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The Olmstead right of individual choice and the duty of guardians: Whose choice is it?

Without question, the 1999 U.S. Supreme Court *Olmstead* decision requires that community placement not be imposed on individuals who do not desire it. The *Olmstead* right of individual choice is clear, but what about situations where the individual with an intellectual or developmental disability (I/DD) has a legally appointed guardian?

While the role of guardians in advancing the right of individual choice has been debated, the law clearly supports the right and duty of guardians to make decisions on behalf of the individual in their best interest.

The Americans with Disabilities Act (ADA) and Olmstead

25 years ago, the ADA was passed to prohibit discrimination on the basis of disability by public entities (Title II) and in employment, transportation, public accommodations, and communications. ADA regulations for Title II indicate that a “public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” [Integration Regulation, 28 CFR § 35.130(d) (1998)].

In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the U.S. Supreme Court considered the scope of the ADA and its Integration Regulation. The issue before the Court was “whether the [ADA’s] proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.” (*Id.* at 587)

Answering this question with a “qualified yes,” the Court held that the ADA requires community placement only when “the State’s treatment professionals have determined that community placement is appropriate, **the transfer from institutional care to a less restrictive setting is not opposed by the affected individual**, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” (*Id.*, **emphasis added**).

Defining Individual Choice and the Role of Guardians

As highlighted above, the Supreme Court held that individual choice is a prerequisite to community placement, explaining further that there is no “federal requirement that community-based treatment be imposed on patients who do not desire it.” Nowhere in the decision, however, is the role of guardian discussed. Attorney Patricia G. Williams found the Court’s silence on this point telling:

“Absent some clear direction from the U.S. Supreme Court to the contrary, we must conclude that the laws pertaining to guardianship, conservatorship, durable powers of attorney and advance directives remain intact.” (Patricia G. Williams, Esq., September 6, 2000)

Even prior to its *Olmstead* decision, the Supreme Court held high the perspective of families and legal guardians (often family members), in residential placement decisions:

[C]lose relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person’s abilities and experiences, have valuable insights which should be considered during the involuntary commitment process. *Heller v. Doe*, 509 U.S. 312, 328-29 (1993) [see also, Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001(c)(3)(1993) (“Individuals with developmental disabilities **and their families** are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families” (**emphasis added**))].

Sam Bagenstos, a former Department of Justice attorney and well-known proponent of deinstitutionalization, also noted that while *Olmstead* and ADA regulations refer to the choice of the “individual with a disability,” one could argue that these same sources “should be interpreted in light of the background state-law principle that guardians can make decisions for their wards.” [Bagenstos, S., “The Past and Future of Deinstitutionalization Litigation,” *Cardozo Law Review* (Vol. 34:1) (2012)].

According to Bagenstos, “courts have not definitively resolved this question, though a number have suggested that it is the guardian’s choice that matters.” One such case is *U.S. v. Arkansas*, in which a Federal Judge, pointing to the strong support of the residents families and guardians of continued placement at Conway Developmental Center (and opposition to community placement), dismissed the Department of Justice’s claims that residents of Conway were “unjustifiably institutionalized”:

“All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States.” [*U.S. v. Arkansas*, 794 F.Supp.2d 935 (E.D. Ark. 2011) at <http://vor.net/images/ArkansasDecision.pdf>].

Likewise, in *People First of Tennessee v. Clover Bottom Developmental Center*, the Court considered the right of individuals to reject a community placement. Noting that the “intersection of citizen choice and the ADA was addressed by the Supreme Court in *Olmstead v. L.C.*,” the Court addressed whose choice mattered by quoting an “eloquent” argument in a brief submitted by the Parent Guardian Association:

“Conservators [and guardians] - who have the longest and most meaningful relationship with their loved ones and the greatest investment in their well-being - are in the best position, after considering the recommendations of professionals and any other relevant facts, to assess the risks and exposure of the less protective environment of community settings against any benefits community settings may provide for that particular individual and to make an informed decision as to whether to exercise the disabled person’s right on his/her behalf to decline community placement.” [*People First of Tennessee v. Clover Bottom Developmental Center*, 753 F.Supp.2d 701, 711 (2010) (quoting PGA)].

In receiving petitions for intervention submitted by families and guardians on behalf of their family members with profound developmental disabilities, federal courts have been accepting of their role in representing the interests of their family members and wards [see e.g., *Ligas v. Maram*, No. 05 C 4331, 2010 WL 1418583 (N.D. Ill. Apr. 7, 2010); *Benjamin v. Department of Public Welfare*, 701 F.3d 938 (3d Cir. 2012); and *United States v. Virginia*, 282 F.R.D. 403 (E.D. Va., 2012)]; and families and guardians are allowed to initiate lawsuits on behalf of their family members and wards with I/DD (see e.g., *Olmstead*, 527 U.S. 581 (plaintiffs, individuals with cognitive disabilities, were represented by a guardian ad litem; and *Sciarrillo, et al. v. Christie, et al.* (2013) (on behalf of 35 individuals with I/DD, all represented by family members and guardians).

