

President's Message

It may have felt like it took a while to get here but Spring is here and like us, there is no stopping it. It is the perfect time for refocusing our efforts and moving forward full speed ahead with our advocacy. Our Annual Conference is fast approaching, and this year more than ever, we encourage all our members and their families and friends to join us again in Washington, D.C., June 8 - 12.

There are several benefits for your family members with I/DD, for you and for VOR by attending our Annual Conference. First and foremost, you can make a difference in their lives. Meeting with your legislators and discussing concerns about current and future legislation, can have a real and positive effect on the quality of life for our family members.

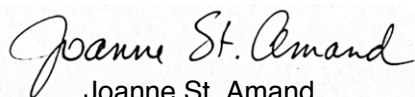
Members attending will gain experience and skill. Participation in the various briefing sessions, and listening and learning from our most experienced members on how to communicate with legislative staff, will build your confidence and give you the tools to communicate effectively.

Attendees will increase their knowledge and networking opportunities. This year we will be sure to provide enough time to here from all our state representatives, as well as having written reports available. It is so important to stay connected and up to date on what is happening across the country and there is no better place to do this than at this conference.

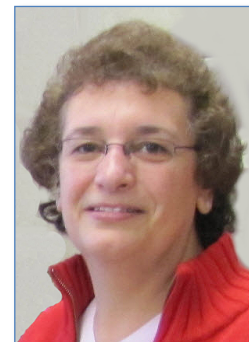
As you know, VOR is 100% privately funded. Our mission could only be accomplished through the volunteer efforts and generous financial support of our members and friends. Every member is important and every gift really does count. We are grateful to you for your years of support to VOR and ask that if you cannot join us this year, that you would please consider being a sponsor, donating or giving a gift to honor a loved for this year's Conference.

I have been honored to have served as the president of VOR for these past two years and I thank you for your support of our very important mission. Your participation is so important in advocating for the highest quality of care and human rights for all persons with intellectual and developmental disabilities.

Thank you and hope to see you in June!



Joanne St. Amand,
President, VOR Board of Directors



VOR 2019 Board of Directors Nominees - Proxy Ballot Voting

VOR's Nominating Committee has recommended three of our members for open seats on the Board:

Darrell Pickney (Arkansas) Debora Wallace (Texas) Sam Friedman (New Jersey)

For short biographies of the candidates, please go to:

www.vor.net/item/vor-2019-board-of-directors-nominees

If you have not already voted, please submit your proxy ballot online, at:

<https://forms.gle/DPDciHaBwbSdGatVA>

Taking Down The Elephant

By Rita Winkeler

"You can take an elephant down one bite at a time....."

What does this have to do with VOR and our disabled loved ones?

Here goes...

Sometimes we have to take a step back from the enormity of our task of keeping quality services available for our most vulnerable, and look at what we HAVE done. Although our task is far from over, we need to celebrate the successes along the way.

One of these successes is Murray Center, a state developmental center in Centralia, Illinois. Faced with closure in 2012 the Murray Parents' Association, Murray staff, the Friends for Murray Center group, made up of staff and community members, along with the state wide organization ILADD (Illinois League of Advocates for the Developmentally Disabled) fought back. VOR was a huge help in working with this group in helping to keep the center open, providing research, and an Amicus brief. After 2 ½ years of litigation a ruling came from federal court saying the state could close the Center, but the state would have to provide the same services in a community setting. That stopped the state in their tracks, and then when a new Governor was elected all closure activity was stopped. During those two and half years everyone bite by bite, slowly but surely, never gave up, and continued the fight to keep Murray open.



"To see our granddaughter smile again is something we thought we'd never see. She's always busy, has a social life, has friends, and isn't sad anymore."

admitted 48 individuals in the past 2 ½ years. A few of the admissions have been court mandated, but the vast majority are coming from failed community placements. These individuals, many who had lived in 4-5 small group homes where their needs were not being met, needed a place to live. They had stories of abuse, neglect, and time spent in hospitals and jails before they arrived at Murray Center. Several of our admissions have come from family homes where parents fought to get their child admitted to Murray because they had attempted to find community placement, and were turned down by over a hundred providers. Others knew their child needed the specialized services only available in Illinois in a state center. The success is in the safety and happiness their loved ones now have at Murray.

So, have we solved all our problems, finished all our work? Of course not, but what we have done, "bite by bite", is make a difference in the lives of not just the 48 residents who have come to Murray Center, but to all the disabled in Illinois who are now being admitted to the state centers. Had we all stepped back, said our task was too big, we would have failed, but we didn't. Bite by bite one can eat an elephant.

