



Welcome to the Summer of 2018 Edition of the VOR Voice!

A lot has happened over the summer. Our Annual Meeting and Legislative Initiative was a huge success. Representative Bob Goodlatte is preparing to introduce legislation to protect families with loved ones in ICFs from class action lawsuits initiated by federally-funded agencies. In July, a contingent of VOR members met with officials from the Centers for Medicare and Medicaid Services (CMS) to discuss several issues of concern to families with members residing in ICFs or waiver settings. And sadly, we experienced the passing of some people very near and dear to us.

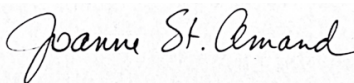


In the last issue of Voice, we spoke about the Joint Report issued by HHS' Office of the Inspector General, The Administration for Community Living, and HHS Office of Civil Rights, concerning the systemic failures in reporting critical incidents of abuse and neglect in the HCBS waiver system. This month, we have a similar case, a report from the Office of the Auditor General of Illinois concerning failures to report critical incidents and misspent funds in the CILA system (Illinois' group homes). Rita Winkeler, VOR Board member and President of the Murray Parents Association was a member of the team that sparked this report. She worked closely with her State Representative Charlie Meier, reporters from the Chicago Tribune, and the Illinois Auditor General over the past several years. In her own words:

"From 2012 to 2015 the then Governor of Illinois attempted to closure Murray Developmental Center, a large congregate care center in Illinois. The company (CRA) hired to close the center was hired under questionable circumstances, and the Murray family group, along with the staff at the center, and surrounding communities fought to keep our center open. After a federal law suit, and a new governor we remain open, and are admitting residents. Rep. Meier fought the fight with us throughout the whole ordeal, and continues to fight for the right to choice. This audit of the CILAs (group homes) and the company CRA was initiated by Rep. Meier. We owe him a debt of gratitude. His dedication to our special DD individuals is making a change in how they are cared for in Illinois."

Also in this month's issue, we are including a topic that has never received enough attention, either by VOR or by other organizations and agencies that advocate on behalf of people with IDD, the Forensic Population. For those unfamiliar with the term, these are individuals with intellectual disabilities or mental illness who wind up in the criminal justice system. Jail and is not the right place for the intellectually disabled, nor is our court system. VOR's Sunny Maden is a member of the Governor's Advisory Board at Porterville Developmental Center in California. She is reaching out to our members to see if others are involved with the forensic population and if they are aware of programs in their states. Please see the article on pages 4 & 5 for details.

Once again, we would like to thank you all for all that you do to support VOR. Please feel free to contact us with news that affects you and your loved ones!



Joanne St. Amand
President, VOR Board of Directors



Hugo Dwyer
Executive Director, VOR

VOR's 2018 Annual Meeting and Legislative Initiative



This year, VOR's Annual Meeting and Legislative Initiative took place at the Hyatt Regency Capitol Hill in Washington D.C. from June 9th to the 13th. Attendance increased again this year and we were happy to see a good mix of old friends and new faces. It was especially nice to see Texas and Kentucky back in the fold, with Liz Belille and Dr. Tom Diaz representing Texas and Karen House and Cheri Ellis-Reeves speaking for Kentucky. Unfortunately, some regular attendees couldn't make it to D.C. this year. Their voices were missed.

Joanne St. Amand started off the meeting of the Board of Directors, updated everyone on the state of VOR. She thanked the By-laws Committee for having completed their revisions of VOR's Constitution and By-laws in time for the annual meeting and the start of the new fiscal year. Larry Innis gave the Treasurers report, showing we are again in good financial health, and this year we both met and exceeded our budget goals. Mary Vitale presented the Issues Oversight Committee's progress on Guardianship issues, and Hugo Dwyer spoke for Laurie Stengler, who sent in her presentation on the Communications Committee. Brad Whitehead and Robert Anthony presented the follow up for the Quality of Care Committee's work on problems and solutions for quality dental care in community settings, and spoke of upcoming projects for the committee's future work. Rita Hoover and Rita Winkeler spoke of their progress in revitalizing the State Coordinator Program.

The State Reports followed after the Board meeting. This part of the conference is always informative, and this year was no exception. There was excellent feedback and participation to several of the presentations. Many of this year's state reports are available on our website, at <https://www.vor.net/in-your-area/item/vor-2018-state-reports>.

On Sunday, we began with a forum led by Rita Winkeler, Susan Jennings and Liz Belille, discussing their work to build strong family organizations within their centers and across their states, and the importance of interacting with state legislators. Each of these advocates brought their experience to the discussion, and the forum continued some of the discussions that had begun in the previous day's State Report Forum. This was followed by a presentation by Kate McSweeney of ACCSES highlighting the need for both individual and group advocacy.

