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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 their 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.” (*Id.* at 602) 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.

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