Bite by bite, VOR families, facility-based advocacy groups like the Murray Parents Association, and dedicated parents, siblings, and guardians can and will make a difference in the lives of the most vulnerable.

"Murray is a jewel that we were never told about. Why is it such a secret? My daughter would be dead if it were not for Murray, and now she is roller skating, smiling, and enjoying life."



"I was ashamed about my inability to handle my son, but now I want to tell the world that children like my son CAN receive help and improve. Since he has moved to Murray, he has lost weight, is healthier, no longer sits in his room all day, and rarely has serious behavior issues. Best of all he is reaching out to and interacting with his peers. He has FRIENDS, something I never thought I'd see."



"There is just a feeling of love on this cottage. It is obvious the staff love and care for the residents. We are so grateful that Murray Center was here for him. Already this feels like family."

Remembering Mary McTernan, Past President of VOR

Our dear friend and fellow advocate for people with intellectual disabilities, Mary Elizabeth McTernan, passed away on January 26th, 2019 after a long battle with Alzheimer's disease. She was 80 years old. Mary was the mother of a child with intellectual and developmental disabilities, Mary Elizabeth McTernan.

Mary was a devoted member of VOR for many years, and served as President from 2004 to 2009. Mary was a passionate advocate for people with I/DD. Before coming to VOR she worked for COFAR in her home state of Massachusetts.

Mary helped to write the legislative language in VOR's "Barney Frank Bill" that we advocated for in the 110th, 111th, and 112th sessions of Congress. The bill would have given families and guardians of residents of ICFs the right to opt out of federally funded class action lawsuits seeking to close the residents' longtime homes.

Mary also helped to write the VOR Amicus Brief that was included in the landmark Supreme Court decision *Olmstead v. L.C.*, 527 U.S. 581 (1999). VOR's brief was quoted in Justice Ruth Bader Ginsburg's majority opinion, and included the language, "each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution."



Nonetheless, Mary preferred to stay in the background, guiding others to do what was right, and giving them credit for their accomplishments. She was a dedicated advocate, who led VOR with wisdom, strength, and love.

Mary McTernan will be missed.

For those wishing to make a donation to VOR in Mary's memory, please mail it to:
VOR 836 South Arlington Heights Rd. #351 Elk Grove Village, IL 60007

For those wishing to make a donation to COFAR in Mary's memory, please mail it to:
COFAR c/o Colleen Lutkevich 3 Hodges Street Mansfield, MA 02048

Condolence cards may be sent to Mary's sister, Irene:
Irene Welch 6667 SE Yorktown Drive Hobe Sound, FL 33455.

Be a Part of our State Coordinator Program

A little over a year ago, VOR created Regions across the country to bring State Coordinators together to start informative conversations between states. Region 8 consists of Texas, Kansas, Nebraska, Colorado, Utah, Wyoming and Washington. State Coordinators and others from Region 8 chose to meet every week. Region 8 meets on conference calls every Tuesday evening at 7:00 p.m. Region 7 consists of Missouri, Arkansas, Louisiana, Georgia, and Florida. Region 7 meets the 2nd Monday of the month at 6:00 p.m. All calls consist of what is happening in your state. We also discuss bills that VOR is tracking. And other issues that arise during the calls. The calls are very informal and informative! Most calls last an hour and some have lasted 2 ½ hours depending on what is going on in the states. We recently began inviting others to the calls in an effort to add more members into the conversations and increase knowledge of our issues. The calls are free! Come join us and be a part of the conversation! For Region 7 and Region 8 call information, please contact me at rhoover0506@sbcglobal.net.

Rita Hoover - AR State Coordinator / VOR State Coordinator Co-Program Leader

Announcing the Recipient of the 2019 Jordy Engels Award

Longtime VOR members David and Leni Engels are proud to announce that the recipient of this year's Jordy Award is Kathy Lewis, of Visalia, California. The Jordy Award was created in loving memory of the Engels' son Jordy (1982-2005), to honor outstanding Direct Support Professionals for their exemplary devotion, care, and nurturing of our loved ones with I/DD.

Kathy Lewis has three generations of her family involved in the administration of her group homes, so there will be continued service by experienced operators. She also built and operates a Community Center, where 50 residents are taken by van daily for various activities. For over 45 years Kathy Lewis has served the people of CA with compassion, professionalism and a desire to do more than what is needed; to go beyond what is expected of her.

In presenting this year's Jordy Award, the Engels family salutes, thanks, and honors Kathy Lewis for her years of dedication and service.

