the VOR Voice

news and Views of VOR Supporters

Fall 2016

Members of VOR's Board of Directors and Legislative Committee at the Washington Initiative in June, 2016
(Left to right, Ann Knighton, Mary Kay Cowen, Laurie Stengler, Peter Kinzler, Linda Lotzi, Joanne St. Amand, Caroline Lahrmann, Joan Kelley, Cindy Bartman, Terry Lafleur, Mary Reese, David Hart, Larry Innis)
~ For a complete list of VOR's Board members and Officers, see page 3 ~

Inside This Issue:

VOR is a nonprofit association speaking out for people
with intellectual and developmental disabilities

VOR CELEBRATES THE 17TH ANNIVERSARY OF THE OLMSTEAD DECISION

Recently, the Department of Justice (DOJ), and the Administration for Community Living (ACL) issued press releases celebrating the 17th Anniversary of the Olmstead decision. VOR shares their view that there is much to celebrate in opening doors to community living for people with intellectual and developmental disabilities (I/DD) who are able and wish to take advantage of such opportunities. Unfortunately, their ideological preoccupation with one key part of Olmstead, community integration, at the expense of the other key part, choice, has reduced options for all people with I/DD. This crimped and inaccurate application of the plain language of *Olmstead* has done significant harm to many of our most disabled citizens.

By insisting that *all* people with I/DD live in the community, the DOJ and ACL are treating people with I/DD as a monolithic group, not as the individuals they are. DOJ and ACL are substituting the wishes of the government for that of the person with I/DD or, where relevant, the legal guardian. While their policies have opened doors for the less severely disabled, they have closed important doors for the more severely disabled. Many of these individuals have lifelong needs that require a very high level of care, the kind often found only in public and private Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID).

DOJ and ACL are pursuing this agenda in the name of the ADA and Olmstead, *but that is not what the ADA and Olmstead call for*. Both the statute and the Supreme Court case embody the best values of American society —nondiscrimination *and* choice. All of our civil rights laws contain both elements. Civil rights laws do not tell people where they must live or work. They guarantee individuals are not denied opportunities based on a particular factor, and they expand choices for individuals who have suffered discrimination. In sharp contrast, DOJ and ACL are using federal dollars to bring lawsuits and promote policies that needlessly and dangerous eliminate important options – ICFs/IID, sheltered workshops and facility-based day programs – that many of our most disabled individuals rely on and prefer over small community residences.

In pursuing its one-size-fits-all ideology, DOJ and ACL are ignoring the vital rights of choice embodied in the ADA itself: As the Court stated in Olmstead:

> *"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. Olmstead v. L.C., 527 U.S. 581, 601-602 (1999).*

In fact, the Court specifically incorporated the right of choice in the second prong of its holding:

> *"(b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual," Olmstead, at 587.*

Even DOJ and ACL's concept of what constitutes the most integrated setting contradicts the view of Justice Ginsburg:

> *"[For some individuals, no placement outside the institution may ever be appropriate. 'Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times - perhaps in the short run, perhaps in the long run - for the risks and exposure of the less protective environment of community settings;' for these persons, 'institutional settings are needed and must remain available.' " . . . Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing on a case-by-case basis, that setting may be an institution" Olmstead, at 605.*

Not only are DOJ and ACL ignoring the plain language of governing law and decision, they are ignoring the harmful effects of their policies. Journalists have time and again documented the high rates of abuse and mortality for our most disabled citizens who have been forced out of congregate care facilities into unprepared communities[1]. Federal agencies should stop dictating the lives of the severely disabled, and instead, join hands with the community of individuals with I/DD to ensure that all people with I/DD receive quality services and supports wherever **they** choose to reside.

The ADA and Olmstead are the beacons for providing more opportunities for people with I/DD, but they do not dictate one-size-fits-all solutions. Individual choice among the widest possible range of quality living and occupational options is what is necessary to realize the goals of the ADA and Olmstead. VOR supports the full reading of *Olmstead*, making individual choice of services paramount and ensuring a full range of living and work options in order to meet the spectrum of needs of this very diverse population.

---

[1] VOR Abuse and Neglect Document: http://www.vor.net/get-help/more-resources/item/abuse-and-neglect-document

A WORD FROM VOR'S NEW PRESIDENT

Caroline Lahrmann

I am honored to serve as President of VOR and look forward to working with our dedicated and knowledgeable members throughout the U.S.

VOR is unique in its mission as we are the only national disability advocacy organization that supports policies and services that provide for the full continuum of care for individuals with intellectual and developmental disabilities (I/DD), from large and small intermediate care facilities (ICFs) to community settings, from sheltered workshops to competitive employment. In doing so, VOR remains true to the Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision, which affirm the need for this continuum and make individual choice paramount in accessing services.

That mission is what attracted me to VOR and in the year ahead we will continue to spread this inclusive message and the true meaning of *Olmstead* to individuals and their families.

