

“OLMSTEAD” TESTIMONY

for

HOUSE of REPRESENTATIVES

HUMAN SERVICES COMMITTEE

by

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Olmstead Testimony by Tom Kashatus for House Human Services Committee

Before I proceed, I want to thank Majority House Chair Gene DiGirolamo and Democrat Chair Angel Cruz and the members of the House Human Services Committee for this opportunity to speak regarding "Olmstead" for my daughter, Maria, and other residents at White Haven Center (WHC) for whom I am honored and fortunate to represent with the right of guardianship and who do not have families and the ability to speak for themselves. I especially want to thank Rep. Toohil and her staff for guiding me to Liz Yarnell who set the parameters for me to follow the get to this point. Although I am grateful for this opportunity, it's unfortunate that after so many years since the "Olmstead" decision, we are still debating what such a clear decision says and means.

As I will explain, "Olmstead" simply supports my daughter's right to call WHC home. I am thankful to the state of Pennsylvania for the high quality professional care and services that are given to Maria, my personal hero, who is a resident of WHC, a state facility for the intellectually disabled. I will be forever indebted to our taxpayers for their financial support to Maria and my family during our lifetimes. However, I am tired – tired of going to meetings, worn out – worn out from growing old, overwhelmed – overwhelmed with trying to learn the ropes associated with the intellectual disability system. I'm exhausted from the pressure of contrary advocacy groups (the DOJ, the DRN, the ARC, etc.) for the past twenty years trying to interpret the Supreme Court "Olmstead Decision" as a means to close all state Intermediate Care Facilities for the Intellectually Developmental Disabled ICF's/IDD. Also at the same time, they stipulate that my daughter and her lifelong friends at WHC can be better served by private facilities in smaller, unlicensed settings by staff unfamiliar and untrained to meet their complex needs. As a member of my local crime watch, I note that these are the same communities where drugs and crime flourish, racial hatred continues to exist, gangs establish their ground rules, and people who are different aren't accepted.

Usually when controversial issues arise within the intellectual disability community, "Olmstead" always seems to be the crux of the controversy. It's no wonder that this highly important House Committee is finally taking testimony specifically centering on the "Olmstead" decision. The large advocacies have their own interpretation of "Olmstead," but I, my family, and my supporters believe that the opinions supported in the decision itself are the most sensible and fairest as they emphasize "choice."

I am a member of VOR, a national advocacy organization which supports choice. Attached to this testimony are papers from VOR (1) "Don't be misled about what the Olmstead Supreme Decision says" and (2) "Olmstead supports residential choice." Due to time restraints, I will furnish copies of these documents along with my testimony for your review. However, I would like to reiterate four comments from these documents. 1. "What Olmstead is not. Olmstead is not a federal law or statute." 2. "How Olmstead is misused. In support of their objective to downsize and close ICF/MR (Intermediate Care Facilities for the Mentally Retarded) certain advocates are emphasizing portions of the Court's opinion regarding "unjustified institutionalization" and ignoring important parts of the Court's decision." 3. "The Olmstead decision supports facility based (institutional care) for those individuals whose severe impairments require close care found in such settings." 4. "A plurality of justices noted "As already observed (by the majority) the American Disability Act (ADA) is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... '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' [quoting VOR's Amici Curiae Brief]."

At this time I would like to put before you a few comments about myself. Besides being a father of Maria, I am President of the White Haven Center Relatives and Friends Association, a member of the White Haven Center Board of Trustees, an "intervener" in the Benjamin Litigation which is a lawsuit initiated by the Disability Rights Network against the PA Department of Welfare. I am directly involved in the guardianship of eleven residents of White Haven Center and attend numerous meetings of various organizations within the intellectual disability community. I am also heavily involved with volunteerism in community programs. You may have the privilege of reading Maria's story which is enclosure # 1 of my testimony.

At the onset of the Benjamin Litigation it was sad to learn that during the early stages that the individuals who most likely appeared on the top of the list for transfer into the community were those residents who had no or very little family contact and couldn't speak for themselves.

