

## **COVID-19 WILL NOT SILENCE OUR VOICE**

As you all know, this year's Annual Meeting and Legislative Initiative have been canceled due to the Coronavirus pandemic.

Over the course of a few short months, COVID-19 has drastically affected every aspect of our society. It has killed over 100,000 of our fellow Americans. It has shut down our economy, destroyed businesses, halted transportation, and altered our social interactions. We have been shuttered in our homes in quarantine. We have been unable to visit our loved ones in their homes, for fear of carrying the virus to their door. We have seen what this contagion has done in nursing homes, in group homes and ICFs, and to friends, family members and neighbors in their own homes. So we stay in.

But we stay active. COVID-19 will not silence us. VOR's mission to speak out for human rights and high-quality care for all people with intellectual and developmental disabilities remains unchanged.

In this issue of the VOR VOICE, we will try to present to you a small piece of what would have been presented in our Annual Meeting. While there is not room here to present all of our State Reports, we will be presenting many of them on our website, as we do after our meeting each year. We will introduce you to our three advocacy committees, and describe some of the work they have put in over the past year. And in place of a guest speaker, we have a short presentation about the importance of Applied Behavior Analysis for people with autism and intellectual disabilities.



While nothing can replace the experience of seeing the Capitol lit up at night, of looking down the National Mall to the Washington Monument, of passing the Supreme Court as you cross from the Senate Office Buildings to the House side of the Hill, or of getting lost in the Rayburn building with three minutes to your next meeting, we will try to describe some of the bills we would have discussed with our Health LA's - legislation that affects our loved ones, their homes, and their activities.

And we will share with you some of the personal stories that come from our families and friends. VOR's former President Caroline Lahrman reports on the settlement in the lawsuit that has occupied much of her life, too much of her life, for the past four years. Micki Edelson, who spent decades building group homes, describes the journey that brought her to VOR, when the rest of the IDD community failed to understand the need for a full continuum of care. We will share our hopes, and our tragedies.

But first, I would like to share some gratitude.

My wife and I came down with COVID-19 on March 20<sup>th</sup> of this year. It was almost inevitable, as we live in New York City, the epicenter of the pandemic in the U.S. While the coronavirus affects different people in different ways, our experience shows that this is nothing like the flu. It hangs on for weeks. It hurts. It takes your energy, your sense of taste and smell, your ability to focus. It makes it difficult to breathe. It is powerful, and it is frightening. You do not want to get this virus. Above all, you do not want your family member with IDD or autism, behavioral disorders, seizure disorders, or other medical challenges to encounter COVID-19. We urge you to do all you can to keep your loved ones safe.

We would like to thank VOR's Board of Directors for their kindness and support through our illness. I cannot describe what a relief it was when a Board member called to tell me that they had voted to give me a leave of absence if I needed it. While I did manage to work through my illness, it's nice to know that people have your back in a crisis. We would also like to thank those members of the VOR family for reaching out with their support, thoughts, and prayers for us. Not to mention the nice woman from Homes for Life who had a gallon (yes, four quarts!) of chicken soup delivered to us from a well-known Lower East Side delicatessen.

Hugo Dwyer, Executive Director

State Reports will be posted to our website at: [www.vor.net](http://www.vor.net)

Follow us on: [VOR Facebook](#)

[twitter @VOR\\_NET](#)

[Instagram vor.net](#)

[VOR – A Voice Of Reason](#)



## **Reports from VOR's Advocacy Committees**

### **Legislative Committee**

VOR's Legislative Committee is chaired by Steve Wallace, an attorney from Austin, Texas. Steve is a relatively new member of VOR but a long-time advocate for Texas' State Supported Living Centers (SSLC).

The Legislative Committee deals primarily with bills in Congress. The committee works on both authorization and appropriations bills. In a word, an authorization bill is one that can establish, continue, or modify an agency, program, or activity for a fixed or indefinite period of time," per the [Congressional Research Service](#). Appropriation bills are the process congress uses to determine how much to spend in each annual budget to fund the various authorization bills.

This year, much of the committee's attention has been directed at the reauthorization and appropriations of the Money Follows the Person Rebalancing Act (MFP). This bill was originally passed in 2005, and has been reauthorized several times since, each time with a fixed period of time. This year, advocates for the bill attempted to authorize the bill indefinitely.

Over the years, MFP has been used frequently to override choice by individuals or their families and guardians, and to give that choice to states and advocacy groups. One example is the state of Pennsylvania, where Governor Wolf decided to close state ICFs, using MFP funds to pay for the transitions of people to HCBS waiver settings. By so doing, the governor was taking away the choice that families had already made for ICF care in a nearby setting and imposing his own choice. Many families were forced to choose between moving their loved ones to an ICF across the state, or waiving their rights to ICF care altogether to stay nearby, albeit in a group home that offers a lower level of care.

The legislative committee has taken action on both fronts regarding MFP, objecting to both the permanent reauthorization of the bill and to inserting language back into the current appropriations bill that had been included in previous authorizations, that language offering (ostensibly) better protections under the law for ICF level care and choice, as written in the Supreme Court's decision in *Olmstead v. L.C. (1999)*. Steve Wallace drafted a letter objecting to permanent reauthorization of MFP, and Peter Kinzler and Caroline Lahrman submitted testimony to the Senate Appropriations Subcommittee on Labor, HHS.

According to a May 29, 2020 statement from the Community Living Policy Center, short-term extensions of MFP have resulted in a significant drop in state efforts to move people out of ICFs. <http://www.advancingstates.org/node/72035>

Another concern of this committee has been the Disability Integration Act (DIA), a bill that aims to eliminate ICFs entirely. The bill is currently stalled in both the House and the Senate. Nonetheless, VOR's Vice President, Joanne St. Amand, and Executive Director Hugo Dwyer met with aides from the offices of Frank Pallone, Jr. of the House Energy and Commerce Committee, and Senator Chuck Schumer, the sponsor of DIA in the Senate, to express their concerns about the bill.