VOR works hard to be a valuable resource for families in their individual advocacy. We urge you to access our website, Facebook and Twitter pages to get updates and policy papers on the most pressing issues affecting our loved ones with I/DD. We are also working to bring advocates across the country together in our state-to-state initiative with periodic conference calls and discussion groups.

Please contact us at ***info@vor.net*** or call toll free at **(877) 399-4VOR** if you would like to take part.

None of our work could be accomplished without the volunteer efforts of our membership. We would like to thank those tireless volunteers and welcome others to become active members as well.

Having a child or family member with I/DD brings a special kind of responsibility. We all feel it when we look into our loved ones trusting eyes and we realize we must be there for them to protect them and support their one of a kind needs.

By being knowledgeable advocates, we can be the most effective advocates. We hope that you find VOR to be a valuable resource in providing that knowledge base, as well as serve as a voice for your concerns at the state and federal levels.

Caroline Lahrmann

Caroline A. Lahrmann,
President & Ohio State Coordinator, VOR
Co-founder, Disability Advocacy Alliance of Ohio

President's Message

VOR Board of Directors and Officers – July 1, 2016 to June 30, 2017

Officers

Caroline Lahrmann (OH) – President
Joanne St. Amand (NJ) – 1st Vice Pres.
Mary Vitale (MO) – 2nd Vice President
Larry Innis (MD) - Treasurer
Terry Lafleur (LA) – Secretary
Ann Knighton (GA) – Immediate Past Pres.

Board Members

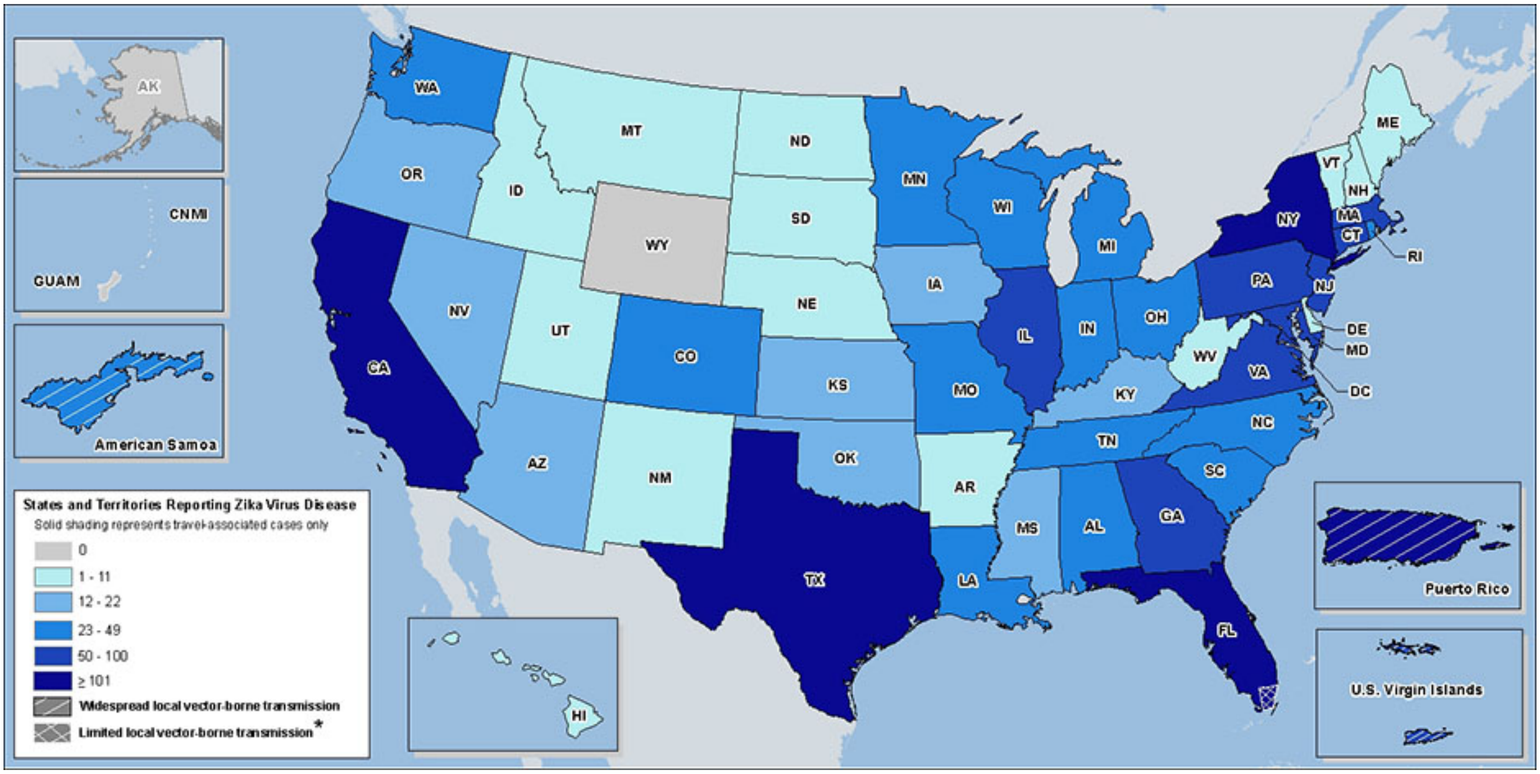
Cindy Bartman (NJ)
Shawn Humberson (WY)
Linda Lotzi (PA)
Mary Reese (MD)
Rita Winkeler (IL)
Mary Kay Cowen (LA)
Joan Kelly (KS)
George Mavridis (MA)
Laurie Stengler (IL)
Brad Whitehead (CA)