The Disability Integration Act

H.R. 555 – Introduced in the House by James Sensenbrenner (R-W) on January 15, 2019

S. 117 – Introduced in the Senate by Chuck Schumer (D-NY) on January 15, 2019

The Disability Integration Act (DIA) states as its goal, “To prohibit discrimination against individuals with disabilities who need, and for other purposes.” The act states that while individuals with I/DD have the right to “institutional” care, they are not being provided with long-term services and supports (LTSS) in HCBS waiver settings if they decline institutional care. If passed, the DIA would force states to provide LTSS to all who request these services.

Why VOR opposes this bill:

1. The DIA explicitly states that it would eliminate institutions. That would deprive families of the choice of an Intermediate Care Facility (ICF) and placing individuals with severe or profound I/DD, many of whom are also diagnosed with medically complex conditions or behavioral disorders, into settings that offer a lower level of care and are more isolating to the individual in question. This is a clear violation of the letter and intent of the Supreme Court’s decision in *Olmstead*.
2. The DIA is unaffordable. No Congressional Budget Office (CBO) score has been requested on this bill, even though it has been around in one form or another for several years. The last time a CBO score was requested on a similar bill was in the late 1990’s, and it was then determined that the bill was unaffordable. Since then, costs have increased.
3. The federal Medicaid system cannot handle an increase of services of this magnitude. There are neither the financial nor the administrative resources available to meet the provisions of this bill. Similarly, most states are currently experiencing budget shortages, and many are cutting back on Medicaid services to make up for their shortfalls.
4. Currently, the HCBS system is not meeting the standards of care and oversight that it should.
 - a. There is a shortage of Direct Support Professionals (DSPs) to care for those who should receive services. The national rate of turnover for DSPs is 45% in the first year. In some states, the annual rate exceeds 65%.
 - b. Reporting of incidents of abuse and neglect in the private group home system is atrocious. A study last year showed as many as 99% of incidents go unreported.
 - c. State Protection and Advocacy agencies (P&As) receive millions of dollars, yet fail to provide oversight of group homes and follow up on incidents when individuals are repeatedly hospitalized for critical incidents.

While VOR supports the idea that all individuals with I/DD should receive the care they require, the current system is incapable of meeting those goals. Eliminating ICFs will not save money, only reduce the level of care and put vulnerable individuals at risk.

At this writing, the DIA has 130 sponsors in the House and 26 sponsors in the Senate.

<https://www.congress.gov/bill/116th-congress/house-bill/555>

<https://www.congress.gov/bill/116th-congress/senate-bill/117>

Money Follows the Person Rebalancing Act Renewal

The renewal of the Money Follows the Person Rebalancing Act (MFP) has been passed through both houses of congress, and is headed to the White House for the President’s signature. Once again, the members of Congress who introduced the bill, Rep. Brett Guthrie (R-KY) and Debbie Dingell (D-MI), hustled it through by bundling it with five other previously-approved health care bills, retitled the package as the Medicaid Services Investment and Accountability Act of 2019, and passed it by voice vote, a process that expedites passage by foregoing any discussion of the content of the bill.

MFP’s proponents claim the bill promotes choice, and re-balances what they claim is an “institutional bias” in residential services. They also claim that the bill is aimed at helping the elderly move from nursing homes to group homes.

Why VOR opposes this bill:

1. MFP only promotes one choice. You can waive your rights to an “institution” and move to a lower form of service in a group home. Sometimes, the choice is determined by a governor, or by the DOJ, if they determine to close an ICF and move residents to waiver services. But the individual’s choice to move to an ICF is not supported by MFP.
2. There is no “institutional bias”. There hasn’t been one for over twenty years, and the number of people in ICFs has been diminished by forced closures to a point far beyond a true balance.
3. This bill is not about seniors or the elderly. It is about attacking ICFs. AARP does not promote MFP. Its active supporters are the ARC, ADAPT, SABE, TASH, and other organizations that have declared a goal to close ICFs to anyone.
4. Closing Medicaid-Certified ICFs hurts the most vulnerable, the severely impacted individuals who need the high level of care offered by these facilities.

<https://www.congress.gov/bill/116th-congress/house-bill/1342>

<https://www.congress.gov/bill/116th-congress/senate-bill/548>

<https://www.congress.gov/bill/116th-congress/house-bill/1839>

Executive Director's Message:

The Importance of Bringing Our Voices to Washington, D.C.

In recent weeks, several new bills have been introduced in congress. Sadly, the most medically and behaviorally challenged ID/DD individuals have not been represented in these bills, or in the actions taken by the agencies tasked with representing the needs of people with intellectual disabilities.

The organizations that want to limit choice in residential settings and employment opportunities for your family have been busy this year. They have lobbied congressional offices to re-introduce the Disability Integration Act, which would eliminate Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID). They have lobbied to renew Money Follows the Person (MFP), which enables states to close ICFs/IID and force the residents into inferior service options. And they have lobbied to introduce bills that take away employment opportunities for people who cannot qualify for competitive employment, and that would eliminate the work centers that provide a safe working environment for people who want to work.