In addition to MFP and the DIA, the committee continues to monitor other legislation. Hugo Dwyer submits regular monthly updates on the appearance of new bills and changes made to the status of existing bills affecting people with IDD, and members of the committee and our state coordinators meet with members of congress in district. The Legislative Committee has been the source of many of the VOR Action Alerts that have been sent out to our members over the past years.

### **Issues/Oversight Committee**

The Issues/Oversight Committee was formed to address challenges to VOR's mission that were not covered by the Legislative Committee, as they fall outside of the purview of congressional legislation. We deal in policy matters initiated by the Department of Health and Human Services (HHS), the Administration for Community Living (ACL), or the Center for Medicare and Medicaid Services (CMS), as well as policies by organizations like the Arc, ANCOR, or ADAPT. Mary Vitale has chaired this committee for the last five years.

Over the last few years, one ongoing issue this committee has been monitoring is the persistent attacks on Guardianship by advocates of Supported Decision Making, who view this informally structured and monitored program as an alternative to court-supervised guardianship, or even as outright replacement of legal guardianship. Families of individuals with severe intellectual disabilities, self-destructive or aggressive behaviors, or complex medical problems know that legal guardianship ensures the rights of the individual and protects the individual from being moved into inappropriate settings or receiving lower levels of care.

This year we continued investigating state laws regarding background checks for direct support professionals (DSPs) working with individuals with IDD, and the differences between the high standards initiated by the State of Ohio and the problems engendered by states with lower standards. Of concern is the idea that during this ongoing shortage of DSPs throughout the group home system, there may be a lowering of the bar to meet staffing needs.

Most recently, we have been involved in defending the existence of vocational centers that provide employment opportunities for individuals with IDD under commensurate wages as determined by Section 14(c) of the Fair Labor Standards Act (1938). This provision allows public and private employers to obtain special certificates from the Department of Labor's Wage & Hour Division that permit

*(Continued on following page)*

them to compensate workers with significant disabilities at rates below the current federal minimum wage based on the individual's level of measured productivity. Over the last few years, some advocates have claimed that all people with IDD who are capable of any level of employment activity have a right to competitive integrated employment, i.e. full-time jobs at competitive wages. While VOR supports the rights of those who are capable of engaging in such employment, we understand that not everyone is capable of engaging in these programs, and that those people are entitled to continue to work for compensatory wages if they so desire. Much as in our policies toward residential settings, VOR believes that the diverse community of people with IDD deserve a full range of options and the right to choose what opportunity is best suited to the individual. We believe that creating opportunities for some to engage in full, competitive employment need not take away the opportunity for others to participate in programs better suited to their needs and abilities.

## **Quality of Care in the Community**

The Quality of Care in the Community Committee (QofC) was created in 2016 to help extend VOR's outreach to families with loved ones living in Home and Community Based Service Group Homes and to give families forced out of ICFs an opportunity to organize around key issues. It is currently chaired by Jill Barker.

This year, the committee has continued the work of examining the contrast between easy access to dental services provided in larger state-operated ICFs and the difficulties families encounter in finding quality dental care in "the community". Mary Kay Cowen is a member of the Louisiana Dental Task Force for Adults with IDD. She has provided a wealth of information on the lack of services in Louisiana, including a lack of training and incentives to treat the specialized needs of this population, problems with Medicaid coverage, and the need for treatments that take into account the inability for many with IDD to tolerate dental exams and cleaning without sedation. These problems are not unique to Louisiana. In the past, the Committee has made proposals aimed at finding ways to encourage dental students and dental colleges to learn about people with IDD, their special dental needs and challenges, and to provide financial incentives toward providing such services in their communities.

Mortality rates are simple and objective indicators of well-being. They especially highlight the vulnerability of the small minority of those with extraordinary needs among all those who receive Medicaid benefits for I/DD. Mortality data can also be used to compare outcomes of those who left state run ICFs for various community supports with those who remained. Ever since the 2012 settlement agreement between the Department of Justice and Virginia required the state to track mortality among those leaving the state run ICFs, Bob Anthony periodically analyzed those data whenever they were released. See these on VOR's website <https://www.vor.net/get-help/more-resources/item/mortality-studies>. This year, DOJ and Virginia are negotiating a final agreement, and Bob submitted to DOJ a critique of the agreement's failure to highlight the vulnerability of those with extraordinary needs and to report that vulnerability to lawmakers and the public.

Most recently, the committee has been joined by VOR's Sam Friedman, who, along with Joanne St. Amand, successfully pushed for testing of all residents and staff in New Jersey's ICFs for COVID-19 using the Rutgers Saliva tests, which had recently been approved by the FDA. We are currently working on a campaign to enable VOR members to encourage their state health officials to commit to regular testing of residents and staff in all long-term care facilities.

## **VOR's Bill Watch**

### **The Disability Integration Act (DIA): H.R.555 - James Sensenbrenner (R-WI) / S.117 - Chuck Schumer (D-NY)**

While this bill has appeared in many forms over the last 25 years, the language the bill in the 116<sup>th</sup> Congress is clearest in announcing its intent to eliminate ICFs. Its supporters insist there is still an "institutional bias" in disability services, a claim that VOR members know from experience to be untrue. Additionally, the bill would require the government to fully fund HCBS waiver services for anyone with an intellectual disability – an unrealistic goal that would cost an astronomical amount of money to both federal and state governments. Advocates for the bill know that it would never pass a cost analysis in the Congressional Budget Office (CBO), but they appear undeterred.

Last summer, members of ADAPT stormed the offices of House members to harass representatives into signing onto the bill. They succeeded in getting a majority of members to sign on, but the bill is still being stalled in the Energy and Commerce committee and seems unlikely to proceed. Several members of VOR's Board and other members from our New Jersey delegation have met with people in Rep. Frank Pallone's office to support his efforts to stop this bill as chair of the E&C. Were he to be overridden and the bill to be passed in the House, it would probably be sent to the CBO, which could hold it for months. Beyond that, it is unlikely that it would come to a vote in the Senate under Majority Leader Mitch McConnell.

