaps more important for our purposes, Bill's sister Stacie was born with profound intellectual disabilities and is a resident at Misericordia, a wonderful, large private facility in Chicago. Bill serves as a member of the Misericordia Board of Advisors and led the team of pro bono attorneys that helped secure intervention and a favorable settlement in the class action lawsuit involving all private ICFs/DD in Illinois with more than 8 residents. Due to Bill's legal representation and advocacy, residential choice was preserved for thousands of Illinoisans with intellectual disabilities and their families, including the choice to stay in a large facility like Misericordia. Bill, and co-counsel Scott Mendel, were recently honored for their efforts on behalf of Misericordia residents, receiving the 2014 Sister Rosemary Connelly Service Medallion.

Bill is back for an encore presentation, having first presented at VOR's conference in 2011. For his presentation in 2014, he will give a presentation titled, "Real choice is a two-way street, not superimposed from above: Combining common sense, law and grassroots advocacy." Bill will draw on both his experience in Ligas and his legal research since then, which will culminate in a law review article. Bill lives in Chicago with his wife Wendy and three children.

Kathleen Brown, RN, BA, CDDN

Kathy is the President of the Developmental Disabilities Nurses Association. She'll be offering VOR conference participants a look at "The Impact of Residential Setting on Nursing Outcomes and Data." Kathy has been working in the field of developmental disabilities for 36 years. She is the Director of Development for Pharmacy Alternatives, that provides pharmacy services and medications systems exclusively for people with I/DD. She has worked in the DD field for the last 36 years. She helped start the Northern Illinois DD Network of nurses in 1994 and has served as president for the past 16 years. She helped craft legislation for medication delegation in Illinois and taught the course for 7 years, training over 600 nurses. She is very interested in developing and expanding DDNA networks and increasing the number of nurses sitting for the certification exam. Kathy recognizes first-hand the varied needs and abilities of the I/DD population, from those individuals capable of self-administration of medication to individuals requiring 24/7 nursing care. Kathy lives in the Chicago-area with her family.



Kim Stagliano

Kim will be our keynote dinner speaker. A nationally recognized autism advocate and lively speaker, Kim will present "Is 50 Nifty with 3 Special Needs Children?" for VOR Annual Conference participants. Although autism typically affects boys 4 to 1 over girls, Kim is in the unique position of having three daughters with autism, which has made her and her family a focus of national media attention. She is author of the memoir, "All I Can Handle I'm Not Mother Teresa: A Life Raising Three Daughters with Autism" and the novel "House of Cards." Kim also serves as Managing Editor of *Age of Autism*, the

nation's first daily web newspaper about the autism epidemic, and she writes for *The Huffington Post* and *The Autism File Magazine*. She speaks at national conferences and has appeared on numerous morning shows and news networks, and in *The Chicago Tribune*, *The National Catholic Register*, and on blogs around the world. In her presentation for VOR, Kim will relate her experiences as a mother and advocate who, like VOR members, has dedicated her life to the daily and future well-being of children with profound disabilities. In the spirit of "we're all in this together and together we are stronger," Kim will give a motivating, lessons-learned in life and advocacy, presentation. Kim lives in Connecticut with her family.

A Legislative Briefing, Voice and Advocacy Awards, and President's Message will round out the formal Conference presentations. The Legislative Briefing will feature panelists David Hart (Chair, VOR's Legislative Committee), Peter Kinzler, Larry Innis, and Jill Barker. The panel will focus on "The Future of Our Advocacy in a Changing World," tying this discussion to VOR's objectives its 2014 Congressional Initiative (see page 7). Other Conference events include a reception and dinner to maximize the networking that past participants cite as the most meaningful aspect of VOR's conference. For additional networking, participants can also take in our annual State Reports and a Hospitality Reception on Saturday, June 7, the evening before the Conference.

On the web:

www.vor.net/events

- **Conference Details**
- **Conference Registration**
- **Hotel Information and Reservations**
- **Sponsorship and Exhibit Opportunities**

The week of Monday, June 9, 2014: VOR's Washington Initiative Carrying our Choice Message to Congress

Join choice advocates from around the country the week of Monday, June 9 as we work together to convey the importance of residential, vocational and service choice and family decision-making directly to Members of Congress and their staff. VOR's 2014 Initiative priorities will be 1) Support for mandatory national background checks for direct care workers in long-term care settings; and 2) Continued education of Congress on the impact of federal policy and actions in support of forced deinstitutionalization and decentralization of services which are resulting in harm and isolation of people with disabilities, counter to federal law and human rights.



