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THE OLMSTEAD ACT ALSO APPLIES TO ELDERS

Promises to keep: The Olmstead Act also applies to elders

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On July, 1999, the Supreme Court issued the Olmstead v. L.C. decision. While this decision has tremendous importance for elders and individuals with disabilities, our older population has not taken advantage of the opportunities the Olmstead Act presents to them to improve access to community based care preventing premature institutionalization and in some cases allowing frail elders living in nursing homes to go back to the community they love.

Now, five years after the Supreme Court Olmstead decision, few states are in compliance with the Act, especially as it pertains to elders with physical and mental disabilities. However, because the Olmstead decision interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulation, elders and caregivers of elderly individuals have assumed the Olmstead decision applies to younger individuals with disabilities and therefore have not pushed to reform the poorly integrated network of services to older disabled individuals.

The Olmstead Act requires that States administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" with no exclusion based on age. The Olmstead decision never intended to exclude elders from the freedom and options the act mandates be available and the fact that a great many elders are dealing with physical, mental and emotional disabilities make them eligible to be covered under the mandates of the Olmstead Act. This important information has not reached elders nor their caregivers and care managers who continue to ask for more funding, not realizing that the Olmstead law is on their side. Particularly, the Olmstead Act is there in the case of frail elders already residing in nursing homes but able to function outside if appropriate services are given to him or her.

In interpreting the Olmstead Case, the Supreme Court recognizes that an unjustified institutional isolation of persons with disabilities is a form of discrimination. This discrimination is reflected in two evident judgments : 1) "Institutional placements of people with disabilities who can live in, and benefit from, community settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life"; and 2) "confinement in an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." (Olmstead Act, 119 S.Ct. 2176, 2179, 2187). The Olmstead decision affects first, all persons in institutions and segregated settings regardless of age, and second, all individuals with disabilities who are at risk of institutionalization, including people with disabilities, regardless of age on waiting lists to receive community based services and supports.

Olmstead provides for elders residing in Nursing Homes the option to be evaluated, and if deemed ready, be given the opportunity to move back to their communities with services in place to support such a move. While the intent of the Act is clear, organizations serving elders have not even developed the appropriate evaluation tools to assess the degree of readiness an elder needs to have to move back to the community. The assessment instruments that are in place focus on the skills and activities of daily living of a person that is still living in the community, but the existing assessment instruments fail to address some of the critical components needed to be in place for an individual that for months or years has not dealt with community living, but now is attempting to go back to that community setting. The lack of appropriate assessment tools has not become an issue because few states are seriously evaluating older nursing home residents in an attempt to comply with the Olmstead decision. The numbers of elders that have never been evaluated to determine their degree of readiness to move them from nursing homes to the least restricted environments constitute a failure on the part of state agencies in implementing the Olmstead Act. Moving an elder to a least restrictive environment can include in some cases the individual's own home

Abstract:

This article analyzes the implications of the Olmstead Act and the impact the implementation of the Act has on the deinstitutionalization of individuals with disabilities regardless of age. It shows how states have frequently displayed predictable responses that focus on cosmetic changes, but not in providing appropriate funding to support the deinstitutionalization of frail individuals at a "reasonable pace". While the Olmstead Act is not limited to Medicaid beneficiaries or to services financed by Medicaid, the attention has been placed on Medicaid recipients as a way to tap into Medicaid funding and not to increase funding to critical areas. Two important points are presented; first, the fact that frail elders have not utilized the Olmstead Act as a mechanism to obtain community based

services and as a way to force state government to divert dollars from Nursing Home funding to community based care. Agencies serving elders have failed to implement the Olmstead Act and therefore has failed to leverage a stronger position to obtain appropriate funding. Second, five years after the US Supreme Court determined in Olmstead that waiting lists for waiver services must move at a reasonable pace, waiting lists for services for elders are not being properly kept, eliminating the only objective measure the court can use to determine compliance with the orders