Legislative Update

<u>ZIKA FUNDING</u> – As of this writing, Congress has still failed to provide funding for the Center for Disease Control's (CDC) initiative to fight the spread of the Zika virus. The Obama administration has managed to move funds from other areas of the HHS and NIH budgets to combat the spread of the virus and to research possible vaccines, but those funds are expected to run out by the end of September.

Zika infection during pregnancy can cause a birth defect of the brain called microcephaly and other severe fetal brain defects. Other problems have been detected among fetuses and infants infected with Zika virus before birth, such as defects of the eye, hearing deficits, and impaired growth. There have also been increased reports of Guillain-Barré syndrome, an uncommon sickness of the nervous system, in areas affected by Zika.

<u>ZIKA IN THE U.S</u> - Meanwhile, Zika has spread through the U.S. and its territories with cases reported in every state except Wyoming and Alaska. Currently there have been 2,920 travel-related cases reported in the U.S. with 43 locally acquired cases reported in Florida, and one laboratory acquired case. 15809 locally acquired cases reported in US Territories, with 15,541 of those cases reported in Puerto Rico, 221 in the Virgin Islands, and 47 in American Samoa.



The CDC also reports that there are currently 671 pregnant women with laboratory evidence of Zika Virus in the U.S. and 1,080 cases in U.S. Territories.

Cases of Zika infection have been reported throughout Central and South America, the Carribean. Zika has been reported in the Pacific Islands of Fiji, Federated States of Micronesia, Marshall Islands, New Caledonia, Papua New Guinea, Samoa, and Tonga. Cases have also appeared in Cape Verde (Africa) and Singapore (Asia).

For more information and regular updates, visit the Center for Disease Control at: <u>http://www.cdc.gov</u>

VOR ON GUARDIANSHIP AND SUPPORTED DECISION MAKING

By The VOR Issues/Oversight Committee

Guardianship is the legal process whereby a state court appoints a person or organization to have the care and custody of an adult or child who has been determined to be legally incapacitated. Parents are the assumed legal guardians of their minor children, but a guardian may be appointed for a child if the parents are not able to fulfill that role. An incapacitated adult is one who has been determined by a court to lack capacity to make some or all personal and/or financial decisions and for whom a guardian has been appointed.

Guardianships are awarded to protect the “ward”, the individual with a disability, from abuse, neglect, and exploitation. Guardians are expected to act in the best interests of the individual and to make decisions over medical, psychiatric, behavioral, and all other aspects of the person’s care that are authorized by the court based on the degree to which the individual is incapacitated. Legal guardianship is both a responsibility and a privilege.

As in every other aspect of providing protection, care, and services to people with IDD, the guardianship system is not problem-free: There are documented incidents of malfeasance, including over-burdened and mismanaged court systems; probate attorneys and professional guardians whose primary interest is to collect fees rather than protect individuals under guardianship; state guardianship systems that fail to adequately protect vulnerable individuals; unjustified isolation by guardians of wards from family or friends; and other forms of exploitation for the personal gain of guardians or guardianship agencies.

Partly as a response to these problems, new initiatives have emerged with the goal of altering, weakening, and even eliminating existing guardianship laws. Supported Decision-Making (SDM) is one initiative that has been promoted by many disability rights advocates. Proponents of this system, notably the Burton Blatt Project at Syracuse University and the Quality Trust for Individuals with Disability, generally appear to be advocating on behalf of individuals with less severe levels of intellectual disability, who are usually better able to interact with their environment and can often express their own desires and articulate their needs.

The Supported Decision-Making movement would change guardianship laws to address the status of those who need guardianship the least, if at all. In the process, these changes could weaken protections for those who are the most vulnerable, the very people for whom guardianship laws were originally written.

VOR maintains that problems with guardianship can be avoided through strong enforcement and monitoring and better access to information on guardianship, especially for family members and friends who make up the vast majority of guardians for people with intellectual and developmental disabilities (IDD). To eliminate guardianship or make it more difficult for family members and friends to pursue will leave people with IDD more vulnerable to the abuse, exploitation, and neglect that guardianship is designed to prevent.