More recently, in January 2014, the Centers for Medicare & Medicaid Services released its final Home and Community Based Services (HCBS) regulation that defines the settings in which people with I/DD can receive Medicaid-funded HCBS. The regulation places the individual with a disability at the center of the person-centered planning process, allowing for the reality that many people with I/DD are limited in their ability to make or communicate decisions for themselves or to exercise their rights on their own behalf and for whom legal guardianship may be necessary:

“We note that where a legal guardian, conservator, or other person has the sole authority under state law to make decisions related to the individual’s care, the state must comply with the decisions of the legal surrogate.” [79 Fed. Reg. 2996 (January 16, 2014); see also, 42 C.F. R. 441.735 (a) (In this subpart, the term individual’s representative means, with respect to an individual being evaluated for, assessed regarding, or receiving State plan HCBS, the following:

(a) The individual’s legal guardian or other person who is authorized under State law to represent the individual for the purpose of making decisions related to the person’s care or well-being. In instances where state law confers decision-making authority to the individual representative, the individual will lead the service planning process to the extent possible.]

Conclusions

The role of guardianship is increasingly under attack. Although initiatives to promote self-determination, person-centered planning, and self-advocacy encourage personal decision-making by the individual with a disability, they do not override the authority of legal guardians to make determinations authorized by state courts in guardianship proceedings, despite claims to the contrary by some disability advocates. Blanket assertions that all individuals with disabilities are capable of making all decisions for themselves, regardless of their level of cognitive disability, are not supported by reality. As a result of discouraging the use of guardianship, some individuals are exposed to the risk for abuse, neglect, and exploitation that guardianship is designed and intended to prevent.

“Supported Decision-Making” is another initiative that purports to replace the need for guardianship with less formal supports. As a replacement for guardianship for people who have cognitive disabilities that impair their ability to make decisions, it could expose vulnerable individuals to the risk of having decisions made for them by agency personnel whose own convenience and interests may conflict with the best interests of the individual.

In a recent blog, Aaron Bishop, the Commissioner of the Administration on Developmental Disabilities, promoted supported decision-making, “a process of working with the person to identify where help is needed and devising an approach for providing that help.” Regarding guardianship he writes, “[t]he trouble with guardianship is that it is a legal process.”

In fact, it is the legal process that protects an individual from unnecessary guardianship and from abusive guardians. Legal guardians are charged by a court to advance the individuals’, not the guardians’, best interests. Failure to do so is cause for removal. In court filings and actual decision-making, the guardian and individual are considered one and the same, with aligned, not divergent interests.

Federal law has consistently upheld the right of service choice and supports the important decision-making role that families and legal guardians play in supporting their individuals with I/DD. *Olmstead* certainly did not change that.

VOR In Action.....

This is a letter and comments VOR sent in support of the Sonoma Developmental Center

Department of Developmental Services
Attn: Cindy Coppage
1600 9th Street, Room 340, M.S. 3-17
Sacramento, CA 95814

Submitted Electronically to Sonoma.closure@dds.ca.gov

RE: Comments on Closure Plan for Sonoma Developmental Center

Dear Ms. Coppage:

VOR is a national, nonprofit, non-provider organization advocating for high quality care and human rights for people with intellectual and developmental disabilities (I/DD). We represent primarily families and conservators of adults with profound I/DD across the country, including many families who have residents living at the Sonoma Developmental Center.

Listening to some of the testimony given by families, staff, and community members at a public hearing in July 2015, it is obvious that the services at the center, the professional and direct service staff, and the beautiful natural surroundings of Sonoma Developmental Center are highly valued by residents, families, and the larger community. Any plan that calls for the total closure of SDC and the eviction of its fragile residents into unprepared community settings, would be a shortsighted, likely to cause harm to people with high medical and behavioral needs, and more than likely would be more costly to California taxpayers.

The plan should offer solutions that utilize the resources already present at Sonoma and expand them to serve a larger community of people with and without disabilities, as well as serving as a safety net for individuals in community settings who are facing a temporary crisis or whose needs, due to aging or illness, have intensified beyond the ability of the community provider to safely accommodate them.

VOR fully supports the recommendations of the Sonoma Parent Hospital Association in its “Essential Elements of a Plan for Closure of Sonoma Developmental Center”

We support provisions for services to individuals who have been deflected to inappropriate living situations due to a multi-year “moratorium” on admissions to SDC. This includes individuals held in jail, psychiatric facilities, temporary housing, those rejected from housing because of behavioral issues, and those who are at risk of harm to self or others due to insufficient supports. The plan for SDC should also include developing medical, dental, and other services not readily available in the community at the Sonoma site concurrent with closure activities.