The Legislative Forum (also known as "What's in the folders this year?") was led by Hugo Dwyer in the absence of Peter Kinzler, who normally covers this part of the program but was unable to attend the meeting this year. The primary focus of this year's initiative was our support of Rep. Bob Goodlatte in introducing a bill in the 115th Congress similar to the one he and Barney Frank had cosponsored in the 110th, 111th, and 112th Congresses. The bill would ensure that families receive notification of, and be given the opportunity to opt out of, any class action suits initiated by a federally funded agency against the Intermediate Care Facility in which their loved ones reside. Other materials in the folders included position papers on the Disability Integration Act, the Misrepresentation of Olmstead, the Crisis in hiring, training, and retaining Direct Support Professionals, and the Joint Report from three HHS agencies on the system-wide failures in reporting critical incidents involving abuse and neglect in HCBS waiver settings (group homes). The conference materials are available online at <https://www.vor.net/news-and-events/item/vor-2018-conference-materials>.

After the legislative forum, Voice Awards were announced. This year's recipients were Terry Anderson of Washington, for her long tenure as VOR's voice in her state, and to Rita Hoover and Rita Winkeler, for their dedication to revitalizing the State Coordinators Program. The day closed with Past President Ann Knighton ceremoniously swearing in the 2018-2019 Board of Directors. After the meeting concluded, we adjourned and met up the block for the 3rd annual Dinner at the Dubliner.

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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.

Update on Representative Bob Goodlatte's Bill

A Bill to Protect the Interests of Residents of Intermediate Care Facilities

for Individuals with Intellectual Disabilities (ICFs/IID) in Federally-Financed Class

Action Lawsuits



Rep. Bob Goodlatte (R-VA) remains determined to introduce this bill in the 115th Congress. He had been hoping by now to have enlisted a Democrat as a lead cosponsor. At the time of congress' summer hiatus, no cosponsor has stepped forward. Rep. Goodlatte intends to resume his appeal when congress returns in September and introduce the bill with no cosponsor if necessary.

We ask that our members be prepared to write their legislators to support the bill when Rep. Goodlatte introduces it. VOR will notify its members and associates when the bill is introduced.

The bill is identical to H.R. 2032, which was introduced in the 112th Congress by Rep. Barney Frank (D-MA) and Rep. Goodlatte, with 80 cosponsors from across the political spectrum. **The text of the previous bill is available on line at:**

<https://www.congress.gov/bill/112th-congress/house-bill/2032>

Rep. Goodlatte's bill would require that **before** any federally-financed class action lawsuit against a Medicaid-certified and funded ICF/IID can proceed, residents and guardians must receive notice of the proposed lawsuit and be given a time-limited opportunity to opt-out of the suit, or do nothing and join in. The notice provision is consistent with that included in appropriations legislation passed by this body and enacted into law for fiscal 2016, 2017 and 2018.

Why this bill is needed and supported by families of ICF/IID residents

Although the overwhelming number of family members and legal guardians typically object strongly to these lawsuits and their closure objectives because they are pleased with the care their loved ones are receiving, **under the law that authorizes these actions, there is no requirement that residents or legal guardians be notified of a lawsuit and they do not have the right to opt out.** Consequently, many residents of ICFs/IID are swept into these lawsuits against their or their family and guardians' wishes.

Class action lawsuits have closed many ICFs/IID and reduced options for those who need fulltime care

Federally-funded attorney groups have pursued at least 28 class action lawsuits against ICFs/IID, driven primarily by a bias against ICF/IID care. In fact, **since 1996, every federally-funded lawsuit against an ICF/IID has been for the primary purpose of removing residents from their ICF/IID home ("community integration")**; the condition of care at the targeted ICFs/IID was **not** at issue in any of these cases.

Fifteen of these cases have led to the closure of ICFs/IID, affecting thousands of individuals with intellectual disabilities (see, <https://www.vor.net/get-help/more-resources/item/p-a-class-action-litigation>). Bizarrely, despite the fact that ICFs/IID are a residential option created by federal law and funded and monitored by HHS, most of these lawsuits are filed under the Protection & Advocacy (P&A) program, whose lawyers are also funded by HHS. Because one program authorized by HHS is suing another program authorized by HHS, these suits could be labelled HHS v. HHS.