VOR is deeply concerned about any effort to weaken the protections of guardianship. Attempts to replace guardianship with Supported Decision-Making affect not only those with severe intellectual disabilities but also people with IDD who are vulnerable to manipulation and coercion by others as well as individuals who lack awareness of the consequences of their own actions that may cause harm to themselves or others.

Guardians of people with IDD usually have an existing network of informed persons to assist them in making decisions for their wards, including other family members, direct care providers, and medical personnel. This is just what SDM claims to promote, but without the formalities and protection of court-ordered guardianship. The more individuals are able to express their wishes and play an informed, responsible role in their own decision-making process, the more their participation should be included. But it is irresponsible to remove an individual who lacks the capacity to make his or her own decisions from the protection of the court and ongoing evaluation. Most individuals with intellectual disabilities change over time, their needs change accordingly, and their ability to make their own decisions in an informed and responsible manner should be examined at regular intervals, to make sure that they are receiving appropriate care and that all of their needs are being properly addressed.

Changes to guardianship laws in many states have already been proposed. Families should keep abreast of these changes, and advocate for their loved-one if the changes could weaken the protections upon which he or she relies. VOR will do its best to keep you informed. Our vulnerable family members deserve nothing less than the protections that family guardians can provide.

Executive Director's Message

MARGINALIZATION AND DISCRIMINATION

By Hugo Dwyer, VOR Executive Director

I would like to take a moment to discuss a disturbing trend in the movement to transition people with Intellectual and Developmental Disabilities (I/DD) from larger congregate care facilities into smaller group homes. That is the deliberate marginalization of and discrimination against an identifiable class of people – the parents and guardians who believe that congregate care facilities offer the best option for their family member or ward with I/DD. What's most disturbing is that this marginalization and discrimination comes at the hands of the very people who are supposed to be protecting their civil and human rights: The Department of Health and Human Services through the Administration for Community Living (ACL), Department of Justice (DOJ), State Protection and Advocacy (P&A) groups, DD Councils, and other agencies and non-profit organizations funded through the DD Act.

These agencies and organizations have been working with increased determination to promote the idea that all individuals with intellectual and developmental disabilities (I/DD) can live safely in smaller, community based settings while unfairly painting congregate care facilities as if they were cruel, overcrowded institutions left over from a different era. At VOR, we know that Intermediate Care Facilities (ICF'S) represent a high standard of care, and are held to far more stringent regulations than HCBS waiver homes. We understand that, by the same measure that larger facilities are not right for some, so are smaller group homes not the best settings for others. The I/DD population is a diverse group of individuals, with a wide range of abilities and disabilities, of physical, psychiatric, and behavioral challenges, resulting in the need for an equally wide range of treatment options. It is for this reason that the Supreme Court in *Olmstead* upheld the need for a range of services and supports for individuals with I/DD and why the Court made individual choice paramount in accessing services.

These opponents of congregate care deliberately misrepresent *Olmstead*, omitting the paragraphs that protect congregate care facilities and endorse this model of care for some individuals with I/DD. *Olmstead* unequivocally states, *"For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available." [Olmstead v. L.C., 527 U.S. 581, 605].*In defiance of the word of law as written therein, these agencies insist that larger ICF's must be eliminated. They claim ICF care is outmoded and unnecessary, in so doing they disregard the views of families who know that this level of care is essential, portraying them as fearful and uninformed. To the contrary, families who have fought to protect the rights of their loved ones to continue to thrive in ICF's are very well informed, and have valid reasons for concern, considering the budget, staffing, and lack of transparency in incident reporting that exist throughout the waiver home systems in their states. These families believe that ICF's should be strengthened as a component of the continuum of care, and the choice of ICF level care should be extended to more individuals who seek it. Yet, over the past two decades, many states have closed admissions to ICF's, depriving families of that choice. This also deprives the ICF's the ability to maintain the economy of scale necessary to save on costs, and lowers the breadth and quality of their offerings as the facilities are forced to downsize. The goal, of course, is to make them small enough that they are forced out of existence, and families are forced to move their loved ones into group homes.

The same trend can be found in employment services for the individuals with disabilities. Look at the controversy involving competitive employment versus sheltered workshops. Certainly, for those who are able to participate, competitive employment or subsidized employment are desirable, offering full wages and integration into the community. But there is no reason that this should lead to the closing of sheltered workshops, which would deprive those who are unable to compete in the open market access to work that give them a sense of pride, productivity, and community. Sheltered Workshops offer a congregate employment setting that is appropriate to the lives of some individuals. Both forms of work should exist in order to serve all of the people who benefit from them. Just as there should be a full continuum of care, there should be a full continuum of employment options. Closing sheltered workshops is, in effect, another form of discriminating against and marginalizing the individuals who do not fit the current model.

If we are to provide a service system that truly meets the needs of the wide range of individuals with disabilities, we need to acknowledge their differences and promote policies that accommodate their disabilities in a safe and compassionate manner. We also need to recognize that individuals with disabilities, and when necessary, their family members and guardians, are in the best position to make lifestyle and care decisions - just as we respect this decision-making right among individuals who are not disabled.