The failure to implement Olmstead can be seen in the lack of adequate funds given by government organizations to support community based programs for elders. Failure could also be seen in the inability of State agencies to eliminate statewide waiting lists. On the other hand, younger individuals with disabilities have seen some significant funding increases, not to the degree needed, but to a higher degree than before 1999. These increases in funding have attracted agencies that have traditionally provided services exclusively to elders who now have seen the financial advantage to expand services to a much younger clientele. In some cases these agencies have eliminated the word elder or senior from their mission statement and instead they have concentrated the mission of the agency on the degree of disability or impediment in the activities of daily living a person has. These new words in their mission statement allow these agencies to expand their client base to individuals with disabilities while not necessarily expanding the number of employees available to provide services to the new client population. As a matter of fact, because the agencies have not added new personnel, and funding for elders has not increased in proportion to the need, the number of elders waiting for services has doubled in the last two years.

To make sure this long waiting list does not attract the attention of the media and be challenged in court as a violation of the Olmstead Act some state agencies have done some cosmetic changes with no real benefit to the elders. Cosmetic change is the terminology used when identifying the frail older individuals waiting for services. State and federal agencies are changing the terminology from words like number of clients on waiting lists to number of assessed clients on the priority list. The sad comment is that the majority of these elders have not been assessed by a professional but by their own statement of need during the first phone contact with the agency. This phone self assessment process is the latest protocol being tested in Florida and is another cosmetic change. This step is designed to eliminate the professional assessor while putting culturally distinct clients and clients with limited English proficiency at a serious disadvantage. If the phone self assessment is finally instituted, it will result in more individuals becoming ineligible for services and by default will reduce the waiting list and the need for more funding.

The fact that the word waiting list is being eliminated altogether to identify those frail elders waiting for services avoids giving the impression that the state has a long waiting list or a waiting list at all. Not having a long waiting list for services, or better yet, not having a waiting list at all, removes the pressure from the heads of the state and federal agencies to ask for additional funding. Therefore, if there is no significant number of elders waiting for services and the period of wait is reasonable, the public will not challenge the agency's budget request to Congress or to the state legislators. If the agencies show no need to divert more elders back to the community because there are no names of elders in nursing homes classified as "ready" or if the agencies show few names of frail individuals waiting for services, technically speaking the agency is meeting its obligation under the Olmstead Act.

One issue that needs clarification is whether or not the elder suffering from Alzheimer's is covered under the mental disability portion of the act. If they are, as I think they should, the states are also failing in this category. The Court indicated that one way states can show they are meeting their obligations under the ADA and the Olmstead decisions is to develop a "comprehensive, effectively working plan for placing qualified people with mental disabilities in less restrictive settings" (Olmstead at 2179). Based on this, almost all states are in the process of developing or have already developed such plans for younger disabled populations, but almost no states have developed a plan for elders suffering from Alzheimer's or other cognitive impediments.

It is important for elders and their caregivers to know that while the Centers for Medicare and Medicaid Services (CMS) plans have reviewed relevant Federal Medicaid regulations, policies and previous guidance to assure that they are compatible with the requirements of the ADA and Olmstead decision and are focused on the needs of persons with disabilities, CMS has not done the same to ensure that Medicaid waivers are consistent with the needs of elders with disabilities. Medicaid is an important financial resource to assist States in meeting the Olmstead mandate. However, the scope of the ADA and the Olmstead decision is not limited to Medicaid beneficiaries or to services financed by the Medicaid program. The ADA and the Olmstead decision apply to all qualified individuals with disabilities regardless of age. This is a very important point that should not be forgotten particularly now when the Medicaid programs are going to be the target of administrative and policy reviews in the next year.

Care managers and caregivers should be aware of the components of the Olmstead Act and how those components impact frail elders so they can successfully argue on behalf of their clients and older family members. The following are key components of the Olmstead Act:

- If an older person's application for community based service is denied, the individual has the right to re-apply (Social Security Act 1902 (a) (3)). Agencies must have Due Process procedures in place for those clients that are denied services. Sometimes denying services

involves refusing to take the client's name because of the long waiting list or could involve telling the client the agency is not accepting applications or referrals at this time.