This bill could help prevent tragic outcomes and preserve residential choice

Families have good reason to be concerned. Closures oftentimes result in tragic outcomes for the former residents (see e.g., <https://www.vor.net/get-help/more-resources/item/abuse-and-neglect-document-2>), listing examples of systemic abuse, neglect and higher death rates in community settings for people with intellectual disabilities who have been moved out of ICFs/IID in many states and the District of Columbia). To view the concerns of several families, see the Judiciary Committee hearing held on March 6th of this year: <https://judiciary.house.gov/hearing/examining-class-action-lawsuits-intermediate-care-facilities-individuals-intellectual-disabilities-icf-iid>

Rep. Goodlatte's bill is consistent with federal law; specifically, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes funds for P&A attorneys, embraces the policy that individuals and their families/guardians are the "primary decisionmakers" regarding the services and supports they receive (see, DD Act, 42 U.S.C.15001(c)(3)(2000)).

Please be sure that we have your current email address!

We are going to send out an action alert to members of congress when the bill is introduced, and we need your support!

A Look at the IDD Forensic Population, Incarceration and Services

As the number of people on IDD waiting lists continues to rise, incidents of abuse and neglect remain under-reported, and providers continue to have difficulty finding enough well trained professionals to staff group homes, the number of individuals with IDD who have entered the criminal justice system has increased. Their crimes range from very mild to severe, though the majority of these cases are not considered severe. Often, the individuals have been accomplices when the crime was committed and were persuaded to “join in”. In other cases, the individual may not have known right from wrong, especially if they were enacting abusive behaviors that had been inflicted upon them in the past, or if they were acting out in manners that had been dealt with therapeutically by direct support professionals within the environment of an ICF or a group home. Nonetheless, offenders enter into the criminal justice system, whether or not they deliberately acted with criminal intent.

The United States incarcerates more individuals than any other nation, nearly 2.2 million adults were held in America's prisons and jails at the end of 2016.¹ According to the Center for American Progress:

“The past six decades have seen widespread closure of state mental hospitals and other institutional facilities that serve people with disabilities—a shift often referred to as deinstitutionalization. The number of Americans residing in such institutions dropped sharply from nearly 560,000 in 1955 to only about 70,000 in 1994. While widely regarded as a positive development, deinstitutionalization was not accompanied by the public investment necessary to ensure that community-based alternatives were made available. As a result, while people with disabilities—and particularly those with mental health conditions—were no longer living in large numbers in institutions, many began to be swept up into the criminal justice system, often due to minor infractions such as sleeping on the sidewalk. Indeed, federal and state jails and prisons are now home to three times as many people with mental health conditions as state mental hospitals.

People with disabilities are thus dramatically overrepresented in the nation's prisons and jails today. According to the Bureau of Justice Statistics, people behind bars in state and federal prisons are nearly three times as likely to report having a disability as the non-incarcerated population, while those in jails are more than four times as likely. Cognitive disabilities—such as Down syndrome, autism, dementia, intellectual disabilities, and learning disorders—are among the most commonly reported: Prison inmates are four times as likely and jail inmates more than six times as likely to report a cognitive disability than the general population.”²

In spite of these figures, we have produced very little information about the effects of incarceration of people with IDD, and we have done little to provide separate forms of treatment for this population. While there is little literature on the subject available, the nature of the problem has been succinctly described in an article from the Royal College of Psychiatrists of London:

“There is some confusion as to whether people with intellectual disability who offend should be dealt with by health or criminal justice systems (or both). A failure to report, and therefore to prosecute, episodes of serious challenging behaviour may lead to an individual believing that such behaviour is acceptable, leading to further and potentially more serious acts. However, an assumption that forensic psychiatry services offer the way forward for everyone with an intellectual disability and offending behaviour could also be potentially reductionist and simplistic. Whether these patients access services through forensic services or through ‘non-forensic’ community and hospital services, what is most important is that their needs are identified in a timely manner and that they receive the appropriate therapeutic input.

When people with intellectual disability do access the criminal justice system there are significant dangers that their specific needs will not be recognised and therefore not met. Even when professionals within the criminal justice system do recognise a person's intellectual disability, they may not be aware of their statutory responsibilities or of how to access appropriate support services. Intellectual disability services in turn frequently lack knowledge of the criminal justice system and, in contrast to mental health services, are rarely party to local health and criminal justice policy and service planning.”³

Many IDD families have never had to consider this problem. For others, it is a matter of “there but for the grace of God goes my family member”. A great many others have been directly involved. All it takes is one elopement, and one unfortunate incident.