These groups don't advocate for our loved ones. They claim that people with higher needs thrive in the same settings as higher functioning individuals. They act like our family members don't count. In many of the programs and bills that are generated in Washington, these "disability advocated" act like our loved ones don't even exist.

Over the last three months, VOR has been laying the groundwork for our Legislative Initiative this June. We traveled to D.C. to deliver our "Welcome Letter to Members of the 116th Congress", spoke with staffers and one member of the House of Representatives about our family members with severe intellectual disabilities, autism, behavioral challenges and complex medical disorders. We have discussed our concerns for the Disability Integration Act, the Money Follows the Person Rebalancing Act, the two bills aimed at eliminating Work Centers that provide employment opportunities for people who are not capable of competitive employment through specialized wage certificates under Section 14(c) of the Fair Labor Standards Act, and the misapplication of the CMS Settings Rule. We have attended every public forum of the President's Committee for People with Intellectual Disabilities. And we have joined coalitions with other like-minded organizations to speak for the rights of all people with intellectual and developmental disabilities.

Now we need you.

Join us in Washington, D.C. this June. Speak to your senators and representatives and their staffers. Tell them your story. Tell them our stories.

We cannot afford to be invisible. We cannot afford to have our voices go unheard. We need to speak for our families.

If not us, who? If not now, when?



Hugo Dwyer, Executive Director, VOR

The VOR Conference and Legislative Initiative is your opportunity to advocate on behalf of your loved one on a national level. It is an opportunity to network with families and guardians from across the country. This conference brings individuals who bring a historical perspective on important legislative issues as well personal interest stories. You will be taking part in hands on lobbying activities around the capitol pertinent to preserving our residential living centers. Through your participation you can acquire the knowledge and experience that will serve you in meeting with your state legislative offices. Most importantly this is an opportunity to meet like-minded individuals and form friendships outside of our communities that can inspire and motivate.

- Tom Diaz M.D., Houston Texas

My sister, Cheri, and I attended the VOR Conference for the first time, last year. We had been using the website to help us in our fight to keep our sister in her home (ICF). We felt like we wanted to learn more, to meet the wonderful people who had been so generous with their time and knowledge, not just on the website, but also through many calls and emails to check on us and give us guidance. The VOR Conference was amazing, we were embraced with such sincere warmth and enthusiasm. Everyone was there to not only work on our common goals, but to also be there for each other.

- Karen House, Kentucky

The thing that stands out in my mind about attending the VOR Conference is the great fellowship and sharing of information from other states. We all face the same hurdles. We share the tears and the laughter. The comradery is amazing. We meet so many people from across the country. We have new members and members who have been attending for years and we all come together one time a year to build up and strengthen each other. From induction of Board members to dinner at the Dubliner. The congressional visits are exciting and exhausting! It's a great connection! Our strength is in numbers. Come join us this year at the annual conference in D.C.!

- Rita Hoover, Arkansas

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





VOR 2019 Annual Conference and Washington Initiative

June 8 - 12, 2019

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

Saturday, June 8, 2019

Registration: Network with families from across the country	11:30 am
VOR Board of Directors Meeting & Report to Membership	Noon
Annual meeting of the VOR Board of Directors, open to all members Committee Reports and Presentations Mentoring our next generation of advocates Time will be provided for member questions and comments	
Installation of VOR 2019 - 2020 Officers and Board Members	2:00 pm
Reports from the States	3:00 – 6:00 pm
Participants report on news from their states. Session is moderated by VOR Board Members	
Hospitality – Meet, Greet, and Eat	7:00 – 9:00 pm
Share regional treats from all over the country!	

Sunday, June 9, 2019

Registration: Network with families from across the country	11:30 am
VOR Legislative Initiative 2019	Noon
Opening Remarks - Joanne St. Amand, President and Hugo Dwyer, Executive Director Guest Speakers – James Edmondson, M.D. PhD. On Medicaid Managed Care Amy S. F. Lutz - National Council on Severe Autism, EASI Foundation Other Speakers - To Be Announced	
Legislative Briefing	3:00 pm
Panel Discussion and Issue Briefing. Folders for Congressional visits will be distributed.	
Awards and Events	5:00 pm

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

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

Monday, June 10 – Wednesday, June 12, 2019

The Washington Initiative

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

Monday, June 10	Informal De-briefing	6:30 - 8:00 pm
Tuesday, June 11	Informal De-briefing	6:30 - 8:00 pm

To register for the conference and legislative initiative or make a dinner reservation at the Dubliner, go to: <http://weblink.donorperfect.com/VOR2019>

VOR 2019 Annual Conference and Legislative Initiative

Register online <http://weblink.donorperfect.com/VOR2019>

or use this form and return to:

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

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

(Reminder: Online Registration is faster!)