(Continued on page 7)

(Continued from page 6)

VOR supports the full range of choices and options, the complete continuum of care and employment options for all people, at all levels of disability. Our goal is to ensure that all options are available to everyone, so that individuals can find the care and employment appropriate to their needs and abilities. In doing so, VOR honors *Olmstead* - its true and compassionate meaning.

Hugo Dwyer

Hugo Dwyer, Executive Director of VOR

Sam Bagenstos, a former Principle Deputy Assistant Attorney General for the Department of Justice, then considered the point man on Olmstead enforcement, also acknowledged in a law review article that mistakes have been made. Although he remains a strong proponent of deinstitutionalization, he points to an alliance between closure advocates and fiscal conservatives as the main reason why community services are not always well-equipped to serve people with significant disabilities safely. Fiscal conservatives expected to save money by closing facilities; they were not then keen on investing in robust community supports.

“It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services,” stated Bagenstos, who also acknowledged that the perceived cost savings for community services would evaporate if such programs were adequately funded.

CONGREGATE IS NOT THE SAME AS SEGREGATE - By Cheryl Felak (WA)

I am very disappointed with the Joint Position Statement published June 23, 2016 by The American Association on Intellectual and Developmental Disabilities (AAIDD) Association of University Centers on Disabilities (AUCD).

While there is quite a bit of quality information in this statement it is obviously clear that these organizations also have a strong bias against choice of residential settings. It is unfortunate that these organizations do not understand that congregate care is not the same as segregated care.

“Everyone with an intellectual or developmental disability deserves to live in the community where they have the opportunity to experience vibrant lives that include work, friends, family, and high expectations for community contributions.” These goals can and are also accomplished in congregate and campus type communities.

Many states have built systems that utilize group homes as a key way to support people in the community. When people find themselves in a situation where they need to live outside of their family home, they are often placed in an “open bed” versus being offered person-centered supports designed specifically to meet their needs. In many of these situations, people remain as isolated in these settings as they do in a large-scale institution. A process for creating and sustaining supports that make their living situation a home in a neighborhood is needed.

It is clear from the above statements that these organizations realize there is a problem with the funding and system that many supports are built around.

Yet AAIDD and AUCD are doing exactly what they chastise others for doing – categorically denying the individual the personal choice for individualized care in the residential setting they choose. The setting is not what necessarily causes the segregation – separation from family, friends and community causes segregation. Unfortunately that segregation can happen in any residential setting.

It is the segregation that needs to be called out – not the setting.

https://becausewecare1.com/2016/08/23/congregate-is-not-the-same-as-segregate

State News

OHIO - Having failed to force closure of Ohio's Intermediate Care Facility (ICF) program through the representative process of the state legislature in 2015, Disability Rights Ohio (DRO), Ohio's protection and advocacy agency, has filed suit in federal court. On March 31st, DRO filed a class action lawsuit, Ball v. Kasich, on behalf of seven plaintiffs alleging that Ohio's disability service system causes individuals with intellectual and developmental disabilities (I/DD) to be institutionalized or placed at risk of institutionalization. The lawsuit also attacks Ohio's system of sheltered workshops and facility-based day programs.

The lawsuit seeks a court order to substantially re-align state funding away from ICF homes and facility-based work opportunities in favor of community services. Approximately 6,000 Ohioans rely on and choose ICF care and more than 31,000 individuals access Ohio's sheltered workshop and facility-based day programs..

VOR does not oppose the plaintiffs right to pursue their interests via the court system, but it does oppose the class action nature of the lawsuit. Should DRO succeed in court on a class basis, Ohioans with I/DD who cannot handle or benefit from community settings will be greatly harmed. These individuals will find themselves forced out of their homes and workplaces into community settings with far too little care and supervision, placing their safety, health and happiness and very lives at risk.

VOR has reached out to individuals with I/DD and their families and guardians in Ohio to provide assistance in fighting DRO's dangerous suit. If you are an Ohioan affected by DRO's lawsuit or would like to learn how you can help in Ohio, please contact VOR today at **info@vor.net** or call toll free to **877-399-4867 (877-399-4VOR)**

CONNECTICUT – Governor Danell Malloy and Department of Developmental Services (DDS) Commissioner Morna Murray, citing a $2 Billion budget shortfall, have ordered two of Connecticut's five state-operated Regional Centers to close. Closing began in June and is expected to be finished by the end of the year, with residents being transferred to empty beds in the remaining regional centers and to group homes. DDS has also cut back on many positions throughout the state's regional centers and Southbury Training School, the largest state-operated Intermediate Care Facility. The administration has already laid off 113 DDS employees, and plans to cut another 492 workers in two stages, most happening after Jan. 1, 2017.This would mean that 25% of the positions at the state agency will have been cut. As a result, several programs and amenities have been cut, and all of the day programs are being privatized. The state is also attempting to privatize its thirty state-operated group homes.