The sponsor of the House Bill, Rep. James Sensenbrenner (R-WI) is retiring at the end of this year, so advocates will have to find a new sponsor in that chamber. VOR's Executive Director has met on several occasions with health and disability aides in the office of Chuck Schumer (D-NY) and have been very clear and persistent about our objections to the DIA. We will continue to press to prevent this bill from proceeding into the 117<sup>th</sup> Congress.

*(VOR's Bill Watch continues throughout the newsletter)*

## Supporting the Murray Center Under Quarantine

By Rita Winkeler – President, Murray Parents Association; Member of the VOR Board of Directors



During this stressful time of the COVID-19 virus there are still some bright shining lights that need to be shared, not only with our VOR members, but across the disability community. Murray Center, is a state congregate care center in a small southern Illinois community of Centralia. Two hundred forty-three individuals call Murray Center home. These individuals live in six different cottages, sharing a dining area, with individual living rooms, and bedrooms.

On March 12<sup>th</sup> a “no-visitor” rule was put in place, and no one but staff and delivery employees were allowed on the campus. I had routinely visited the center twice a week, not just spending time with our son Mark, but with many of the other residents, who had become our friends. The staff immediately began to arrange FaceTime or Skype visits, and send me pictures every day that I posted on the Murray Parents’ Association Facebook site. I am the president of the organization that is 200 members strong; including parents, guardians, family members, community members and staff.

The Murray Parents’ Association (MPA) then began to think of ways we could support our staff during this time. We established a “Employee Recognition Week”. The MPA sent thank you cards to staff, including the staff who are frequently overlooked...housekeeping staff, clothing staff, boiler house staff, etc. We flooded the center with cards and letters. We sent over 600 cookies for the staff, “Sweets for the Sweet”. Each day on Facebook I posted pictures of our staff honoring them. On Friday of that week we sent in pizza for every staff on every shift. Due to the “no visitor” rule we were allowed to have businesses drop off food at the administration building where the packages were sanitized. For three weeks the center remained COVID-19 free.

Then on April 1<sup>st</sup> our first case was diagnosed on Grape Cottage, then another, and finally by April 20<sup>th</sup> there were 25 cases, all contained on Grape Cottage. Along with the 25 residents with positive cases, there were 20 staff with the virus. This is when the MPA, along with the community got in to gear, and began a full-fledged effort to support our Grape Staff. Businesses in the community sent drinks and meals for the staff. Former employees sent money that could be used to purchase meals. One staff who was on maternity leave arranged a “buy one get one free” hand cream sale, and then donated over 70 small hand lotions for the staff on Grape. Local sewing circles donated over 500 masks, not just for Grape but for the entire center. Our local state Representatives and Senator arranged for N95 masks to be delivered, and a large supply of hand sanitizer. Every day someone was sending something to Grape Cottage.

The MPA worked with the Center Director and Grape Cottage director on supplying anything they needed. The MPA sent large supplies of craft items, coloring books, games, basketballs, and other items to help keep the individuals occupied not only for those in isolation on Grape Cottage, but for all residents across the center. Several staff volunteered to join the staff on Grape Cottage, and several retired staff, including nurses, came back to work at the center. The staff worked with the individuals making signs saying “Murray Strong” and this not only helped the residents stay busy, but it enabled them to feel they are part of the Murray team. Within two weeks of the first diagnosis the center has received so much support from the local community and the MPA that the Director is now storing the drinks and snack items, and rationing them out for the cottages, so the drinks and items will last for weeks. Families and friends continue to send items every day, and the MPA will continue to purchase any items needed by the staff and residents.



On April 22<sup>nd</sup>, the Murray Parents Association decided we needed to show our appreciation in a big way. A group of us lined the city sidewalk that borders Murray Center, and from 5:30-8:30 a.m. we cheered and welcomed staff as they came to work, and left from work that morning. Later that day from 1:30-2:30 p.m. we cheered the second shift workers as they came in for duty. Many of the staff had tears in their eyes as they saw us cheering and thanking them.

At this time the residents and staff who have tested positive are doing well, and expect to be released from isolation in the near future. It has been a very stressful time, not only for the residents and staff, but the family members too, as we miss our loved ones, and are always concerned if more of the residents will test positive, but through it all once again Murray Center has shown that a large congregate care center is HOME, and during times of crisis is surrounded with the love and concern of not only staff and families, but the entire community. Murray Center WILL survive the COVID-19 virus, and continue to provide the best, and least restrictive environment for many individuals with disabilities.

## **Settlement Announced in Ohio P&A Lawsuit**

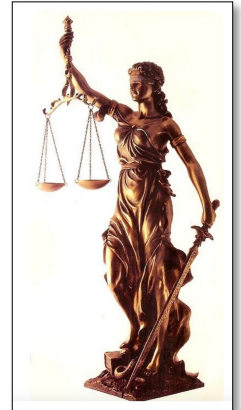
**By Caroline Lahrman**

For the last four years, Ohio families have been instrumental in fighting and changing the course of a lawsuit brought to pressure the state of Ohio to remove funding from intermediate care facilities (ICFs). The lawsuit was filed by Disability Rights Ohio (DRO), Ohio's protection and advocacy (P&A) system for individuals with intellectual and developmental disabilities (I/DD) under the guise of promoting "meaningful choice." Ohio families knew better. Because of their efforts, true choice - the choice between and ICF and a community setting - still exists.

On Friday April 24, the U.S. Southern District Court of Ohio issued an Order approving a modified settlement between the State of Ohio and Disability Rights Ohio (DRO) in the *Ball v. Kasich* lawsuit. DD families' intervention in the lawsuit was critical to the Court dramatically narrowing the class to protect and preserve the ICF choice.