¹ <https://www.bjs.gov/content/pub/pdf/cpus16.pdf>

² <https://www.americanprogress.org/issues/criminal-justice/reports/2016/07/18/141447/disabled-behind-bars/>

³ <https://www.rcpsych.ac.uk/pdf/FR%20ID%2004%20for%20website.pdf>

Dear Fellow Members of VOR,

I am a parent and a member of the Governor's Advisory Board at Porterville Developmental Center in California. The Special Treatment Program serves people with intellectual disabilities who are Regional Center clients. Our residents have been involved in a crime, are submitted through the courts because they are incompetent to stand trial. The clients are forensic clients.

The Special Treatment Program services include an array competency training for court appearances and testing, vocational, educational training, medical, dental, and recreational services in addition to individualized services as needed for the client and his family. The program, through professional support, deals with emotional, self-confidence, anger, drug addiction, and other physical issues.

Porterville Developmental Center Special Treatment Program is unique in the state and supported only with state funds. California does not receive Federal Funding for this program.

Jails are not suitable for our clients. Jails do not provide proper care or individualized programs and can be very dangerous for a person with developmental disabilities. The need is obvious and many family members of people with developmental disabilities, as well as the judges and people in law enforcement, can relate to the security, safety, supports and services this program provides. The Porterville Developmental Center staff are licensed, professional, creative, and trained to work with this special population. Federal funding would allow this program to serve more clients. Currently, we are limited to serve only 211 persons in the program. The program is full and there is a waiting list.

Please contact me if you are aware of similar programs in your state. I would like to compare funding sources. Email is preferred. I would like to hear from family members, advocates, and staff persons. Thank you, I look forward to knowing more about the special programs for this very special population in other states.

Sunny Maden

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Virginia Lee Lambert Carraway

It is with sorrow that we announce the passing of Virginia Carraway. Virginia was a devoted advocate and longtime member of VOR.

Virginia worked at Porterville State Developmental Hospital as the Training Officer for over 2200 personnel, nursing home Charge Nurse., taught nursing to State and local Colleges including DD/ID/MH Dual Diagnosed Psych Tech College level classes. When she retired, she moved with her husband to Florida where she volunteered her time as Parish Nurse with the Methodist Church in Yulee Florida and on Board of Directors of local County Mental Health Department, Nursing Administrator, Barnabas Crisis Health Center, Amelia Island, Florida, and Court Certified Victim Witness Advocate on Domestic Violence, a Founding member of the Board of Directors of Florida's only non-profit for Families of Children with Disabilities. Co-State Coordinator for Ca., and Fl. of VOR, a National non-Profit for the DD/ID/MH.

Virginia was the Dual Diagnosis Representative to Congress. and served on NGO Communications Coordinating Committee of the United Nations (CCCUN), the Women's Gender Issues and Disability Convention, (CPRD), Olmstead Committee of the Ca. Forensic Mental Health Assoc. and past co - Vice President of California Association of State Hospitals. (CASH/PCR). She served for twelve years as the International Ambassador of the NDP to the United Nations General Assembly, both as a panelist and an organizer for a treaty signed by 148 Nations. She used the American with Disability Act (ADA) as the instrument to establish Protocols for the Convention on the Rights of Persons with Disabilities (CRPD) Platform. She felt one of her greatest disappointments in life was not being able to encourage enough members of the U.S. Senate to ratify this legislation.



Virginia and Ed Carraway

VOR Meeting with the Center for Medicare & Medicaid Services



On July 27th, VOR President Joanne St. Amand, Executive Director Hugo Dwyer, and members Jill Barker of Michigan, Debora Henretta of Arizona, and Peter Kinzler of Virginia met with CMS' Deidre Gifford, Deputy Director of the Center for Medicaid and CHIPS Services, and three members of the Disabled and Elderly Programs Group, Michael Nardone; Director, Alissa DeBoy, Deputy Director; and Melissa Harris, Senior Advisor. The meeting with Dr. Gifford took place in CMS' offices in Washington, D.C. The three members of the Disabled and Elderly Programs Group attended from their offices in Baltimore via videoconferencing.

VOR's team raised several topics for discussion, starting with our concern that the widespread misrepresentation of Olmstead has evolved into a dangerous "Integration Mandate", which insists that the integration of people with intellectual disabilities into environments where they are surrounded by a preponderance of non-disabled individuals is the primary consideration for all policies, residential placements, and employment options. While we applaud efforts to integrate people with IDD into the non-disabled environment if they so desire, we are concerned that integration is essentially a goal for some, not all, people with IDD. For those with more severe intellectually disabilities, the priorities for quality of life consist of residential choice, ready access to quality health services, and a safe and familiar environment. The aspirations of more abled members of this population must not come at the cost of the needs of the individuals who are more severely intellectually and physically disabled.