I was dumbfounded to learn from a county caseworker that Luzerne County Human Services MH/IDD does not offer state ICF's/IDD as a provider of services for PA residents in need of services. This is one factor that has resulted in an overwhelming and expanding "waiting list" of people seeking services. It's tragic when a family needs emergency services, which may involve life or death, and are told by a provider that they have thirty days to provide services – normally hundreds of miles away from home.

My wife and I remember the days of the "Five Year Plan" and the resulting Fairchild House Hearings back in the 1990's. That sub-committee traveled throughout the State, took a great deal of testimony, and tried to initiate legislation to no avail. State facilities were referred to by advocacy groups as "prisons with bars on the windows." Those hearings were eventually discontinued as those anti state center advocacy groups caused disruption and upset the normal routine and continuity of the committee. Eventually the ODP initiated many programs over the years to increase the quality of life in their ICF's and in the community. It is hoped that the legislators of today will take the time to visit our state centers and community facilities to draw conclusions rather than just come to conclusions from testimony. It is hoped that you will see, only then, the need for various choices in a system that that has proven to be highly complex.

"Olmstead" offers choices and that is exactly the path that our sister commonwealth of the state of Virginia recently followed when they passed SB627 by votes of 99-0 and 38-0 which currently sits on Governor McAuliffe's desk for signature. The bill was highly supported by families of training center residents and stipulates for the Department of Behavioral Health and Developmental Services (DBHDS) to (1) Certify, before any resident is transferred to either the community or other Training Center, that the receiving placement "provides a quality care that is comparable to that provided in the resident's current training center regarding medical, health, developmental, and behavioral care and safety." (2) Disclose "all permissible placement options available under the Commonwealth's August 23, 2012 agreement with the U.S. Department of Justice, including the option to remain in a training center." (3) "Convene a workgroup on interested stakeholders, which shall include members of the General Assembly, to consider options for expanding the number of training centers that remain open, in whole or in part, in the Commonwealth.

Let's have the patience to listen to all advocacy groups to make the system better for the quality of life of all those in need, but keep in mind to have the courage and compassion to make tough decisions while remembering that "choice is imperative and all reasonable choices should be on the table. As the saying goes – "one size does not fit all."

Biography of Maria Kashatus



Maria & Dad 2013

Maria was born on 09/23/68 in Wilkes-Barre, PA to Thomas and Margaret Sabanos Kashatus. Maria's mother stated that she had a cold with a fever at eight and a half months of gestation, which was treated with antibiotics, and she had an Upper Respiratory Infection type illness one month prior to pregnancy. Pregnancy lasted nine months. Mrs. Kashatus was in labor for five hours and delivery was normal. Maria weighed six pounds, ten ounces and spent her first twenty-four hours in an incubator because of mucous in her lungs. Maria sat without support at five months, walked alone at fourteen months, and used words clearly at seven months. At about seventeen months, Maria had a one to two week illness with a fever of 106 degrees. There seemed to be a slight arrest of development with fine motor clumsiness and a plateau of her language at that time. At thirty months, she had another illness with a temperature of 103 degrees, upper respiratory signs, vomiting, and lethargy (probably seizures). There was a significant arrest of development from this time, including some stiffness of extremities, loss of fine motor skills, and loss of language. However, Geisinger Hospital and a relative doctor of the family had noted that Maria showed signs of a mild motor lag as early as one year of age.

An EEG on 09/74, at Hahnemann Hospital showed bi-lateral slowing and left hemisphere Epileptiform discharges. On 12/17/74, a Child Neurologist at Hahnemann Hospital found a marked lag in language-social development, placing her in the low to moderately retarded range with a mild motor handicap. An evaluation at Children's Hospital in 06/01/76 indicated chronic, non-progressive Encephalopathy of undetermined etiology with psychomotor retardation and Mental Retardation considered profound. Doctors at that time advised that she would probably develop seizure activity around the time of her first menses. She had an onset of Grand Mal Seizures starting in 01/79. The consensus of medical opinion indicated that Maria had a development delay and functioned in the severe range of retardation. Whether she was ever normal from birth could not be determined.

Maria resided in four community living arrangements from 05/16/75 until 12/31/79. Two were in Wilkes-Barre and one was in Kingston and one was in Mountaintop, Pa. She then returned home because her parents were not satisfied with the community arrangements. Her parents felt they could not provide the level of care that she required, and they made the difficult decision to place Maria at the White Haven Center on 04/24/80 following a court hearing. She had lived in Hickory Hall for eighteen years, in Pine Hall for two years and currently resides in Pocono Hall.