Judge Edmund Sargus ordered protections for ICF families to be added to the settlement after receiving hundreds of objection letters and hearing hours of testimony from DD families opposed to settlement provisions. The settlement was modified to include the following commitments:

1. Nothing in the agreement is intended to force an individual from an ICF or remove the ICF option.
2. Nothing in the agreement requires an individual to accept an exit waiver from an ICF.
3. Families who objected to the proposed settlement will be excluded from options counseling.
4. The State of Ohio will not reduce funding to ICFs in the current budget cycle, and it will use best efforts to maintain ICF funding at present levels in the next budget cycle.



These protections are all the more important in light of the present Coronavirus epidemic and the resulting economic downturn. The State and DRO have repeatedly assured the Court and DD families the settlement will not affect the provision of ICF services or funding to ICFs. DD families note that the State had one month to withdraw the settlement upon ordering \$14 billion in budget cuts on March 23rd. In his Order on settlement, Judge Sargus specifically recognized the commitments and representations State Defendants made to the Court:

"Defendants conclude (their brief to the Court ) with the following:

'Defendants take commitments in the Agreement and their representations to the Court very seriously, and they will act in good faith to meet these commitments.'" (Order on Settlement, Doc 473, page 9)

ICF families will not forget this solemn commitment made by the State to the Court and to the thousands of ICF residents who are entirely reliant on the good will of others.

Opposition to the settlement arose because its provisions are primarily targeted at non-class members – people who prefer ICFs. The State and DRO crafted settlement provisions totaling approximately \$100 million designed to push non-class members out of ICFs. These provisions include "options counseling" to pressure families to leave ICFs; 700 "exit waivers" (representing \$70 million per year) to fund exits from ICFs; and financial incentives to ICF providers to pressure them to reduce and close ICFs. These provisions do not increase options for people with I/DD, as DRO wrongly alleges, but rather they undermine a primary care option - the ICF entitlement.

The unpopularity of settlement provisions is evident from the fact that the vast majority of ICF families refuse to meet with options counselors to discuss exit waivers. It is estimated that as many as 500-900 exit waivers remain *under*-subscribed since their allocations in 2015 and 2017. With the addition of this settlement, Ohio's supply of unused and unwanted exit waivers rises to possibly as much \$160 million in idle funding.

DD families urge the state of Ohio to heed the prescient words of Justice Anthony Kennedy in his concurring opinion in the U.S. Supreme Court *Olmstead* decision,

*"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...In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings, devoid of the services and attention necessary for their condition."* (*Olmstead v. L.C.* 527 U.S. 581, 610)

The efforts of Ohio families exhibit the importance of educating officials and courts about the full continuum of need and choice in the disability community. By bringing together this continuum throughout the country, VOR is crucial to this advocacy, as the only disability advocacy organization that promotes the interests of all people with I/DD.

### **Post-Corona Bills in Congress**

Several bills have recently been introduced in the 116<sup>th</sup> Congress that would affect people with IDD and the long-term care facilities where they live. Many of these bills do not have text or summaries posted, but our best guess is that they are not intended to praise ICFs and open them up to new admissions, as they have been introduced by elected officials who have opposed ICF care in the past. We will continue to follow these bills, expecting that the sponsors intend to introduce these provisions into the next COVID-19 Emergency Appropriations bill rather than to promote them as separate authorization bills.

## **Message From The President**

Under “normal” circumstances it would be that time of year I would begin collecting my thoughts on key happenings during the past 12 months of my term as President and putting them to paper. I would be anticipating the excitement of meeting, and the privilege of addressing, all of the wonderful VOR members who had traveled to Washington D.C. to take part in our annual June Conference and our Legislative visits on Capitol Hill.

But as we all too well know; we are not living in “normal” times. The coronavirus pandemic that struck our country, and practically the entire world, has drastically changed the way we all live. I hope and pray that any of you who may have been medically affected by the virus have totally recovered from the illness and now doing okay. I also pray that the time is soon coming when we all will no longer be subject to quarantines, social distancing, and other inconveniences that prevent us from interacting with our loved ones and returning to life as we knew it before Corvid 19.

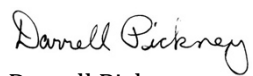
But since I won’t have the opportunity and privilege to address you at a June Conference this year, I want to take the opportunity to give you a look behind the scenes at your VOR leadership. Even though VOR has only one paid employee, we have a tremendous number of volunteers working for you in a way that is almost like fulltime for many of them. Without these people volunteering their time and expertise, VOR could not fulfill its mission and remain the strong voice that it is today.

The volunteerism begins with your VOR Board of Directors. I have been honored this past year to work with such a great group of professionals and you should feel proud too because it was your vote that elected each of them. With your most recent proxy votes you have selected six new members for 2020 who I know, based on the experiences listed in their resumes, will be great future leaders and advocates for our organization. As a matter of fact, three of them have already been serving in an interim capacity, awaiting your official vote, and the other three will officially begin their terms on July 1st. This new group brings a wealth of experience and professionalism to the Board. Their resumes include titles such as Attorney, Legislator, Corporate CEO, Military, Administrative Social Worker and Nurse Manager, which gives you a glimpse of the expertise our newest members will be bringing to the Board. And the election of these six brings our Board to full strength with the maximum number of 20 as outlined in our By-Laws. To my knowledge this is the first time VOR has had the benefit of a full 20-person Board.

Another group of dedicated volunteers are the Chairpersons and the members of the various committees who produce the volumes of work required to meet the challenges that VOR faces on a daily basis. Most all of the real and important work of our organization is identified, cultivated, and processed through the various internal committees. We all owe a debt of gratitude to our committee chairs and members for the work they do.

I will end my message by asking for your help. The Board of Directors recently identified membership growth as a primary goal for the upcoming year. If each member was successful in identifying just one parent or guardian and invite them to join our organization, it would be a huge step forward toward achieving this most important membership goal.