Our delegation asked that CMS strengthen its commitment to Intermediate Care Facilities (ICFs) and to actively support a full continuum of care. Over the years, ICFs have all but disappeared from several states, though the need for this level of care has not diminished. **While CMS administers and certifies ICFs, they have failed to protect this part of our system.** Peter Kinzler pointed out the high mortality rates of individuals forced out of ICF care and into community settings, and we cited the examples of Georgia, California, and Virginia. We asked that CMS:

- Re-invest resources into the ICF system as it continues to invest in waiver settings.
- Include ICF representatives in all stakeholder meetings and insist that we be treated with the same dignity afforded people who favor other options.
- Require states to maintain a legitimate ICF capacity to meet the entitlement requirement under law and that such capacity be in-state so that families can remain connected to their loved ones' lives.
- Require states to fulfill their obligation to inform people of their right to an ICF.

We also expressed our concerns about consequences of the HCBS Settings Rule, especially as it applies to individuals not living in ICFs, but who don't fit well or do not receive the proper level of care in waiver settings. Debora Henretta brought up the problem that families are having at the Arizona Training Program at Coolidge (ATPC). Nineteen senior citizens with IDD have been living in five group homes on an eighty-acre expanse that also houses six ICFs. The average age of these residents is 68, with the eldest being 79. Most have no living parent. All have multiple disabilities, including but not limited to severe and profound intellectual disabilities, physical disabilities, specialized medical needs and, in some cases, have demonstrated behavioral challenges. Most have attempted to live in integrated settings, but were unsuccessful and moved back to the ATPC campus. They receive a level of integration that is appropriate to their needs, in their community as well as in their homes. They benefit from living in the comfort of a group home while having access to emergency medical care and other benefits of provided by the ICF on campus. Provisions in the Final Rule would move these individuals out of their homes, against their wishes, and into new, unfamiliar settings. We asked that CMS reconsider the Settings Rule, and that the administrators:

- Intervene, in any way possible, to honor the individuals' decision not to be forced out of their homes and to allow natural attrition of these settings.
- Look more closely at the benefits of this model, and consider creating new models, in order to fill the gap that exists between the highly regulated ICF system and the far less governed HCBS waiver system.

Jill Barker brought up the fact that while the settings rule emphasizes person-centered planning and individual control of services, it has been frequently misinterpreted by advocates and local agencies as a reason to ignore the decisions of legal guardians. We asked that CMS:

- Emphasize that the rule does not change state guardianship law., that they this fact more prominent in the literature, and that they remind states and local agencies that the rule does in fact confirm the authority of guardians appointed under state law to make decisions for the person they represent.
- Confirm the rights of guardians and their overriding authority in determining the residential choice for the person they represent.

Because so many of VOR's families have loved ones who, by choice or by force, have moved to waiver settings, we spoke of our concerns with the under-reporting of critical incidents by providers in the HCBS system, and the fact that this has been going on for years. Recent reports by the Chicago Tribune, as well as older series by the Augusta Chronicle and the NY Times have shown that this problem has been allowed to continue unresolved for years. A Joint Report released last January by HHS' OIG, ACL, and HHS' OHR admitted that the current system of protection and advocacy has failed to protect these individuals from critical incidents involving abuse and neglect.

We asked who is responsible for making sure that critical incidents are fully reported. Would this be CMS, HHS, ACL, State DD Departments, or the state Protection & Advocacy agency? We never received a satisfactory answer, but we did ask that CMS:

- Develop a better system for monitoring HCBS waiver homes.
- Require hospitals to submit critical incident reports of any intellectually disabled individual who is hospitalized or taken to the Emergency Room (much as they are required to do with gunshot wounds) and require providers to submit their own reports, independently. Enlist P&A or other state agencies to examine any suspicious incidents, or any homes with frequent incidents. We suggested that CMS could withhold payment for services rendered until such reports are properly filed.

Overall, we felt the meeting was positive. We understand that CMS meets with a number of other groups, most of whom follow an "integration for all" agenda and oppose many parts of VOR's platform, but we felt that Deputy Director Gifford listened to our perspective and was genuinely interested in our concerns. Again, we asked that people who support the ICF level of care be included in all discussions of policy.

Announcing the Recipient of the 2018 Jordy Engels Award

Longtime VOR members David and Leni Engels are proud to announce that the recipient of this year's Jordy Award, Melanie Lewis, of the Arkadelphia Human Development Center (AHDC). The Jordy Award was created in memory of David and Leni's son Jordy and honors outstanding Direct Support Professionals for their outstanding devotion, care, and nurturing of our loved ones with I/DD.