Name(s): _____

Address: _____

City, State, Zip: _____

Home Phone: _____ Cell Phone: _____

Email: _____

Sponsoring Organization: _____

INITIATIVE REGISTRATION

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

___ Monday, June 10 ___ Tuesday, June 11 ___ Wednesday, June 12

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

Registration is \$150 per person, and includes a one-year membership in VOR

ACT NOW! REGISTER BY APRIL 30 FOR THE REDUCED PRICE OF \$125 PER PERSON!

Names of Registrants:

Email:

Donations to help defray the event's costs are appreciated

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

Total Amount to Charge: _____

Credit card number: _____

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

Charge card: MC ☐ Visa ☐ Discover ☐

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

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

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

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

HOTEL INFORMATION

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

We have a bloc of rooms available for conference attendees.

The VOR Group rate is \$259 for single or double rooms, plus tax, per night. Larger rooms & suites are also available.

Hotel Reservations are due by May 10, 2019

To make your reservations online, go to: <https://www.hyatt.com/en-US/group-booking/WASRW/G-6VOR>

If you do not have internet access, call 1-800-233-1234 and mention "VOR's Annual Conference" when making your reservation.

I/DD Managed Care Threatens The Survival Of Certified Residences

By James Edmondson, M.D., Ph.D.



VOR is committed continuing the availability of institutional care for people with intellectual and developmental disabilities (I/DD). Many threats to the survival of I/DD institutions have arisen in the past several years, including sensational media coverage of institutional horror stories, the misapplication and deliberate misrepresentation of the Americans with Disabilities Act and the Supreme Court Olmstead Decision, the Money Follows the Person Demonstration, and the proposed Disability Integration Act and Transformation to Competitive Employment Act. Behind these threats is increasingly noisy campaigning by advocates who make a glib moral argument for universal community integration while deliberately dismissing the higher needs of the more severely intellectually disabled.

State-run I/DD certified residences, known as Intermediate Care Facilities (ICFs), have been emptied and closed in 14 states. Some estimates predict that if current trends persist unchanged, all state-operated certified residential institutions will close by 2028, leaving only voluntary sector institutions. Voluntary residential placements may include ICFs as well as smaller group homes with a range of supervisory and support levels. In the past decade capitated managed care, a new threat to I/DD institutional care, has captured the imagination of state budget directors as a tool for disrupting long-standing provider relationships. What is different about managed care is that it is a purely financial threat rather than a moral ideology. It reduces human lives to actuarial calculations. Whether any residence is subject to managed care financial pressures depends on whether payments to the residence are carved into or carved out of the capitated managed care rate.

Managed care, imported wholesale from the acute care medical sector and deceptively wrapped in anodyne hype, is an insidious threat to the continued survival of institutional care for people with intellectual and developmental disabilities. Regardless of the selling points, managed care is nothing less than a Medicaid privatization scheme. By reframing funding decisions in ruthlessly utilitarian market-force terms, managed care threatens to accelerate deinstitutionalization without regard for the human consequences for the most seriously disabled. It is essential that advocates for the continuation of institutional care inform themselves about managed care in order to mount an effective defense against it.

The imposition of capitated managed care on I/DD LTSS is based on flawed ideology and dishonest hype, with shockingly scant evidence of safety and effectiveness for the I/DD LTSS population. Since 2012, at least 26 states have begun to mandate the replacement of the traditional fee-for-service payment model with a capitated managed care payment model for I/DD LTSS. In 2018, already 7% of Medicaid LTSS costs for people with I/DD was expended through managed care. While a few states have passed laws banning I/DD managed care, many states are succumbing to the hype.

Whereas advocates and lobbyists for existing certified residences can presently appeal to elected officials and executive officers to resist changes to current funding arrangements, in the future the financing of certified residences could come under the control of for-profit managed care plans that are relatively immune to political pressure. If certified residences are “carved-in” to capitated managed care rates, then private for-profit managed care plans will have a powerful financial incentive to move people out of expensive certified residences and into less-expensive settings. In fact, the simple act of terminating existing long-standing fee-for-service contracts with states and replacing them with newly-negotiated contracts with capitated managed care plans is a financial and actuarial minefield. Many early adopters already report logistical failures causing months of non-payment.