- ... Older disabled persons are covered under the Freedom of Choice. Freedom of Choice means that a Medicaid client can choose between receiving services in the community or in an institutional setting. If an elder meets the institutional care requirement, that elder has the right to select where he or she will receive that care. Furthermore, states cannot impose limits on the number of Medicaid eligible clients they are able to serve. Twenty five states are facing lawsuits for imposing limits in the number of slots available to Medicaid eligible individuals (Social Security 1902(a)(3)). Elders and caregivers continue to accept the limits states are imposing without disputing the legality of such caps.
- Olmstead gives frail elders the right to evaluate if the state is operating the Medicaid program to their best interest. Some states have even been sued for failure to operate their Medicaid program in the best interest of recipients as required by Social Security 1902(a) (19). An example is the case of a Medicaid program that contracts only with agencies that have no bilingual personnel even though 35% of the recipients do not speak English; or a Medicaid program that excludes competition for a variety of services including but not limited to care management; or a Medicaid program that allows self referral of clients to other units of the agency that has done the original assessment whether or not that is the most appropriate agency to provide such services.
- Once the client's application is approved, or, in the case of Florida, once the client is assessed and his or her name is placed on the assessed priority list formerly known as the waiting list, placing that client's name on that list definitely violates the Social Security rules. Federal courts have ruled that Social Security Act 1902 (a)(8) bars states from wait listing individuals for entitled Medicaid services. Services should be delivered in a timely fashion. A waiting list or a priority assessed client list that is not moving and is keeping elders for months with no in home services is not considered delivering services in a timely fashion.
- A variation of the above violation involves agencies that have placed Elders that are Medicaid eligible in other funded program categories that offer fewer options and fewer services to the frail elders. Agencies that use this method to balance their own agency's budget by moving elders in and out of different program categories are in violation of the Olmstead Act and the Social Security Act. Elders and care managers need to realize that the authorization for services should not be less than what the client requires. This involves the type of services, frequency of the services, the intensity and duration of services. Designing a care plan that only shows the services the agency offers or limits the frequency of services to the available budget is again in violation of the Olmstead Act.
- Access to services, all type of services should exist in all geographical locations. Social Security 1902 (a) (10) states that Medicaid services need to be available in a comparable basis to all eligible individuals. Offering a waiver in one part of the state and not in another is in violation of this rule. This involves Medicaid waiver programs like Consumer Directed Care, PACE, Nursing Home Diversion and Assisted Living facilities. Waivers should be available in all geographical areas of the state if the state possesses such a waiver program.
- Advocates should evaluate if the particular state has placed more restrictive financial eligibility criteria to frail elders than to individuals with disabilities. If this is the case, this is also a violation of the Social Security regulations which mandates the same eligibility criteria for all clients. In some states younger disabled individuals can qualify for Medicaid services if their income does not exceed 133% of the federal poverty line while the older disabled individuals need to spend down until he or she reaches 100% of the federal poverty line. This represents 33% of disparity in their income.

Conclusion:

At the time of this article the Centers for Medicare and Medicaid and the Administration on Aging are providing seed funding to create one stop centers where individuals with disabilities and elders will come together to receive services. While the idea of merging this to uniquely distinct populations could present some benefit from a federal budget stand point, it could be a disservice to both populations because even though the degree of impediment could be similar, the fact that they represent different cohorts with different values, expectations and historical background could detract from serving their needs. This type of integration without proper funding is in direct contradiction to the intent and the spirit of the Olmstead Act.

About the Author:

Gema G Hernandez, D.P.A. is the former Secretary of the Florida Department of Elder Affairs and a former professor at NSU. During Dr Hernández' tenure as Secretary, the first 21 elder residents of

nursing homes in the state were able to move back to a community setting after being in a nursing home an average of 5 years. Dr Hernández was a caregiver for her parents for 18 years and during this time she learned to challenge the service delivery system to comply with the Medicaid regulations. At the time of her departure she has accomplished a long list of initiatives on behalf of elders and caregivers.

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