Concurrent with these changes, the state has passed a law to close its State-run Protection & Advocacy agency on June 30, 2017 and replace it with a privately operated, federally funded organization. Advocates from the Arc and other groups have been pressuring the governor and state legislators for years to this effect, having closed admissions to STS and the Regional Centers in the mid-1990's. The governor and Commissioner Morna Murray claim that the closures and cut backs are all budget-related, and not a result of any particular ideological preferences or pressure. However, in budget plans submitted by the leaders of 26 other state agencies, all announced that no additional layoffs of state employees would be necessary to balance their budgets.

MISSOURI - There are proposed changes to Missouri's guardianship law compiled by the Missouri Working Interdisciplinary Network of Guardianship Stakeholders, or MO-WINGS (www.mo-wings.org). MO-WINGS started meeting in 2012 to review and recommend changes to the 100-page guardianship law. They used the National Guardianship Summit Standards and Recommendations as a guideline to Missouri revisions, and included **Supported Decision Making** as an option or as a replacement of guardianship in their recommendations.

Missouri House Bill 2778, the proposed guardianship law revision, was introduced in the 2016 MO legislative session. It did not go anywhere, but it will be back next year. (www.house.mo.gov/billsummary.aspx?bill=HB2778) Some of the changes are reasonable. However, there are concerns. For one, the new wording states: "The guardian shall give priority to home or community-based settings when not inconsistent with the ward's goals and preferences." *The guardian should not be limited in this way. The needs of the wards must be the priority in making decisions concerning their welfare.* Also, the proposal repeatedly requires including the ward that has been determined by the courts to be "incapacitated" in the decision making process. *If one has been declared by the courts as incapacitated how can that person participate in decision making? If one is indeed capable of decision making then maybe a guardianship is not needed. It would be better to keep the old wording of "in the best interest of the ward".*

FOR MORE STATE REPORTS, VISIT:
http://www.vor.net/in-your-area/item/state-reports-from-vor-s-2016-annual-conference-and-washington-initiative

INSPECTOR GENERAL'S REPORTS - The Office of the Inspector General at the Department of Health and Human Services has released reports on investigations involving incident reporting by group homes in Connecticut and Massachusetts:

Connecticut Did Not Comply with Federal and State Requirement for Critical Incidents Involving Developmentally Disabled Medicaid Beneficiaries

May, 2016

A 2012 report issued by the Connecticut Office of Protection and Advocacy for Persons with Disabilities triggered an investigation of incident reporting of HCBS waiver beneficiaries residing in Connecticut group homes. The Inspector General of the Department of Health and Human Services conducted the audit, reviewing 347 emergency room claims for 245 beneficiaries aged 18 through 59 residing in group homes. They had 310 hospital emergency room visits and were diagnosed with at least 1 of 40 conditions that were similar to many of the causes of death identified in OPA's 2012 report.

The Office of the Inspector General's report found that Connecticut's State agency, the Department of Developmental Services, did not comply with Federal waiver and State requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.

Specifically, the State agency did not ensure that:

- Group homes reported all critical incidents to DDS **(14 percent unreported)**
- DDS recorded all critical incidents reported by group homes **(22 percent unrecorded)**
- Group homes always reported incidents at the correct severity level **(57 percent incorrect)**
- DDS collected and reviewed all data on critical incidents
- DDS always reported reasonable suspicions of abuse or neglect **(99 percent unreported)**

The State agency did not comply with Federal waiver and State requirements for reporting and monitoring critical incidents because staff at DDS and group homes lacked adequate training to correctly identify and report critical incidents and reasonable suspicions of abuse or neglect, DDS staff did not always follow procedures, DDS lacked access to Medicaid claims data, and DDS did not establish clear definitions and examples of potential abuse or neglect.

The State agency did not adequately safeguard 137 out of 245 developmentally disabled Medicaid beneficiaries because the DDS system of reporting and monitoring critical incidents did not work as expected.

In addition, the report noted several issues that while outside the scope of our review are worthy of further discussion and action. These issues involve:

- DDS's revision of its definition of "severe injury,"
- Hospital-based mandated reporters' failure to report to OPA all critical incidents, and
- Inadequate care contributing to the death of developmentally disabled Medicaid beneficiaries.

The full report is available online at:
https://oig.hhs.gov/oas/reports/region1/11400002.asp

Massachusetts Did Not Comply with Federal and State Requirement for Critical Incidents Involving Developmentally Disabled Medicaid Beneficiaries

July, 2016

The Office of the Inspector General of the Department of Health and Human Services has been performing reviews in several States in response to a congressional request concerning the number of deaths and cases of abuse of developmentally disabled residents of group homes. This request was made in response to media coverage throughout the country on deaths of developmentally disabled individuals involving abuse, neglect, or medical errors.