Maria is the first of five siblings. Lynn was born 10/03/69, Tommy 12/09/70, Jeremy 01/15/73 and Jonathan 04/22/75. All are reported to have no mental or physical disabilities. Since residing at the White Haven Center, Maria's loving paternal grandfather passed away. Her parents were granted guardianship of the PERSON for Maria on 06/22/98 and her mother is her Financial Representative Payee.

Maria's family has been instrumental in helping White Haven Center through leadership in the WHC Friends and Family Association. Additionally, Maria's father serves on the White Haven Center's "Board of Trustees". Her parents are very involved in all aspects of Maria's life, attending her annual ISP's, medical appointments, family functions and responding to all center correspondence. Maria's siblings and aunt, Mary Margaret Kashatus also play active roles in Maria's life through attending family functions, visiting and remaining updated on Maria's care needs.

Today, Maria is non-verbal, confined to a wheel chair, and must be fed by staff. Maria will respond, at times, to attention by smiling and laughing. She is diagnosed to have the mental capacity of three to six months.

DON'T BE MISLED ABOUT WHAT THE OLMSTEAD SUPREME COURT DECISION SAYS

(1) What Olmstead is Not:

"Olmstead" is not a federal act or statute. Rather, it is a U.S. Supreme Court decision which reinforced the rights of individuals with mental retardation and their parents and guardians to choose the residential setting that is best for these persons.

(2) How Olmstead is misused:

In support of their objective to downsize and close ICF/MR (Intermediate Care Facilities for the Mentally Retarded), certain advocates are emphasizing portions of the Court's opinion regarding "unjustified institutionalization" and ignoring important parts of the Court's decision.

(3) The Olmstead decision supports facility-based (institutional care) for those individuals whose severe impairments require the close care found in such settings.

A majority of Justices in Olmstead recognized an ongoing role for publicly and privately-operated institutions:

"We emphasize that nothing in the Americans with Disabilities Act 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." 119 S. Ct. at 2187

"Unjustified isolation, we hold, is properly regarding as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand." 119 S. Ct. at 2185.

The plurality opinion in Olmstead stated:

"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." 119 S. Ct. at 2189.

(4) Olmstead encourages a continuum of service options for disabled persons - home, community and institutional:

In addressing the issue of when a disabled person's care may be changed from institutional placement to community placement, the Olmstead decision set forth a three part test to determine if community placement is appropriate:

- "(a) the State's treatment professionals have determined that community placement is appropriate;
- (b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
- (c) the placement can be reasonably accommodated, taking into account resources available to the State and the needs of others with mental disabilities." 119 S. Ct. at 2181

(5) People with mental retardation, especially individuals with severe and profound mental retardation, and their families have vastly different support requirements than those with physical disabilities. As families age, their abilities to be the primary care givers (and fiscal intermediaries) will also change. Arkansas should continue its continuum of services for each stage of care-giving.

We are families and friends of disabled persons who support the full continuum of residential options required by the disability community and addressed by Olmstead. For many years, states have offered competent and compassionate care through its state-operated and private intermediate care facilities. In recent years, the state has also offered support for families who care for their disabled children at home and has steadily increased its support of community-based services (through the home and community-based waiver).

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Olmstead Supports Residential Choice!

The Supreme Court, in its Olmstead ruling, recognized the need for a range of services to meet to the varied and unique needs of the entire disability community:

- (1) **Unjustified isolation is discrimination based on disability. Olmstead v. L.C., 527 U.S. 581, 597 (1999).**
- (2) The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when --"[a] the State's treatment professionals have determined that community placement is appropriate, [b] the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and [c] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. *Id.* at 587 (emphasis added).
- (3) The Supreme Court explained that this holding "reflects two evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Second, historically "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Id.* at 600-601.
- (4) However, a majority of Justices in Olmstead also recognized an ongoing role for publicly and privately-operated institutions: "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." *Id.* at 601-602.
- (5) A plurality of Justices noted:

"[N]o 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'" (quoting Amicus Curiae Brief for the American Psychiatric Association, et al).