Your Board of Directors and I appreciate the support of each and every member. We hope and pray that you and your families stay safe and healthy throughout the year, and we look forward to seeing you again when we are able to meet again in Washington D.C. at our 2021 June Conference.



Darrell Pickney

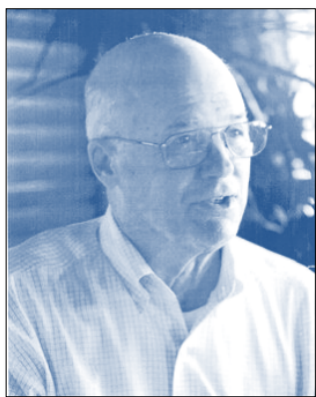


### **VOR's Bill Watch**

#### **Money Follows the Person (MFP)**

As noted in the article on VOR's Legislative Committee, MFP continues to be a problem for families with loved ones in ICF care. Most recently, attempts to re-authorize the bill only managed to extend it through the end of this year. There will undoubtedly be another bill to extend the authorization, but there is currently no bill number for an authorization bill for MFP. The last few times MFP has been reauthorized, it has been added to a package containing several other bills that are favorable to people with disabilities. This bill has appeared almost overnight, passed by a voice vote in the House, thus avoiding any deliberation on the merits of the individual bills that have been included therein. This bill is then moved to the Senate, where it is again passed by voice vote, with no deliberation, and passed on to the President, who signs it into law.

It is difficult to intercede in the above process, yet we persist in hopes that Congress will examine the bill, consider whether or not it is serving people as intended, and allow us to testify about the protections that we would like to see in a revised bill that would protect and preserve ICF care as intended under *Olmstead*.



The very first conversation I ever had with Bill Sherman was sometime around 1990 when he called to invite me to an FF/CFR meeting in Little Rock. My home was 125 miles away and I could not imagine anything would be going on at that meeting that would be worth me wasting a day in Little Rock. Man, was I ever wrong? That phone call introduced me to a man whom over the years I grew to admire and respect, due to his untiring and relentless advocacy work on behalf of a most vulnerable population; individuals like his son and my daughter who live in ICF's with severe cognitive, developmental, and intellectual disabilities. Up until the phone call that night I had advocated solely on behalf of my daughter but Bill became a mentor who showed me that I could, and should, broaden my role as an advocate.

Bill was calling that night because Disability Rights Center, as they were called at that time, had filed a lawsuit trying to close the Human Development Center (HDC) where my daughter resided in Jonesboro. As he so often did, Bill was volunteering his time, doing pro bono work, in helping to ensure that the lawsuit did not succeed. He recruited me to be a witness in that lawsuit. Thankfully, like so many other fights that Bill Sherman fought, he came out victorious in this one also. The Center remains open and was my daughter's safe and wonderful home for 36 years.

Bill, along with Carole Sherman, was the stimulus that created Friends & Families of Care Facility Residents (FF/CFR) in Arkansas. I became a member of the FF/CFR Board in 2004 and sat through many, many meetings observing Bill's remarkable leadership. By the time I joined the Board Bill was already a "Past President" but no matter what office he held, or if he held no office at all, he was always ready and willing to coach and teach the newer members. In 2012 Bill placed my name in nomination for President of FF/CFR. I tried to refuse the nomination, telling the Board that I had neither the knowledge nor the expertise to lead the organization. I will never forget Bill's rebuttal---It went something like this, "Darrell, I have observed you closely at these Board meetings during the past several years. You sit quietly and don't say much. You listen to both sides of every argument. And at the appropriate time you always speak up and say what needs to be said". I don't know if Bill was right or wrong but coming from Bill Sherman, I considered it the best complement I had ever received.

Bill would always say that FF/CFR was the strongest voice in Arkansas for a full continuum of care and VOR was the strongest, and only, voice we had supporting us at the national level. Bill always encouraged us all to become members of VOR. His strong belief in the work and value of our national organization was my motivation for joining VOR in 2012.

William "Bill" Sherman passed away on March 11, 2020. During his amazing life he had many successful careers: military, attorney, legislator, and advocate, just to name a few. His achievements and awards were many, far too many to list here. I considered him my mentor and my life has been blessed by knowing him and enjoying his friendship. He set the example for people working together to pursue common goals. As was stated in his obituary, he truly led the way in reversing the trend of past decades to close ICF's through class action litigation. In this time of sorrow, may GOD BLESS the Sherman family.



*Carole, John, and Bill Sherman*

### **Recognizing the Role of Direct Support Professionals Act: H.R. 6045 – Kathleen Rice (D-NY)** **S.3369 – Maggie Hassan (D-NH)**

This bill was introduced to address the shortage of Direct Support Professionals (DSPs) and the high turnover rate (45% in 2016) in the field. This bill would direct the Office of Management and Budget to revise the Standard Occupational Classification system to establish a separate code for Direct Support Professionals, ensuring better data on these pressing workforce challenges. The bill is an important first step in ensuring better training, certification, and wages for DSPs.

More information on these bills is available through Senator Maggie Hassan's website:

[https://www.hassan.senate.gov/imo/media/doc/RecognizingtheRoleofDSPsAct-One Pager FINAL.pdf](https://www.hassan.senate.gov/imo/media/doc/RecognizingtheRoleofDSPsAct-One+Pager+FINAL.pdf)

## Homes for Life    By Micki Edelson

On a lovely spring day in 1972, I held my youngest son Robert for the first time not knowing that this little baby would change the trajectory of my life. Birth injuries that occurred during that difficult delivery resulted in Robert suffering significant intellectual disabilities. As the extent of these disabilities slowly unfolded, I knew that Robert's challenges would be different from his older brother and yet my goals for him were the same. Robert would get the best education possible to reach his full potential and someday hold a job, live in his own home and enjoy life in his community.