The objective of this review was to determine whether the Massachusetts Executive Office of Health and Human Services, Office of Medicaid (State agency), complied with Federal waiver and State requirements for reporting and monitoring critical incidents involving developmentally disabled Medicaid beneficiaries residing in group homes from January 2012 through June 2014.

The Office of the Inspector General reviewed 769 emergency room claims for 334 beneficiaries aged 18 through 59 who were residing in group homes. These beneficiaries had 587 hospital emergency room visits and were diagnosed with at least 1 of 149 conditions that we determined to be indicative of a high risk for suspected abuse or neglect.

The report found that Massachusetts' State agency did not comply with Federal waiver and State requirements for critical incidents involving developmentally disabled Medicaid beneficiaries. Specifically, the State agency did not ensure that:

- Group homes reported all critical incidents to DDS **(15 percent unreported)**
- DDS obtained and analyzed data on all critical incidents
- Appropriate action steps were identified in all incident reports that could prevent similar critical incidents **(29 percent unidentified)**
- DDS always reported all reasonable suspicions of abuse or neglect to DPPC **(58 percent unreported)**

The State agency did not comply with Federal waiver and State requirements for reporting and monitoring critical incidents because group home staff did not always follow procedures for reporting critical incidents. In addition, the staff of DDS and group homes lacked adequate training to identify appropriate action steps for all reported critical incidents and to correctly identify and report reasonable suspicions of abuse or neglect. Furthermore, DDS did not have access to the relevant Medicaid claims data, and DDS policies and procedures did not establish clear definitions and examples of potential abuse or neglect that should be reported. The State agency did not adequately safeguard 146 out of 334 developmentally disabled Medicaid beneficiaries because the DDS system of reporting and monitoring critical incidents did not work as expected. In addition, we noted another issue that while outside the scope of our review is worthy of the State agency's attention. This issue involves the failure of hospital-based mandated reporters to report to DPPC all critical incidents with reasonable suspicion of abuse or neglect.

https://oig.hhs.gov/oas/reports/region1/11400008.asp

DOES CLOSING DEVELOPMENTAL CENTERS MEAN THE END OF CHOICE IN CALIFORNIA'S DDS SYSTEM?

Kathleen & Dan Miller at Sonoma Developmental Center

By Kathleen Miller - PHA President, representing Residents, Families, and Friends of the Sonoma Developmental Center

California's Developmental Centers are closing and for many of the residents and their families it is a bitter pill to swallow. What makes it even more difficult is hearing all the comments from the same voices who have opposed developmental centers for years. They are forever saying how residents will live in less restrictive environments, or how they can be part of the greater community outside of developmental centers. These remarks along with other comments make no sense to most of us familiar with life at developmental centers. Many of us have also had our loved ones live in community residences, and that only makes us more frustrated with the one size must fit all vision espoused by these voices.

The truth is that board and care facilities, where almost all developmental center residents will be placed, are extremely restrictive for individuals who live in them. Staff decide when the residents eat and what they eat. They decide what they get to watch on TV and what they do with their time. They may even decide what they wear and when they bathe. Most residents cannot set a foot outside the front door unless staff agree to accompany them. Some of those same concerns can be said about the developmental centers, but anyone walking the grounds of Sonoma Developmental Center will notice how common it is to see the residents out and about. They often walk independently or they walk in groups with staff. They take rides in the tram. Medical clients have afternoon groups outside. Least restrictive has become a very empty phrase to families who have experience with board and care facilities vs life at the centers.

I am reminded of a young man on my son's residence who was placed in a board and care facility. When he was at SDC he used to spend time every day walking the grounds. He sought out time most days to be on his own with nature on the beautiful SDC campus. When I visited him in his new setting, staff bragged about how they had broken him of the dangerous habit of simply walking off. He no longer attempted to leave and take a walk on his own. No doubt this was needed because now it was no longer safe for him to walk on his own as he had at SDC. But it is difficult to make the case that he is in a less restrictive setting or that his choices are being honored.

The fact is many, if not most, of the remaining residents of developmental centers prefer life in the centers. They see the centers as home. Knowing the preferences of those who are nonverbal is challenging. How can one assert that they would have a preference for the developmental center or anywhere else? Actually nonverbal individuals have many ways of making their preferences known if we only take the time to notice. Some are social while others are not. Some love to be by the nurse's station where the action is. Others prefer it quiet. Almost all seem to enjoy being outdoors on a pleasant afternoon. Some will adapt to life outside the center. Some may well express their reluctance to move to a new facility by expressing increased anxiety or developing health issues over a move they do not choose. However such reactions are easy to ignore.

There can be no denying, however, the feelings of many of the more verbal residents. One mother quoted her son in a recent article where she says with his limited verbal ability her son is adamant. When asked where he would like to live, he says "stay here" -at the Sonoma Developmental Center.

Yet another young man was about to be placed in a board and care facility outside of SDC. Staff took him on a couple of visits and fed him lunch in the facility. He seemed to enjoy these visits. They then took him to his new facility to stay. After lunch he became agitated. He kept asking to return to SDC. When he finally understood he would not be returning to SDC, he exploded. He tore apart his surroundings and began attacking staff and residents. Many SDC residents make a very clear choice to remain at SDC.