Melanie was nominated for this award by Carole Sherman, another longtime supporter of VOR and parent of John, who resides at AHDC. Carole wrote of Melanie:

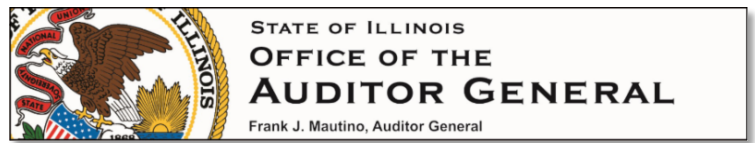
"Melanie is one of the bright-star-constants in our experiences with AHDC. When I first met her, she was about our son's age: she had a cloud of brown hair, an indescribably beautiful smile and a gentle, and a patient, firm manner in carrying out her work. When she left for nurses training, we missed her in John's home and then were delighted when she returned. ("I always knew I would come back," she once told me). Melanie's experienced, compassionate work is evident to all; her passion for our center's residents and our center's work and mission are inspirational."

Melanie Lewis began her career at the AHDC at the young age of 22 in 1989. During the years that followed, she pursued he education to become an LPN in 1998 and an RN in 2009. She worked for 8 years as a home staff and also attended LPN school during that time. In 1997 Melanie transferred to the Arkansas Health Center for one year to get her mandatory year of experience as a LPN that was required at the AHDC. Upon returning to the AHDC in 1998, she began her career as a LPN that spanned 12 years. During that time, she attended RN school. She successfully completed the RN program and began her RN career in 2009 at the AHDC.

Melanie has been a faithful and compassionate RN for 9 years at the AHDC. The clients love her and those she worked with years ago will forever have a special place in her heart and she in theirs.



Illinois Auditor General Report on DHS Oversight of the Community Integrated Living Arrangements (CILA) Program



VOR Board Member and Murray Parents Association President Rita Winkeler has been working closely over several years with her state representative, Charlie Meier, to defend ICFs like the Warren G. Murray Developmental Center in Centralia, Illinois. Rep. Meier has himself been working with the Illinois Auditor General to look into how state funds are being spent, or misspent, as the case may be. On July 18th, the Auditor General Frank Mautino released a 227-page report detailing the systemic failures in the state's licensing and oversight of thousands of taxpayer-funded group homes for individuals with intellectual and developmental disabilities.¹ The audit focused on oversight of over 3,000 group homes (CILAs) within the state, which serve about 10,000 individuals with Intellectual and Developmental Disabilities (IDD).

Rita and Rep. Meier have been working with reporters from the Chicago Tribune, as well, to compile additional data and documentation. According to the Chicago Tribune:²

The report also questioned whether the state did enough in recent years to ensure the safe transition of more than 400 vulnerable adults from large developmental centers into the smaller group homes. And auditors found the state used "questionable procurement strategies" when it awarded multimillion-dollar contracts to the company managing that transition.

Among other issues, Thursday's report found communication failures between various divisions within Human Services. For example, officials who license the group homes "routinely" did not receive findings and reports from those who investigate abuse, neglect and exploitation complaints. That allowed vulnerable adults to languish in facilities where serious deficiencies persisted.

Excerpt from the Executive Summary – DHS Oversight of the CILA Program

For the period FY12-FY16, DHS:

- expended over \$2 billion on CILA services with the majority for clients with developmental disabilities;
- additionally expended nearly \$6.1 million for a contractor to provide transition planning and support, and expended more than \$28 million on 17 Independent Service Coordinators whose primary role is to assist with finding individuals appropriate living arrangements; and
- transitioned 408 individuals to CILA from State-Operated Developmental Centers (SODCs).

The audit found weaknesses in DHS' licensing process including failures to:

- publish accurate survey data
- complete timely annual reviews
- accurately account for notices of violation in its database
- complete all surveys, require plans of correction, and approve all plans of correction
- exercise ability to revoke a CILA license

The audit found weaknesses in DHS oversight and monitoring of the CILA Program including failures to:

- conduct all CILA reviews by the Bureau of Quality Management (BQM)
- monitor CILA residents' personal funds by DHS
- maintain supporting documentation for community placement interest by individuals at SODCs
- share findings from DHS bureaus/offices with licensing staff; and
- recover funds from CILA providers not providing services for which they were paid

There was a lack of documentation to support that all required transition visits were conducted for individuals that transitioned to CILA from SODCs. DHS utilized Community Resource Associates (CRA), on a decision from the Governor's Office from the previous administration, to assist in closing SODCs. We found weaknesses in the oversight by DHS of CRA including questionable procurement strategies and failure to maintain documentation to support required CRA contractual deliverables. Also, DHS paid CRA an additional \$233,000 for services already required by the contract.