Please plan to participate and help cover your state's Congressional Delegation (most participants stay Monday and Tuesday). There will be informal de-briefings for and by participants on Monday and Tuesday evenings at the Hyatt hotel. **For more information, please contact Tamie Hopp at thopp@vor.net or 605-399-1624.**

HOTEL INFORMATION

Hyatt Regency Capitol Hill
400 New Jersey Ave., NW
Washington, D.C. 20001
Reservations due by May 5, 2014



All Conference, Dinner and VOR Meetings held at Hyatt Regency Washington on Capitol Hill. Room-mates will be arranged, if possible, upon request. To make your reservations, call 1-888-421-1442 or at https://resweb.passkey.com/Resweb.do?mode=welcome_gi_new&groupID=19794401. The VOR

Group rate is \$239 for single or double, plus tax, per night. Triple (\$264, plus tax) and Quadruple (\$289, plus tax) suites are also available. To receive group rate, mention "VOR."

Exciting Sponsorship Opportunities, in Partnership with EP Magazine!

VOR is pleased to announce our sponsorship partnership once again with *EP Magazine*, the preeminent leader in publishing for children and adults with disabilities and special health care needs. **VOR's partnership with *EP Magazine* allows us to offer the following sponsors the opportunity to be listed in *EP Magazine*, which reaches 300,000 readers, in its June and July 2014 issues of *EP Magazine*:**



- Platinum Sponsors (\$10,000 +)
- Gold Sponsors (\$7,500 +), and
- Protecting Choice & Quality Sponsors (\$5,000 +).

All Sponsors of the 2014 VOR Annual Conference and Initiative will receive the following marketing outreach opportunities through VOR's recognition promises:

- Direct recognition in VOR's print publication, which reaches over **3,000 thousand family members, organizations, companies, facilities, professionals and educators** from every State, Puerto Rico, and Aruba.
- Recognition on VOR's website and in social media for one year.
- Recognition for one month in VOR's Weekly E-News Publication, received by thousands of recipients each month.
- Links to sponsor recognition page on all VOR staff emails for one year reaching hundreds of recipients each month.
- Recognition in the Conference Program and signage.
- Attendance (networking) at VOR's Annual Conference.
- Opportunity to share your literature with Conference attendees (\$350 level or higher)

This is your opportunity to have your name associated in support of national advocacy for choice and quality care for people with intellectual and developmental disabilities. Complete Sponsorship details, including categories, benefits and pledge form, can be downloaded from VOR's website at www.vor.net/events. To be a sponsor or refer a sponsor, contact Julie Huso at 605-370-4652 or jhuso@vor.net.

H.R. 831, The Fair Wages for Workers with Disabilities Act of 2013

H.R. 831, introduced by U.S. Rep. Gregg Harper (R-MS), directs the Secretary of Labor to discontinue issuing any new special wage certificates (which permit individuals with disabilities, including individuals employed in agriculture, to be paid at lower than minimum wages). It would prescribe requirements for a three-year phase-out of all certificates by amending the Fair Labor Standards Act of 1938 to repeal authority and requirements for the issuance of such certificates, and would revoke of any certificates remaining at that time.

VOR supports a full array of employment options, including sheltered workshops, supported employment, and competitive employment based on individual abilities. H.R. 831 would eliminate sheltered workshops, leaving thousands of severely disabled people without work. Instead many will be left sitting at home. According to one survey by the Special Olympics and conducted by Gallup and the University of Massachusetts at Boston, of the 420,000 disabled people who work at sheltered workshops, only 5 percent ever leave for other jobs alongside non-disabled workers. Only 34 percent of intellectually disabled adults are in the labor force. H.R. 831 would decrease employment options at a time when expanded employment opportunities are desperately needed.

Federally Defined “Community” Continued from page 4

States must demonstrate to CMS that their Medicaid HCBS Waiver and State Plan settings remain eligible for HCBS funding, or how these programs will be transitioned to conform to the new community criteria. If approved, CMS will give States up to five years to make changes. CMS will be developing additional guidance letters to states on several key provisions within the new rule, including how the “heightened scrutiny” review standard will be interpreted and what person-centered modifications to ensure health and safety will be allowed, and when (before or after predictable problems).