In the long run, capitated managed care has the potential to be the most powerful deinstitutionalization mechanism of all, because it is administered by a private insurance plan that is separated by contract from the representative democratic process, depriving advocates and families of a voice. Unless the capitated managed care contract contains numerous detailed and extensive participant protections, enforced by a suitably empowered ombudsman’s office, there is a clear risk that purely financial calculations will determine the fate of certified residences.

The private insurance companies and hospitals quietly pushing I/DD managed care in state government exploit the troubling lack of sophistication in state legislatures on I/DD systems to sell managed care as compassionate and user-friendly, as opposed to current fragmented fee-for-service payment model. This distracts from the real problem of low wages for the direct service provider (DSP) workforce. DSP wages could be increased under existing fee-for-service contracts without the chaotic disruption of switching to managed care payments. Since few legislators have even a rudimentary grasp of Medicaid budgeting, privatizers are not challenged on their misrepresentations until people start getting hurt.

I/DD managed care promoters try to blame fee-for-service “fragmentation” rather than inadequate wages as the root cause of DSP shortages, dangerous mandatory DSP overtime, and institutional abuses. The managed care ideologues claim that privatizing I/DD services to managed care companies will somehow fix whatever troubles the I/DD world. In truth, managed care will simply hide these perennial problems behind a corporate veil.

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The only successful I/DD managed care systems to date have been developed over years and decades in small pilot programs. The best example is the 20-year pathway taken by Wisconsin. New York, Arkansas, New Hampshire, Michigan, North Carolina, Arizona, Pennsylvania, Wisconsin, Tennessee, and Texas are either expanding county-run managed care plans or have small home-grown managed care pilot programs. However, several of these states are on the cusp of precipitously scaling up local pilot programs into statewide mandates without adequate protections. Kansas and Iowa in contrast invited external managed care plans to run statewide I/DD managed care plans all in one step in a misguided spirit of wanton cost-cutting, and they have been notoriously unsuccessful in linking with existing state provider eligibility and billing systems. For I/DD providers with thin operating margins, the resulting payment delays have been damaging or fatal. We can expect commercial plans such as Centene, UnitedHealth OptumCare, and Aetna to market one-step I/DD managed care plans to more states in the coming years.

Several states that rushed their I/DD populations into managed care soon heard a predictable crescendo of complaints. Some state legislatures are now refusing to continue funding for I/DD managed care until current problems are addressed. There is a realistic chance that some states may eventually revert back to fee-for-service. Much of the opposition to managed care is voiced by residential operators who have been stung by non-payment and who perceive managed care plans as faceless and heartless and a threat to their very existence.

Capitated managed care for I/DD populations remains unproven and is still having trouble gaining traction nationwide, despite a loud academic cheering section and glitzy commercial marketing. It remains possible that I/DD managed care will prove unworkable in enough bellwether states that its momentum will slow. However, it is just as possible that I/DD managed care plans will ratchet up their hype and will proliferate. In this latter case, they could have considerable contractual leverage to impose financial and operational changes on certified residences, up to and including forcing closures, while being contractually shielded from legal accountability.

The decision whether to impose managed care on the I/DD population is made at the state level, with federal encouragement and permission but with little federal oversight. A pattern that repeats itself in state after state is that the governor listens to deep-pocketed lobbyists and mandates switching I/DD payments from fee-for-service to capitated managed care, then after years of trouble, the legislature eventually reins in I/DD managed care. The best strategy for VOR members and readers is therefore to speak with elected state officials to alert them to the threat to the survival of institutional care posed by I/DD managed care schemes.

Managed care is generally sold as a cost-cutting tool, but there is no way to cut I/DD costs except by cutting services, closing institutions, and hurting people. Managed care is a transparent privatization scheme that inserts a middleman to take his own cut by reducing services and pocketing the “savings.” I/DD managed care is a fraudulent scheme designed to divert Medicaid money away from those who need it most into the deep pockets of Big Medicine and Big Health Insurance, two political and financial superpowers with little emotional investment in the survival of I/DD institutional care.

The author is retired neurologist in New York City with two sons on the autism spectrum who participate in Medicaid waiver services through New York State's Office for People With Developmental Disabilities (OPWDD). Before retiring from clinical practice, Dr. Edmondson was employed for 13 years by a multispecialty medical group that was paid though a capitated managed care payment model.

Note: Dr. Edmondson will be speaking on Medicaid & I/DD Managed Care at the 2019 VOR Annual Meeting on June 9th.

VOR's Ed Orzechowski Receives the Benjamin Ricci Award

Ed Orzechowski accepted the 2019 Dr. Benjamin Ricci Commemorative Award on Wednesday, March 20th. The award is named for Ben Ricci, the original plaintiff in the 1970s landmark federal class action lawsuit, Ricci v. Okin, that brought about upgrades in care for residents of Belchertown and other Massachusetts facilities for the developmentally disabled. The annual award celebration recognizes the accomplishments of individuals served by the Department of Developmental Services, and the dedication of caregivers and advocates.