¹ The full report and a 12-page summary report are available at <http://www.auditor.illinois.gov/recent-audits-07-19-18.asp>

² <http://www.chicagotribune.com/news/watchdog/ct-met-illinois-group-home-audit-20180719-story.html>

According to State Representative Charlie Meier, “This audit reaffirms that more work must be done to improve the quality of care our most vulnerable population should expect to receive. Not all group homes are bad, but there is no excuse for these mistakes to happen again.”

Rep. Meier’s website goes on to say, “The audit requested by Rep. Meier was in response to the tragic reports of abuse and neglect which came to light thanks to the Murray Parents Association’s work with the Chicago Tribune, which sparked an investigation by the newspaper, then followed by the Tribune publishing its story in 2017 titled SUFFERING IN SECRET: Illinois hides abuse and neglect of adults with disabilities,” in which the newspaper “identified 1,311 cases of documented harm since July 2011 and determined at least 42 deaths linked to abuse or neglect in group homes or their day programs over the last seven years.”

Rep. Meier added, “I want to make sure what has been exposed in this audit doesn’t happen again which is why I am calling on the General Assembly to hold public hearings throughout the state this summer and fall to improve the way our state cares for the developmentally disabled. We should bring stakeholders from throughout the state and hold public hearings in southern Illinois, central Illinois, northern Illinois and Chicago. This audit released will help us learn more about what went wrong and how Illinois can improve the quality of care for our most vulnerable. It shouldn’t be a one-size-fits-all approach for caring for our developmentally disabled.”

“The audit exposed Governor Quinn’s administration for not having any decertification documents to justify closing the Jacksonville Developmental Center,” said Rep. Meier. Nor did Governor Quinn have any documentation to justify his effort to close the Murray Developmental Center in Centralia other than his vendetta against state operated developmental centers. Despite no records of decertification of Murray, Governor Quinn still tried to shut it down.”

The Illinois Department of Human Services has seven State-operated developmental centers (SODCs) serving approximately 1,800 residents. Individuals also receive services in community-based settings through Community Integrated Living Arrangements (CILAs), which house one to eight residents each otherwise called “group homes”. In 2012, then-Governor Quinn announced a “rebalancing initiative” with the goal of moving individuals from SODCs to community settings. In 2012, the SODC in Jacksonville was closed and the majority of its residents were transitioned to CILAs a.k.a. “group homes”. Followed by the Warren G. Murray Developmental Center in Centralia being slated for closure, resulting in some residents being transitioned out of their home they call Murray and being placed into group homes. To this day, Murray Center is and will remain open.

Pennsylvania’s Hamburg Center Closed - August 3, 2018

The Hamburg Center has been closed by order of PA Governor Tom Wolfe.

About 100 people, mostly former employees, gathered Friday for an emotional ceremony that marked the center's official closing. At the end of the ceremony, a Hamburg State Center flag was lowered for the final time.



The Windsor Township facility served the developmentally disabled for 58 years. The campus consisted of 278 acres with 39 buildings. Approximately 145 acres had been leased to neighboring farmers. At one time, more than 900 people lived at Hamburg Center. In January of 2017, when the governor announced its closing, the center had 122 occupants, many with physical as well as intellectual challenges. Most of the residents have been placed in waiver settings. Only few were allowed to transfer to other Intermediate Care Facilities within the state. Most of the employees have found new jobs or have retired.

Hamburg Center provided a wide range of services and programs, including recreational programs, living skills and vocational training, occupational and physical therapy, speech therapy, psychological and social services, and medical and dental care.

We hope that state agencies in Pennsylvania, P & A, the Governor’s office and others responsible for closing the Hamburg Center will follow up on the individuals who have been displaced, and make certain that their needs are being met in their new homes.

Many VOR members and readers of this newsletter are familiar with Mary Reese, a long-standing member of VOR, member of the Board of Directors, and of the nearly two decades she spent advocating to have Ginger placed into what she knew to be the most appropriate residential setting, Maryland's Holly Center. We are sad to announce Ginger's passing, and hope that you will all read of Mary's determination to carry on the struggle for others who may need the level of care that Ginger received. The following is a letter Mary sent to the Governor of Maryland to advocate on behalf of Holly Center.

Dear Governor Hogan,

On Sunday, July 8th, my beloved Ginger, Virginia L. Massa passed away at her home at the Holly Center in Salisbury. She peacefully left while surrounded by her loving professional staff and myself.

In the nearly six years she lived at Holly Center she benefited and enjoyed the highest quality of care, medical attention and every opportunity to enjoy her life.