In 1989 I had a small dream. I would find a way to raise the funds to build a group home where Robert could live with his peers when he completed his schooling. There were a few group homes in Delaware; but my vision of what a group home should look like was quite different! It should be in a beautiful, safe community near all appropriate amenities. When my first group home was completed other families liked what they saw, and the State of Delaware asked for more. My husband Lanny and I then established Homes For Life Foundation and, thanks to the generous and ongoing support of the Delaware community and friends around the country as well as corporations and foundations, we have built and furnished 25 debt free group homes and purchased two condos. Today one hundred and four deserving men and women now have a safe and comfortable place to live and enjoy life. Their intellectual disabilities range from high functioning with drop-in support to high needs with 24/7 awake staff.

It didn't take long to appreciate that building the homes was the easy part. Finding caring, dedicated and competent staff would turn out to be the difficult part. Ironically in the 1990's, as I was fundraising and building four-person group homes, the State of Delaware approached The Arc of Delaware requesting that they become a landlord by providing homes for those with IDD. I was a board member of the Arc of Delaware at the time. When the Homes For Life homes began to multiply we recognized that as an all-volunteer non-profit organization with no staff to provide property management, we voted to deed each property to The Arc of Delaware for \$1.00. The organizational arrangement was as follows.

- Homes For Life would build and furnish the homes
- Homes For Life then deeded the homes to the Arc of Delaware for \$1. The Arc became the landlord responsible for upkeep of the homes, including a maintenance reserve fund.
- The State of Delaware contracted with provider agencies to support the residents living in the homes and compensate the agencies according to the acuity of the disability of the residents in the homes.
- The residents in the homes would always have the right to change provider agencies if they felt that their needs were not met.

When the last home was donated in 2009 the value of the homes was approximately 10 million dollars. Each home was HCBS waived. Little by little I began to understand CMS and the Medicaid system. The Medicaid funds are the "lion's share" of lifetime support due to the costs of direct care for persons with IDD. Each home is only as good as the Direct Support Professionals and the managers who, despite inadequate wages, make a house a home.

It was during this time, that I met many other Delawareans whose adult family members were longing for a more independent life. I also became acquainted with The Mary Campbell Center in Wilmington, a 55 bed ICF with amazing amenities for those with higher needs and medical complexities. I found others online like VOR members Tamie Hopp and Jill Barker, and I met people from across the country who shared my views that a "one size fits all" solution would not be sustainable.

In 2011, I was appointed to the President's Committee for People with Intellectual Disabilities (PCPID). This position gave me more insight into the way services were being allocated, and the ideological direction the agencies administering DD services were taking. At that time CMS began reviewing and changing HCBS regulations. The Administration on Aging and the Administration on Disabilities were combined into the Administration Community Living (ACL), taking the focus from the needs of the individual to a determination to support a single service model of "community living." The push to move people from ICFs was well underway, and now various government agencies were shifting again and urging families to keep their loved ones in the family home as a new "alternative."

I had to accept the sad reality that not only were ICF's no longer being presented as an option by most states' departments of disability services, but HCBS waiver models were also being deemed congregate, even 4 person homes. By 2010 our Delaware DDS director was no longer requesting the group home model from Homes For Life. Our group homes were now referred to as "mini-institutions."



So today, as Robert turns 48, I am no longer a "home builder" but an activist working to ensure that all voices are heard and all housing and work opportunities are valued and receive the funding streams needed to meet all people with IDD, especially those with the highest needs. Those with IDD, regardless of severity, have the right to choose where and with whom they would like to live whether it be in an ICF, a group home, an intentional community, an apartment, a farmstead or in their own home with their family members.

When I first started this journey, I never imagined where it would take me or what wonderful people I would meet along the way. For me, life's great irony is learning that, although we start out by simply wanting to care and provide for our own very special children, we discover that to do so we must embrace every child.

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

*Note: The letter below was submitted by VOR's Secretary, Terry Lafleur, pictured below at Pinecrest with "Heroes" sign*

The closure of intermediate care facilities that provide homes for those unable to care for themselves is a disturbing trend that continues to gain traction around the country. Decisions on closures are being made with disregard for the residents who, in many cases, have lived in these facilities for most of their lives. Decision-makers are instead focusing solely on the financial gains that could come from discontinuing these facilities.

Those of us who have loved ones at facilities such as the one where my brother lives - Pinecrest Supports and Services Center in Pineville, La. - are their advocates and we are compelled to speak up and safeguard their well-being. They are the innocents who are lightly regarded by those with authority, when in fact they should be at the center of the debate. We are here to present their voices so that they are not forgotten in the rush to save dollars. It is simply too important for us to ignore.

My younger brother, John, has been a resident of Pinecrest since 1987. His care has always been excellent and those associated with his well-being are consummate professionals. The caregivers in each cottage are truly special people, as are all of the teachers, doctors, nurses, attendants and sitters. He participates in daily activities, goes on day trips in the community and around the state, lives in a loving cottage setting and is monitored daily by a highly qualified staff.

My parents, now deceased, worked tirelessly to support Pinecrest. They provided support for events and served on the Pinecrest Parents Association. It was their lifelong wish that their special child should be able to live out his life at Pinecrest after they were gone. It gave them great comfort to know that he was well cared for and comfortable. All of us with siblings or children at Pinecrest are working hard to make sure that this facility remains in place to care for our loved ones who can't care for themselves.

***I suspect that my story is similar to those of many who will read this.***

At one time, there was a push to move as many residents as possible to group homes outside of Pinecrest. Many parents and guardians vigorously opposed this move. Even though John needs constant supervision by skilled and highly trained professionals, he was moved on a trial basis - and unbeknownst to my parents - to a community home in another town. His demeanor changed abruptly, and with no verbal skills, expressed his terror and disorientation through crying, pulling others' hair and other destructive behavior. He was moved back to Pinecrest, where he quickly reoriented to his home and returned to his sweet and non-disruptive ways.

John's experience has likely been the same for others who have been moved from care facilities. The prospect of putting others through the same experience is unacceptable.