"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... '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'[quoting VOR's Amici Curiae brief]." *Id.* at 605.
- (6) Justice Kennedy noted in his concurring opinion, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." *Id.* at 610.

Visit VOR's website for more additional Olmstead resources



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The Olmstead "choice" provision and guardianship rights

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The Court's conclusion, expressed in a 3-prong standard which has become known as the "Olmstead Rule," requires community placement "when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Some clarification is still necessary, however, in determining whether the decision in Olmstead impacts upon who is qualified to object on behalf of an individual with developmental disability where that individual lacks the capacity to make an objection to placement. The Olmstead case is completely silent on surrogate decisionmaking. The Supreme Court was not asked, so did not address, the question of what decisions guardians, conservators, or parents can make on behalf of persons with mental retardation (Note that the only place the word "guardian" appears in Olmstead is in the case heading. The case was filed, not by the two persons with mental retardation themselves, but by a guardian ad litem, exercising their rights and choices on their behalf. The guardian ad litem was appointed because the court determined the individuals were not competent to act in their own best interests without assistance).

We must then, as is common and correct practice in interpreting court decisions, go beyond the four walls of the decision to use other existing law to answer this question. If the Court were to say that persons with mental retardation were entitled to choose their own physician from those available in their geographic area, we would combine that principle with other existing law regarding health care decisionmaking and conclude that a conservator who has the power to make health care decisions on behalf of an adult with mental retardation is authorized to make the choice of an appropriate physician. If an adult with mental retardation has authorized an agent through a durable power of attorney to make such decisions, the agent would also have authority to make that decision.

There is no indication in Olmstead that the Court intended to redefine settled statutory mechanisms for decisionmaking found in state law in every state of the United States, evolved over hundreds of years from their origins in common law. 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. Where a court has exercised its judgment through judicial proceedings to authorize an individual to make decisions on behalf of a person with a disability, that individual's authority must necessarily carry greater legal weight than any other individual purporting to speak on behalf of the person with a disability. California law pertaining to the involvement of parents, guardians and

conservators in decision making pertaining to institutional and community residential placement of individuals with developmental disabilities is undisturbed by the Olmstead decision.

It is not so long ago that the U.S. Supreme Court expressed its opinion on the importance of family participation in decisionmaking on these issues in the case of Heller v. Doe (509 U.S. 312). Reviewing statutory provisions for involuntary commitment of persons with mental retardation in the State of Kentucky which provided for participation of family members in commitment proceedings, the Court found a rational basis for the participation of families, arguing "Kentucky might have concluded that close relatives and guardians had valuable insights which ought to be considered during the commitment process." The Court specifically noted that such participation "increased the accuracy of the proceedings" . . . "without undermining the liberty interest of the person facing commitment." Respect for the importance of such familial participation is echoed in the Bear [Pennsylvania] case.

Although there has been much discussion within the disability community of the meaning of "choice" and how "choice" can be exercised by persons with severe developmental disabilities, there has been no genuine legal challenge to the authority of parents of minor children and guardians or conservators of adults with developmental disabilities to be primary decisionmakers in those areas recognized by competent courts of jurisdiction. V

10. Virginia: "Very Good News," says families: Revised training-center bill advances in House

Earlier this week, the Virginia House of Delegates passed SB627 with amendment by a vote of 99-0; and the Virginia Senate approved the same by a vote of 38-0. The bill now goes to Governor McAuliffe, who has 30 days to sign it. Passage of the bill was strongly supported by families of training center (state ICFs/IID) residents. It requires Department of Behavioral Health and Developmental Services (DBHDS) to:

- 1. Certify, before any resident is transferred to either the community or another Training Center that the receiving placement "provides a quality of care that is comparable to that provided in the resident's current training center regarding medical, health, developmental, and behavioral care and safety."**
- 2. Disclose "all permissible placement options available under the Commonwealth's August 23, 2012, settlement agreement with the U.S. Department of Justice, including the option to remain in a training center."**
- 3. "Convene a work group of interested stakeholders, which shall include members of the General Assembly, to consider options for expanding the number of training centers that remain open, in whole or in part, in the Commonwealth."**

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