The plan should assure transparency in reporting to assist in placement and support of individuals being moved including injuries received by the individual during behavioral episodes, unexplained injuries, and death. Also included should be emergency services to support and maintain individuals with complex behavioral and dual diagnosis needs.

The SDC plan for closure must respect choice and family decision-making.

The U.S. Supreme Court in *Olmstead* held that individual choice, with the assistance of legally-appointed conservators, is paramount. No transfer from institutional care to community care may occur without the agreement of the individual, or

where appropriate, their court-appointed legal guardian or conservator. Furthermore, the federal DD Act confirms that, “individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families; [Developmental Disabilities Act, 42 U.S.C. 15001(c)(3)(2000)]

The SDC plan for closure must not ignore the lessons learned from Deinstitutionalization in California and other states.

The failure of the deinstitutionalization experiment as it has impacted people with mental illness is well-known. Likewise, people with I/DD who have been forced from developmental centers and separated from life-sustaining specialized care have suffered well-documented abuse, neglect, death, incarcerations, and isolation. The problems with deinstitutionalization are documented in testimony from VOR submitted to the California State Senate in April 2015 regarding closure of developmental centers.

SOLUTION: Re-Invent Sonoma Developmental Center to Serve Current Residents, Non-Residents, and Neighbors

Sonoma Developmental Center now provides highly specialized care to Californians with profound I/DD, who are also medically fragile and experience extremely challenging and dangerous behaviors. Its beautiful campus is fully integrated with its surrounding community.

Consider solutions that will better utilize the resources of the Sonoma Developmental Center, increasing the Center’s ability to serve as a safety net for individuals in community settings who are facing a temporary crisis or whose needs, due to aging or illness, have intensified beyond the ability of the community provider to safely accommodate them.

Preserve the resources that provide medical and dental care that is often difficult to find in community settings along with specialized services for wheelchair users, respite care, and crisis housing. Preserve the enjoyment of the land for recreational purposes for all citizens of California and to honor California’s natural beauty.

For further information on Olmstead protections for people residing in institutions, the myths and problems with cost comparisons, predictable problems and lessons learned from deinstitutionalization, and more solutions that should be considered, please refer to VOR testimony provided to the California State Senate regarding the closure of Developmental Centers.

Thank you for your consideration of our comments. Please contact us with questions or for further information.

Monthly Donations to VOR: Giving made easy, one month at a time

33 years ago, VOR was formed around a kitchen table in Illinois. Who would have known that today and in the future that the fight to protect all individuals with intellectual and developmental disabilities (I/DD) would be more important now than ever! We must fight for quality care and upholding the Supreme Court Olmstead decision.

Together we will continue the fight.

Please consider committing to VOR with a monthly donation and help us to continue to protect your loved ones.

Your monthly donation helps form a predictable source of income we can count on to fund our mission.

It’s the easiest way to give and ensure that VOR receives your ongoing support. Your recurring monthly donation means, together, we will help families and your loved ones.

Your recurring online donation is secure and flexible. You choose the amount you wish to give each month and you can change, or cancel, your pledge at any time. Sign up now and make your first donation by credit card online.

Your monthly donation will mean so much. Please become a Monthly Donor today.

Thank you for your loyalty and support! See back page for further details or online at: <http://vor.net/donate-now>.

Friends of Fircrest is a volunteer 501(c) (3), non-profit organization, advocating for the right to quality living and care choices for all citizens with developmental disabilities located in Washington state.

This is a message from the President of Fircrest

Dear Friends of Fircrest,

A bit about climate change. The political climate. Like the earth's climate, the changes are slow enough that big changes can occur before we are completely aware that things are different.

We who advocate for service and home choices that include Residential Habilitation Centers have been kicked around so much, abuse feels natural and is expected. That was then, this is now.

Now we have political support from the governor and most legislators. The Secretary of DSHS is supportive. I have felt it in the atmosphere at Fircrest and Rainier. Professional staff are smiling, care staff are cheerful, and this is good for residents.

We've been conditioned to expect bad news and opposition from off campus DSHS administration. We need to reassess that conditioning. RHCs surely still have detractors in the bureaucracy. But they no longer rule the roost.

Wasn't it just yesterday that the auditor refused to read the Olmstead case and simply adopted the Justice Dept. misinterpretation of it? Governor Inslee is a lawyer who can read a case and we are better off for it. DSHS Sec. Quigley can read a case as well, and we are better off.

It's time to regard our political leadership as friends of people with severe disabilities who understand the importance of RHCs and the safety net they are. In this, we are all friends.

Kumbaya maybe, not nirvana. There are and there will continue to be problems. But the problem solving process is changed. It's the climate.