There has been an argument put forth regarding the constitutionality of these moves. Those in favor of the moves say the civil rights of the residents of Pinecrest are being restrained by not moving them. This is certainly not the case. John, for example, cannot live in a community home without constant supervision by trained professionals. There is no constitutional guidance for removing someone from their home and care. Our children and our siblings are entitled to their civil rights as surely as the rest of us.

We have to get this right. It is not an issue that should be determined solely by financial concerns. Our loved ones, these innocents who cannot fend off the ambitious politicians and cold-hearted decision makers, are dependent upon us.

If a facility is being considered for closure, I urge families to stand up for those who live there, considering the lives that will be disrupted and the confusion and loneliness that will result. We must explain to those with influence how forcing our loved ones to leave their homes would be disturbing, unsafe and in the best interest of no one.



**Isaiah Baker and Margie Harris-Austin Act: H.R. 5443 - Mary Gay Scanlon (D-PA)**  
**Ensuring Access to Direct Support Professionals Act: S.3220 - Rob Portman (R-Ohio)**

These bills allow state Medicaid programs to cover certain home- and community-based services, self-directed personal assistance services, and home- and community-based attendant services that are provided in acute care hospitals. The bills specify, among other criteria, that such services may not be duplicative of, or serve as a substitute for, necessary or obligatory hospital services.

These federal bills were introduced into Congress before the Coronavirus pandemic hit the U.S. Subsequently, states and hospitals initiated quarantine measures which prevented anyone from accompanying any patient into a hospital in order to stem the spread of the virus and protect frontline caregivers. As people with IDD began to be hospitalized, some states recognized the need to have a designated family member or DSP accompany the individual during hospitalization, to ease the transition for the individual and to ensure that hospital workers understood the individual's specific needs, medications, and treatment protocols.

*VOR supports state bills and executive orders that allow individuals with IDD to be accompanied by a designated party during a hospital stay.*

# **Applied Behavior Analysis for Individuals with Autism and Intellectual and Developmental Disabilities**

By: **Vicki Madaus Knapp**, Assistant Professor of Applied Behavior Analysis, Daemen College

**Deborah A. Napolitano**, Assistant Professor of Applied Behavior Analysis, Daemen College and  
Golisano Institute of Developmental Disabilities Nursing, St. John Fisher College

**David B. McAdam**, Associate Professor of Pediatrics, University of Rochester School of Medicine  
and Warner School of Education

## **What is ABA?**

Applied Behavior Analysis, often referred to as ABA, is a science for addressing socially significant human behavior. Behavior analysts practice ABA with people to help them meet their goals for behavior change and to have the best quality of life possible. ABA, which is a science that focuses on the interaction between behavior and environmental and biological factors, relies on the evidence of peer-reviewed, published findings. It is important because it works.

## **Advances Made in the Field**

As a field of study and practice, ABA evolved since its early beginnings to the development of ABA as a distinct field of study in 1968, with the publication of the first issue of the Journal of Applied Behavior Analysis. Today, ABA has become a sophisticated science, based on the careful and planned use of positive reinforcement, the assessment of the reasons for a behavior, and the use of the least intrusive, most effective, intervention possible. While applied behavior analysis was first demonstrated effective with persons who were diagnosed with intellectual and developmental disabilities, thousands of publications since 1968 have demonstrated that the principles and procedures of applied behavior analysis are effective for a wide variety of real-world problems.

## **Development of Behavior Analysis Credentials**

The Behavior Analyst Certification Board, Inc. (BACB) is the primary credentialing body for the field. The BACB has developed four levels of certification, the pre-bachelor's level (Registered Behavior Technician; RBT), the bachelor's level (Certified Behavior Analyst Assistant; BCaBA), the master's level (Certified Behavior Analyst; BCBA) and the doctoral level (Certified Behavior Analyst-Doctoral; BCBA-D). According to the BACB there has been an 80% increase in demand for behavior analysts with the BCBA or BCBA-D credentials from 2018 to 2019 with a steady, rapid increase since 2010. Similarly, there has been a 157% increase in demand for those with the Board Certified Assistant Behavior Analyst (BCaBA) credential. Board certification in behavior analysis is recognized nationally, and 31 states in the US also have licenses in behavior analysis. If your state has a license in behavior analysis, the licensure laws, rules, and regulations must be followed in addition to the certification requirements.



## **How and Where Do Behavior Analysts Practice?**

Although ABA is the most well-studied, evidence-based intervention for the learning needs of individuals with autism, behavior analysis is very effective for the needs of persons with other disabilities (Down Syndrome, Prader-Willi Syndrome, or Cornelia de Lange Syndrome, for example). ABA is a clinically effective treatment for challenging behavior, such as self-injury, aggression, wandering, and pica (eating inedibles). However, the tools of behavior analysis also can be used to help with myriad of problems (for example, improving recycling or preventing child maltreatment). Behavior analysts often work in early intervention, schools, child welfare programs, hospitals, medical clinics, businesses, among many other places. Behavior analysts typically work with differently trained professionals as part of an interprofessional team (for example, psychologists, teachers, and speech therapists) to produce the best possible outcome.