In the Spring of 1961, Ginger was a vivacious, intelligent high school student, when at age 16, she contracted a life-threatening illness which left her profoundly intellectual disabled and with intractable seizures. With an indomitable spirit, she survived State institution care (1961-96) and 16 years (1996-2012) of inadequate, neglectful community agency residential services which resulted in furthering her decline in health.

The State of Maryland finally responded to her guardians' request for admission to Holly Center, one of two remaining state Intermediate Care Facilities (ICF), after it was proven terms of the legal settlement her guardian signed with the State and ARC of Howard County, that stipulated conditions of her care be provided by the community agency residential program, had been violated repeatedly. While in residence at this house she was dangerously injured by the neglect of a caregiver employee while being transferred onto the wheelchair van.

This year was a very difficult medically for Ginger. She required 4 hospitalizations, including 10 days of treatment at George Washington University Hospital in Washington D. C, and 6 days at the University of Maryland Hospital in Baltimore. Even with the access to the best medical services available, Ginger continued to experience serious health issues and finally there were no medications available to resolve her illnesses. With the advice of a palliative care specialist, with heavy heart, I agreed to place her in palliative care at Holly Center. As Ginger's legal guardian, I personally witnessed first hand the dignity, respect and loving care she was provided by the Holly Center's medical professionals and experienced, trained staff while receiving palliative care. This excellent care was under the direction and supervision of Holly Center's Medical Director Dr. Ghulam Waris, who is also an expert in hospice and palliative care.

I am respectfully urging you, Governor Hogan to immediately direct the gatekeeping Maryland agencies and their staff to support and allow other Marylanders with intellectual and developmental disabilities (IDD) access to the excellent care and services available at Holly Center when they experience prolonged illness and/or in need of palliative care. The opportunity for this level of care at Holly Center would be cost effective for Maryland and would provide these individuals the specialized care and excellent services which Holly Center is renown in delivering to Maryland's IDD population.

My humble plea is that you open the doors of Holly Center to citizens with IDD facing the end of life issues so they may receive the same extraordinary compassion and care my Ginger had until she joined her Mom and Dad in heaven.

We will be celebrating Virginia "Ginger" Massa's life on what would have been her 74th birthday at Holly Center. You and your representatives are cordially invited to join us in remembering Ginger on September 14, 2018, 11 am, in Holly Center's wheelchair garden.

Thank you for your kind consideration of this request which will be a blessing to Marylanders with disabilities in their final days.

Sincerely,

Mary L. Reese

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's Annual Meeting, Continued from page 2)

Over the next three days, VOR members met with legislators and legislative aides in their offices on Capitol Hill, followed by nightly "debriefings" where we exchanged stories about our achievements and challenges in getting our message out to decision makers and determined how best to follow up on our conversations in their offices.

Once again, we saw that what makes this conference so good is not just the presentations and reports. It's the interaction, the camaraderie, and the sharing. The collaborative spirit of the conference forums, the Saturday night hospitality meeting and Sunday Dinner at the Dubliner, and the Monday and Tuesday night debriefings empower us to become better advocates. There was a feeling of excitement and unity at this year's meeting, something that is so important for our members to experience in our long uphill struggle to protect the needs of our loved ones. These feelings can't be described in a report about the conference or read in the conference materials. It has to be experienced firsthand. Those who were at this year's meeting can attest to that. We returned to our states recharged and ready to attack the issues important to us and our family members.

We hope even more members will join us next June 7th – 11th in D.C. for the 2019 Annual Meeting and Legislative Initiative. We urge you to plan now, to work toward getting your family groups to sponsor your trip, and to bring others along to make next year's conference even better.

VOR would like to express our gratitude to our sponsors, and all of the members who donated to make this year's conference a resounding success.



VOR's 2018-19 Board of Directors: (L-R) Larry Innis, Rita Hoover, Mary Vitale, Mary Kay Cowen, Brad Whitehead, Sue Jennings (hidden), Ann Knighton, Linda Lotzi, Rita Winkeler, George Mavridis, Joanne St. Amand. Absent from photo: Cindy Bartman, Terry Lafleur, Mary Reese, Laurie Stengler



Press Contacts Needed!

VOR is compiling a list of favorable and unfavorable contacts in various media outlets, to better communicate our message. If you have been in contact with members of the print or television media in your state, please share their contact information, along with a brief description of their outlook on IDD issues, by sending an email to info@vor.net



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

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

Membership / Contribution Form

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

Thank you for your dues and contributions!

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☐ **\$45 per year per individual;**

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☐ **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:**

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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.

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