Ed is a long-time VOR member and State Coordinator, a former vice president of COFAR, and the President of Advocacy Network, an organization in Western Massachusetts that advocates for individuals with I/DD.

Ed authored “You’ll Like it Here,” a book about the life of Donald Vitkus, a one-time resident of the former Belchertown State School. The book chronicled Vitkus’s childhood in the 1950s at Belchertown, which was then notorious for its inhumane and unsanitary conditions. The book also described Vitkus’s battle throughout the rest of his life to come to terms with his past at Belchertown.

Ed called for the establishment of a “lasting memorial” at the former Belchertown State School. “I urge the Department of Developmental Services, the Legislature and local officials to create a lasting respectful memorial, a tangible commemoration to all the living and deceased former residents of Belchertown and the other institutions. What they experienced, what they endured, must not be forgotten.”



The Movement to Eliminate Work Centers and 14(c) Wage Certificates

The Raise the Wage Act:

H.R. 582 – Rep. Bobby Scott (D-VA)

<https://www.congress.gov/bill/116th-congress/house-bill/582>

S. 150 - Sen. Bernie Sanders (D-VT)

<https://www.congress.gov/bill/116th-congress/senate-bill/150>

The Transformation to Competitive Employment Act:

H.R. 873 Rep. Bobby Scott (D-VA)

<https://www.congress.gov/bill/116th-congress/house-bill/873>

S. 260 – Sen. Bob Casey (D-PA)

<https://www.congress.gov/bill/116th-congress/senate-bill/260>

Thousands of individuals with intellectual disabilities enjoy the opportunity to work in a specialized environment that nurtures them, accommodates their mental, physical and behavioral challenges, and rewards them with specialized wages that, while not equal to full minimum wages, are appropriate to their level of productivity and their capacity to work. These opportunities rely on specialized wage certificates as provided for under Section 14(c) of the Fair Labor Standards Act. The employment often takes place at facility-based work centers, sometimes referred to as sheltered workshops. These work centers provide more than employment. They provide a protected atmosphere suited to the intellectual and behavioral challenges of the individuals who work there. They provide a community of peers, and they provide a sense of productivity and accomplishment not found in day programs.

In the first weeks of the 116th Congress, Representative Bobby Scott introduced two bills that would eliminate these employment opportunities for individuals with disabilities, including intellectual disabilities. Rep. Scott frames his bills as a civil rights issue, and asks:



"If a non-disabled person has the right to work for competitive wages, why should a person with intellectual disabilities be denied the right to work for full, competitive wages?"

This appears to be a perfectly reasonable question, as long as you limit your scope to this rather simplified argument. But the real situation is far more complex. A more honest question would be:

*"If a non-disabled person has the right to work for competitive wages, why should a person with intellectual disabilities **who is capable of working at an equal capacity** be denied the right to work for competitive wages? And why should a person who is **not capable of working at a competitive capacity** be denied the opportunity to perform any work at all?"*

Why VOR opposes these bills:

The movement to move disabled individuals, which includes visual, auditory, and physical disabilities as well as people with I/DD, is a noble effort, a true civil rights issue that is overdue. We, as a society, *should be* creating opportunities for those who want to work, and who are capable of working at a competitive level. But the implications of Representative Scott's bills echo the "one-size-fits-all" mentality that dominates the DD system and marginalizes those who are outside to the "one size" population.

"One-size-ism" doesn't work for disability policy. The I/DD population is too complex and diverse to be treated with simplistic, one-sized solutions.

Both of Representative Scott's bills, and their companion bills in the Senate, are aimed at providing competitive, integrated employment opportunities for those capable of achieving this level of employment, but they also insist on eliminating the current opportunities provided for those not capable or not desiring this level of employment. Mr. Scott, Mr. Sanders, and Mr. Casey all feel they know better than individuals and families of individuals who appreciate these opportunities.

Both of these bills seek to phase out wage certificates and eliminate work centers over the next few years. The main difference between the two is that the Raise the Wage Act focuses on raising the Federal Minimum Wage, an idea that many members of Congress feel is long overdue. This part of the bill has strong support in the House, with limited support in the Senate. In the current political environment, any bill raising the minimum wage is unlikely to be brought to a vote in the Senate, and even less likely to be signed into law by the President. So the Transformation to Competitive Employment Act avoids the issue of raising the Federal Minimum Wage, but retains many of the same principles that deny individuals with I/DD the right to work in centers that operate on 14(c) wage certificates.