If you are interested in further information about the field of behavior analysis or think that someone you know could benefit from the help of a behavior analyst, you may go to:

The Behavior Analysis Certification Board: <https://www.bacb.com>

Association of Behavior Analysis International: <https://www.abainternational.org>

Association of Professional Behavior Analysts: <https://www.apbahome.net>

Cambridge Center for Behavioral Studies: <https://behavior.org>

ABA Therapy is covered by insurance in most states, but laws vary on who may be covered, and what ages are covered. In some states, only children under 12 must be covered by insurance; in other states, all ages are covered. Some states only cover people with autism, while other states cover all people with intellectual disabilities and autism. To find out about your state's laws, go to: <https://www.appliedbehavioranalysisedu.org/state-by-state-guide-to-autism-insurance-laws>

This article is condensed from a longer piece on our website, at [https://www.vor.net/images/stories/2019-2020/What\\_Is\\_ABA.pdf](https://www.vor.net/images/stories/2019-2020/What_Is_ABA.pdf)

Southbury Training School (STS), a state-operated congregate facility in Southbury CT that houses approximately 158 individuals with I/DD in 10 cottages on 420 acres, has acted aggressively to curb the spread of COVID-19/ Commencing early in March, STS Director Eugene Harvey began implementing precautions to minimize the spread of COVID-19. These included restricting staff members to a single cottage and minimizing the cottages in which nurses work. In addition, all campus and community recreational activities have been discontinued, no visitors, including family members and guardians, are permitted on campus, and all quarterly and annual resident-review meetings are being held remotely. Only off grounds medical appointments deemed critical by the medical staff are allowed and only on grounds specialty clinic appointments deemed necessary to maintain residents' health are taking place, and only in a staggered fashion to prevent infection. All on and off grounds day programs have been cancelled. Temperatures of both staff and residents are taken twice each shift. All staff are wearing masks and gloves and, if they are in contact with anyone who has tested positive, eye protection and gowns. Cleaning protocols have been intensified and increased.



COVID-19 first appeared on the STS campus on March 30. At this point, The State of Connecticut still did not have sufficient testing supplies. At Southbury Training School, only 9 tests that were about to expire. These tests were given to patients who were considered to be at risk, and found 5 negative 4 positive.

As of April 9, 19 residents have tested positive. Fortunately, there have been no new positive tests of STS residents since April 11. [Nineteen] staff, including six nurses have tested positive. There have been three staff deaths, one resident.

Due to a cluster of positive tests (12) in one of the cottages, on April 9 its residents were moved to another cottage that was recently refurbished and cleaned for easier social distancing. There are four common areas in the new cottage and there was only one in the old cottage. That move is permanent. The move was accomplished in 4 hours thanks to very dedicated staff.

Three other cottages have been reopened. Two are being used as isolation units for residents who have tested positive. The third is being used for residents who are awaiting test results. When individuals have completed their 14-day quarantine, they are moved to the 4th cottage, a step-down facility. A volunteer organization that runs two thrift stores on the campus paid for staff to purchase additional TV's, so all of the rooms in these cottages have TV's.

STS presently has enough gowns, masks, gloves and eye protection. Sixty-seven hundred N-95 masks were found in storage and, as they are old, new elastic has been attached to most of these. Staff and volunteers have been making cloth masks and gowns. Director Harvey continues to make arrangements to ensure that there is an adequate supply on hand. In the meantime, some of the extra supplies are being provided to staff of the Connecticut Department of Developmental Services who work with individuals in their own homes. To date 4,500 kits (10 gloves, 3 masks) have been distributed to the community of Southbury and the surrounding area.

According to Director Harvey, "Morale at STS is excellent. It has never been higher."

On behalf of all of the families of the Southbury Training School, we wish you all health, comfort, and hope throughout these difficult times.

*Marty Dwyer is the President of the Home and School Association of the Southbury Training School.*

### **Raise the Wage Act: H.R. 582 – Bobby Scott (D-VA) / S.150 – Bernie Sanders (I-VT)**

### **Transformation to Competitive Employment Act: H.R.873 – Bobby Scott (D-VA) /S.260 – Bob Casey, Jr. (D-PA)**

The Raise the Wage Act gained popularity with Democrats in the 116<sup>th</sup> Congress who supported increasing the federal minimum wage over a 7-year period and contains provisions to raise wages for tipped employees, newly hired employees less than 20 years old. The bill would also eliminate vocational centers (sheltered workshops) and wage provisions under Section 14(c) of the Fair Labor Standards Act (1938), which allows people with IDD to work in non-competitive, supervised employment facilities. The Transformation to Competitive Employment Act (TCE) contains the provisions to eliminate vocational centers and 14(c) wages but does not cover raising the minimum wage provisions of the Raise the Wage Act.

Both of these bills are currently stalled in the House and lack support from the GOP in either chamber. In the current political and economic climate, neither is likely to pass.

Nonetheless, our concerns about these bills center on their supporters' assumption that everyone with an intellectual disability is capable of participating in competitive, integrated employment or else belongs in a day program. These overly zealous advocates fail to acknowledge the harm they would inflict upon the tens of thousands of people who benefit from the opportunity to work in a vocational center, would be unlikely candidates for competitive employment, and whose behaviors and social skills would regress from being placed in day programs. VOR will continue to oppose this legislation, along with our allies in the National Council on Severe Autism, Together for Choice, ACCSES, and other organizations that recognize the need for more, not fewer options.

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



**Due to the COVID-19 Pandemic,  
VOR's Annual Meeting & Legislative Initiative  
has been canceled.**

**COVID-19 WILL NOT SILENCE OUR VOICE!**

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

## **Membership / Contribution Form**

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

**Thank you for your dues and contributions!**

**I would like to give a gift membership to:**

NAME \_\_\_\_\_

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_

TELEPHONE \_\_\_\_\_ FAX \_\_\_\_\_

TELEPHONE \_\_\_\_\_ FAX \_\_\_\_\_

EMAIL \_\_\_\_\_

EMAIL \_\_\_\_\_

☐ **MY CONTACT INFORMATION HAS CHANGED**

☐ **\$45 per year per individual;**

☐ **\$200 per year per family organization**

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

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

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

☐ **\$2,500** ☐ **\$1,000** ☐ **\$500** ☐ **\$250** ☐ **\$100** ☐ **\$50** ☐ **Other \$ \_\_\_\_\_**

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

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

**Signature:** \_\_\_\_\_

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or [hdwyer@vor.net](mailto:hdwyer@vor.net).

June 2020/NL

**To make a memorial or honorary donation, please  
visit our website at:  
<http://www.vor.net/get-involved/donate-to-vor>**