The regulation provides for ongoing stakeholder input at the state and federal levels. States are required to seek public input as part of their application for HCBS funding. Housing and service choice advocates are compelled to remain involved and provide input at every opportunity. The final regulation presumes that any form of congregate care to be institutional and not community. Although CMS supports “meaningful choice” among all available residential options, the bias against congregate settings that offer friendships and benefits from living together and accessing services and amenities “under one roof” remains. It will be up to choice advocates to (1) urge states to seek HCBS funding for such settings, and (2) urge federal reviewers to approve such applications. Advocates will have to fight for settings with true community.

VOR: National Background Checks are Necessary

Without question, having competent, trusted staff is key to ensuring high quality of care no matter the setting. Yet, there is no federal requirement that states or providers pursue background checks. Bad apples can (and do) simply move and be hired in direct care positions in other states, placing vulnerable people at risk.

VOR will take this concern to Congress as part of our June Initiative focus. See pages 7 for details, and a registration form on page 11.

Will you join us?

Kentucky: Legislation would create disabled adult protection registry

Senate Bill 98 will allow individuals, their families and care providers to see whether the Cabinet for Health and Family Services has substantiated allegations of abuse involving a prospective employee, subject to certain due process protections for the accused. The bill would require agencies that provide caretakers for vulnerable adults to ask whether potential employees, contractors and volunteers were on the registry.

Ohio: Neglect and abuse of Ohio’s disabled slips under the radar

A six-month investigation of the Ohio Department of Developmental Disabilities revealed that providers failed to conduct criminal background checks or consult an existing abuser registry that resulted in individuals with criminal and abusive records being hired, resulting in great risk and injury to the people they were left alone with. As a result, more than 2,000 people with disabilities were victims of abuse last year - ranging from physical and sexual assaults to neglect. In addition - according to statistics provided by the agency - of 1,587 compliance reviews of service providers in 2012, 38 percent, or 603, were cited for failure to follow state health and safety regulations.

In response, Ohio State Senator Mike Skindell is proposing new legislation that would require the Ohio Department of Developmental Disabilities to post inspection and compliance reports online. Skindell said without a requirement to post reports, key information about service providers is largely kept secret, protecting service providers and allowing them to operate in secrecy. (Source: NewsChannel5 * November 8, 2013)

Wyoming Department of Health Concludes Center is Necessary Safety Net and Should Not Be Closed

On November 1, 2013, the Wyoming Department of Health (WDH) released the findings of its 8 month legislatively-directed study, concluding that the residents of the Wyoming Life Resource Center (WLRC) should not be forced to transfer to smaller programs. “The WDH considers the WLRC to function as a safety net in Wyoming. While there are many reasons for this recommendation, perhaps one of the most basic (yet critical) reasons is the fact that a majority of the current WLRC clients have resided at the facility for the majority of their lives. A transition could impact their physical and mental well-being, resulting in a decline in their current conditions,” the report concluded. In addition, WDH noted that the “guardians/family members of WLRC clients that chose to respond to this survey indicated they (and their clients) are very satisfied with the services at the WLRC. Some also stated that in previous placements outside WLRC, they and their wards were unsatisfied with the arrangement. Finally, the perception reported by the majority of the guardians/family members was that their clients would not experience as high a quality of life as they do at WLRC if they transitioned to a community setting.”

California: Final Report on Future of Developmental Centers Released

VOR Is Quality

In May 2013, Diana Dooley, the Secretary of California’s Health and Human Services Agency, established a Task Force on the Future of the Developmental Centers. The Task Force included a cross-section of consumers, family members, regional centers, consumer advocates, community service providers, organized labor, and the Department of Developmental Services. In January 2014, a final report was released. The task force’s report makes an overarching recommendation: “The future role of the state is to operate mostly smaller, safety-net crisis and residential services coupled with specialized health care resource centers and public/private partnerships, as well as the Porterville DC Secure Treatment Facility and the Canyon Springs Community Facility.”

Brad Whitehead, a Lanterman Developmental Center Psychiatric Technician and Task Force member, emphasized that, while the draft document isn’t a closure mandate and offers hope for continuing and reimagining state developmental services, much in-depth data and choice-driven work remains. In a letter to Secretary Dooley in response to the Final Report, Whitehead outlines three areas of concern: (1) More data is needed prior to taking any action; (2) Individual choice must always be respected; (3) Developmental centers and staff are valuable resources. Whitehead, along with the family advocates for developmental center residents who also served on the task force, express hope that the “task force has not been a mere formality, but that it actually marks the start of what must be a much more involved statewide and national conversation on the need for quality, professional services for all Americans with developmental disabilities.” To read the report, Whitehead’s letter, and a response by Kathleen Miller, Task Force Member and President of the Sonoma Developmental Center Parent Hospital Association, visit <http://vor.net/get-involved/vor-advocacy-letters>.