The thinking behind this movement is that work centers are bad things that limit the individual's capacity, and that given the opportunity to work in a competitive, integrated environment, all individuals will rise to their full capacity. Proponents of this movement, when forced to admit that some people will be shut out or left behind, speak as though this is an acceptable consequence of their plan. It is not. These are human lives. These are not disposable, expendable individuals. These people have families who love them and want the best for them.

There is no reason to accept these "acceptable consequences", especially when there is no correlation between eliminating 14(c) wage certificates and investing in employment opportunities for individuals with disabilities.

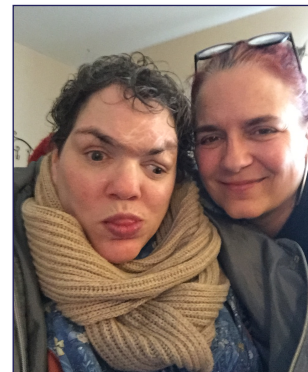
Notes from the Front

By Liz Belile

The Texas legislature is in session this year and yes, there are several bills in play that could potentially destroy our lives and erode the rights of our loved ones and families... again.

I am tired of having to defend my sister's high level of need for support.

Her neurologist recently confirmed, in writing, what I already knew: that her seizure disorder is so severe that if they moved her out of the State Supported Living Center (what they call our state-run Intermediate Care Facilities here) and into a group home her life would be in danger. I am tired of hearing from so many people that she can get exactly the same services in "the community." I am tired of hearing how much it costs the state to provide care for these people who have already fallen through the cracks, who have finally arrived at sanctuary in the State Supported Living Centers. Yet, there are still those who are languishing in nursing homes, or trapped at the state hospitals because there is NOWHERE else for them to go, except jail.



I want the fighting with "the community" advocates to end. I can't argue or reason with someone who insists that nobody "deserves" to live in an institution. Who sees my sister's home campus and views it as horrific, dilapidated, a prison. WHICH IT IS NOT. Who does not know the details of my sister's life and medical condition yet insists it is not "severe" that NO ONE is "severe" and that she CAN live in a group home "with the proper supports."

I feel like we are all being pitted against one another, fighting for scraps from one of the wealthiest states in the country, Texas. Our state has received nearly half a BILLION dollars in funding from the federal government through the Money Follows the Person program, just to "transition" people out of intermediate care facilities and into "the community." Meanwhile, untold numbers of those people have died. And I do mean UNTOLD. We, as guardians and protectors of our loved ones, can never get the data or vet the homes and caregivers with whom we are supposed to entrust the lives of our fragile people, because the state and the corporations that operate these homes and provide services are NOT transparent and refuse to give us the information we seek.

Advocates who are working so hard to close or "right-size" the SSLCs should take a good hard look at themselves, and realize that we are all fighting for the same thing: a robust, fully functional, and permanently funded and supported system that provides what every single person with a disability needs.

Follow-up on the President's Committee on People with Intellectual Disabilities

In the previous issue of the VOR VOICE, I spoke of my attempt to speak on behalf of VOR families, an on behalf of my brother Tom, at the meeting of the President's Committee on People with Intellectual Disabilities (PCPID). Since then I have applied three times to be nominated as a member of the committee, which had only filled eight of its twenty seats. I assume I was not accepted, by the fact that no one contacted me to let me know I had been accepted. The committee did, however, fill one seat with a very nice woman who represents her community as a self-advocate. Unfortunately, our loved ones (*i.e. people with severe I/DD, severe autism, complex medical conditions or behaviors that put themselves or others at risk*) still do not have a seat at this table.



In the past four months, the PCPID has held two teleconferences and one more two-day meeting, all of which I have attended, though still without having been allowed any opportunity to address the committee.

The committee plans to proceed with a short presentation on efforts to promote competitive, integrated employment. What they have not openly stated, is whether they are still committed to eliminating Work Centers and 14(c) wage certificates, as was part of their original plan. Not all members are in agreement on this issue. During a break, I spoke with Chris Neely, the Chair of the Committee, who understood that this would take away opportunities for some people with I/DD, and that keeping work centers and 14(c) certificates for some would not hamper efforts to create opportunities in competitive, integrated employment for others. However, the two members of the Administration for Community Living (ACL), which is guiding the committee, appear steadfastly opposed to retaining work centers and 14(c) certificates. As in the past, some members of the ACL seem to feel their responsibility is to the concept of "Community Living", not to the needs of people with intellectual disabilities.

We will see what and who this committee stands for, and against, when they submit their final report to the President at the end of the summer.

Can't make it to D.C. this year? You can still help!

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