All human endeavors encounter problems and there will be differences of opinions. But we friends acknowledge a common goal and best efforts in serving, protecting, and enhancing lives of those with profound disabilities.

That's the word today.

J.R. Hardman J.D., CPG

President, Friends of Fircrest

Make a Lasting Impact

Will bequests are the most popular and personal way to making a difference beyond your lifetime. A bequest is a charitable gift to be delivered at death. You can direct a will bequest by simply providing the sample language below:

"I give to VOR, an Illinois corporation, Arlington Heights, Illinois, the sum of \$_____ (or _____ percent of the remainder of my estate) to be used by VOR for its unrestricted purposes."

For additional information contact VOR at info@vor.net

Tribute

Thank you to all individuals who requested or gave donations in honor of someone special, or in memory of a loved one.

For those who have lost someone special, please accept our deepest sympathy.

IN MEMORY

Clayton Sinclair
Warren Bayer
Martin, Ellen, and Nancy Pratt
Robert Zimmerman
Mary and Craig Brace
Dale Loween
Roger Sale

IN HONOR

Kathleen Roberts
Judith Price
Julie Huso

Please note that at the request of the family names have been changed.

My brother, Matt, lived in a string of group homes until he was 30. One or two of them were good, others were OK, and two were really bad. He was severely mentally handicapped and could not speak. And in his late 20s, he started to run away from his homes as a lark. He knew nothing of traffic, strangers, danger, etc. and had no plan or place to go. He was always found soon, but the homes would expel him for liability reasons. Hence my parents finally had to place him for his own safety in a locked unit at Sonoma Developmental Center (formerly State Hospital), California's largest facility for the mentally disabled. By the time he got there, it had been much improved from what it was. My parents had peace of mind, and he was reasonably contented, since Sonoma is in the countryside and he had plenty of opportunity to walk here and there accompanied by staff. I don't know what we would have done without Sonoma. Matt lived there for 20 years until his death from colon cancer in 2009.

So you can imagine my shock and distress upon reading a month or so ago that the state plans to close all of its developmental centers soon. As you and I know, some handicapped individuals need congregate care, so it should always remain an option. Large facilities are also much more easily monitored than are small ones scattered here and there. I plan to contact my state legislators very soon.

VOR Member

**VOR Member illustrated and wrote a book –
“Gloria Goldfish Loses a Loved One”**

Long-time VOR member, Sally Kitt Chappell, faced a worry facing many parents of children with profound intellectual disabilities: “When I die, will Jennifer understand why I have stopped visiting?”

“As a writer, my solution to every problem is a book,” says Chappell. So I illustrated and wrote one for Jennifer entitled “Gloria Goldfish Loses a Loved One.”

The story is simple. Gloria loves swimming and having lunch with her mother. One day her mother warns her that she might die soon, but tells her that the sadness she feels will stop one day and she will enjoy life again, and this comes true. The book's beautiful watercolor illustrations, by Chappell, also tell the story for non-readers.

“To my surprise, the staff at Shapiro Developmental Center reacted with great enthusiasm for the book,” says Chappell. They said it would help thousands like my daughter, but also countless very young typically developing children face the loss of a loved one.

Chappell is an accomplished author. She is a member of PEN, a worldwide association of writers, and is the recipient of the Association of American Publishers award for the best book in architecture in 1992. Gloria Goldfish Loses a Loved One is her first children's book.

“I have published many books and articles over the years, but this slim volume has brought me more satisfaction than the rest of them put together,” says Chappell

If you would like a copy of this wonderful book please send \$12 to: Sally Chappell, 3750 N. Lake Shore Drive, Suite 10 D, Chicago, IL 60613, and include your shipping address.



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



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Membership/Contribution Form: VOR, 836 S. Arlington Heights Rd., #351
 Elk Grove Village, IL 60007 or donate online @ <http://www.vor.net/online-membership-form>

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

Name _____

Address _____

City _____ State _____ Zip _____

Telephone number(s) _____

Fax _____ E-mail _____

Referred by (if applicable): _____

My contact information has changed.

Membership Categories

- Individual --- \$40
- Family/Parents' Association --- \$200
- Professional Assoc./Corp. --- \$250

I would like to make an additional donation to support future efforts of VOR. An additional gift is enclosed for:

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Checks made payable to VOR, or by credit card: **Visa** **MasterCard** **Discover**

Card Number: _____

Amount to charge: \$ _____ 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 it is our best interest that you receive VOR's information, so please call if \$40 per year poses a financial hardship.

**I would like to give the gift of a
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Telephone number(s) _____

Fax _____ E-mail _____

I would like to make a tribute gift:

This gift is in ___ In Memory ___ In Honor of: _____

Send Acknowledgment to: _____

**I would like to make MONTHLY donations
 to VOR. Please charge my credit card
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