Delaware: Repurposing Stockley Center

Citing a new report, Rita Landgraf, Secretary of the Delaware Department of Health and Social Services, called the Stockley Center “one of Delaware’s gems,” and encouraged greater public access as a medical training center, public nature preserve, farmer’s market, community center and possibly the keystone of a mixed-use development. The 750-acre facility is one of the largest parcels of state-owned land in Delaware outside of its state parks.

Arkansas Legislators hear from families and VOR on importance of family decision-making and choice

On January 8, 2014, the Arkansas Legislative Council’s Joint Hospital and Medicaid Study Subcommittee considered the value of Arkansas’ Human Development Centers, publicly-operated Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities. In addition to public comment from 10 families/guardians, Darrell Pickney, President of the Families & Friends of Care Facility Residents (FF/CFR) (Jonesboro HDC), Jan Fortney, FF/CFR’s Secretary (Conway HDC), John Morris, an FF/CFR Member (Arkadelphia HDC) and Tamie Hopp, VOR’s Director of Government Relations & Advocacy (in writing) also testified. VOR’s testimony covered legal, cost and quality arguments in support of residential choice and encouraged lawmakers to begin their analysis with the informed perspective of families/guardians.

VOR Board and Officers July 1, 2013 – June 30, 2014

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Illinois: Judge tosses most State motions in federal Murray case

A federal judge tossed out the majority motions filed by the state in a court case that has the futures of Murray Center residents at its core. Judge Marvin Aspen scolded the Department of Human Services for their motion seeking to have hundreds of letters and affidavits submitted in the case thrown out. The Judge noted that some of the letters—particularly the letters from guardians describing in detail their wards’ conditions and experiences in different types of housing—include facts relevant to the issues to be determined at the preliminary injunction hearing.

The State also asked the court to strike testimony from witnesses who describe what it called “inconsequential” incidents, specifically, taking issue with two declarations from Murray employees who state that they were instructed to transfer a resident’s belongings to a home, only to discover upon arrival that the home was not yet habitable.

Judge Aspen disagreed, saying the employees’ testimony describes an incident where defendants planned and initiated a move to a home that was still under construction, without inspecting the physical condition of the building or confirming that staff or safeguards were in place. Such evidence, he said, may support the plaintiffs’ assertion that the state is rushing the assessments and transfers of residents and failing to ensure that the new housing arrangements are suitable for the disabled residents displaced from Murray. (Source: WILY/WRXX News, Dec. 9, 2013)

New Jersey Court dismisses families’ lawsuit; appeal planned

On August 1, 2012, the “Task Force on the Closure of State Developmental Centers” issued a “Final Report” for the Governor and Legislature calling for the closures of Woodbridge and North Jersey Developmental Centers. In response, on June 5, 2013, families/legal guardians, on behalf of their family members, filed a complaint in federal court alleging, among other claims, that their loved ones have been denied independent and reliable evaluations of their needs by treating professionals (as required by Olmstead); have been harassed and intimidated to accept inadequate and dangerous placements despite their lack of consent; and have been deprived of or threatened with the loss of a Medicaid ICF/IID- level of care. The State filed a motion to dismiss in September. Unfortunately, the Court granted the motion and dismissed the case. Families have appealed, while also encouraging Governor Christie to reverse his decision. In January 2014, they delivered a petition with 10,000 signatures of families, advocates and others calling on the Governor to keep the two northern New Jersey developmental centers open.

Tennessee: Arlington Developmental Center lawsuit dismissed after 21 years

Tennessee Gov. Bill Haslam has announced that after 21 years of litigation, a federal judge has dismissed the lawsuit originally filed over conditions at the now-closed Arlington Developmental Center in Memphis. Judge Jon Phipps McCalla of the U.S. District Court, Western Division, entered an order and final judgment yesterday that the state has “complied with all material provisions of the Exit Plan” aimed at resolving the litigation agreed to by the parties in January. Under the agreement, the state enrolled a small number of additional people in the Arlington class to receive home- and community-based services and provided additional efforts to assist class members in nursing homes to transition to the community.

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Registration Form – Return to VOR

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