One of the most difficult things for the families of such residents to hear is providers, and even high functioning regional center clients, claiming to support the concept of choice in one breath and maintaining developmental centers need to close in the next.

(Continued on next page)

LETTER FROM A PARENT - MY DAUGHTER MONIQUE

There are many similarities I draw from "My Sister Rosemary" [a letter by Joanne St. Amand that appeared in the Spring, 2016 edition of The Voice]. My daughter Monique was also profoundly retarded, functioning at a level of eighteen months. She was able to understand who Mom and BobBob (her stepdad, but really her dad) were, and to respond to simple commands like stand up, sit up, we're going to the doctor's, we're getting into the car (she knew to duck her head), bath, food, drink, clothes on, clothes off, lift up (for diaper change), we're almost there, we have to wait, and many other everyday communications.

Sadly, we lost our sweet baby on October 3, 2015, a week before her 50th birthday, from kidney failure with a congenital heart defect as a contributing factor, which had also compromised her lung function. Monique was 4' tall, weighed 68 pounds, and was blind from the age of seven. At an early age, her doctors told us not to expect her to live beyond her teens. Monique lived at home until she was twelve, and then began a series of placements in the community. In 1985, after several hospitalizations, her group home would not take her back. She stayed in an acute care hospital while a statewide placement search went on. She finally found a new home at Porterville, and later transferred to Fairview.

I don't believe that Monique would have lived so long if she had stayed in the community. The DDS staff at Fairview was kind, loving, patient and devoted to those they cared for – I can't thank them enough. I was always welcome to visit. I was often there from lunchtime until well past midnight, when Monique would finally go to sleep.

I am sickened by the plan to close her DDS in 2018. The total service is within DDS – shelter, food, clothing, doctors and nurses 24/7, dentists, school, transportation to outside appointments or workshops or community outings – and most important – kind and loving quality care, all day, every day.

Monique was well loved by many and is greatly missed. We take solace in knowing that Monique is with God, another angel in heaven, with her beloved BobBob who passed away a year before she did.

(*Continued from previous page*)

Some try to deny that residents really make the choice to live in developmental centers. They maintain that SDC residents have not yet experienced the wonder of community settings. However, many have, and have very bad experiences. Some say staff and family have hoodwinked the SDC residents into saying they prefer SDC. They do this while ignoring the fact that many of the community based clients crying for closure of developmental centers, and denouncing them as evil, have never set foot inside a center or are those who should have never been there in the first place. They simply refuse to accept that others may want something other than what they might want, that they want to remain at SDC.

This issue actually goes much deeper than closing California's remaining developmental centers. It is an issue of choice being taken from society's most powerless. Thus children are another powerless population not allowed the choice. When the Children's Center in Santa Rosa closed they were not given the option of living in children's centers over foster care homes. Some may well choose foster care. Clearly, however, not all foster care homes are quality homes. Some are not even safe. Maybe instead of forcing all children into one model the issue of choices needs to be more fully explored for them. The same is true of the individuals with developmental disabilities. It always seems to be individuals with no power who are forced into settings "for their own good."

Choice, real choice, may not always fall into preferred boxes. Folks don't always choose what we want them to choose. My son walks to the on grounds to the SDC store every day and buys himself a candy bar. I would rather he buy himself an apple. He would rather have a candy bar. That is his choice. Many SDC residents would rather remain SDC residents. Regional centers, community providers, and paid advocates want them to choose board and care facilities. They prefer SDC.

They will no longer have that choice. From here forward they have less choice in their lives - and those of us who love them mourn that loss with them. They will be forced into board and care facilities where their choices will be limited or nonexistent. They can no longer walk on their own, go to the store and buy candy bars on their own, go to church services or choose not to go on their own, or make any number of day to day choices they have been making daily at SDC. Choice has taken a hit. Let's not pretend otherwise.

836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
877-399-4867 toll free
www.vor.net

U.S. Postage

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

www.vor.net /VOR info@vor.net @VOR_NET

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!

Name ______________________________

Address ______________________________

City ______________ State ______ Zip ______

Telephone ______________ Fax ______________

Email ______________________________

☐ MY CONTACT INFORMATION HAS CHANGED

I would like to give a gift membership to:

Name ______________________________

Address ______________________________

City ______________ State ______ Zip ______

Telephone ______________ Fax ______________

Email ______________________________

I WOULD LIKE TO MAKE A TRIBUTE GIFT:
☐ IN MEMORY OF: ☐ IN HONOR OF:
____

Send acknowledgement to:
____

☐ $40 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:

☐ $5,000 ☐ $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). If is our best interest that you receive VOR's information, so please call if $40 per year poses a financial hardship. If you have included VOR in your estate planning, please let us know. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

September16NL