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Assessing the Impact of the Olmstead Decision

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1 The Americans with Disabilities Act

The Americans with Disabilities Act (ADA), signed into law by President George Bush on July 26, 1990, is a civil rights law that is intended to protect individuals from discrimination in regards to employment and ensure access to public transportation, accommodations and services, and telecommunications (Desonia, 2003). The ADA was preceded by the Rehabilitation Act of 1973, which was the first civil rights legislation for people with disabilities. Section 504 of this Act prohibits discrimination on the basis of disability by state and local governments receiving federal funding. The ADA reinforces many of the requirements set forth in Section 504 of the Rehabilitation Act (2. **Id**. § 794; Essex-Sorlie, 1994).

The ADA was passed after several years of lobbying and demonstrations by the disability community in an effort to gain recognition as a minority group that deserved appropriate accommodations and legal protections against discriminations (Meneghello and Russon, 2008). The ADA ensures that individuals with disabilities have the right to independence to the greatest extent possible so that they may participate fully in the community and contribute to the economy. The ADA protects individuals with disabilities from discrimination by providing legal recourse if it has been determined that they have been discriminated against (Desonia, 2003). There are five distinct Titles to the ADA – Title I addresses employment discrimination, Title II deals with public services, Title III covers public accommodation, Title IV addresses telecommunication service (i.e.: telephone and television access), and Title V covers the miscellaneous provisions (Rosenbaum and Teitelbaum, 2004). This paper will focus on the Olmstead Decision, which was brought to the Supreme Court as a violation of Title II of the ADA.

The ADA is a historically significant piece of legislation both in the United States and internationally. A large proportion of the world's population is considered disabled and in many nations this automatically puts them at an economic, social, and physical disadvantage. The ADA can act as a model to other countries in the development of non-discrimination policies on the basis of disability (Herr, 1999).

2 The Evolution of the Olmstead Decision

In June 1999, nearly ten years after the enactment of the ADA, the United States Supreme Court reached a landmark decision regarding the interpretation of the anti-discrimination provisions of the ADA. The *Olmstead Decision* has been described as the *Brown v. Board of Education* for the disabled population. The plaintiffs at the center of *Olmstead v. L.C.* were two women with developmental disabilities (L.C. and E.W.) who were residing in a locked psychiatric unit within Georgia Regional Hospital in Atlanta, a state psychiatric hospital (Desonia, 2003). When their conditions stabilized, the women remained confined in the institution, even though it had previously been determined by professionals from the state

hospital that they were each ready for discharge to the community (Velgouse, 2000). This was also despite the fact that the state of Georgia had available slots under the Medicaid home-and community-based services waiver for individuals with MR/DD (Desonia, 2003).

When Georgia refused to transfer the plaintiffs to a less restrictive setting, they brought suit under the ADA to the Georgia Department of Human Resources, which at the time was led by Commissioner Tommy Olmstead (Desonia, 2003). The suit argued that the decision constituted discrimination under Title II of the ADA. This Title states "no qualified individual with a disability shall, by reason of such a disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." (Toland, 2008, p. 1)

The first court to hear the case was a district court, which determined that Georgia violated the ADA by keeping the plaintiffs isolated in an institution against their will. The 11th U.S. Circuit Court of Appeals also agreed that the plaintiffs were discriminated against and, thereby, protected by the ADA. Georgia, in turn, appealed these rulings and the case went to the U.S. Supreme Court (Desonia, 2003).

In reviewing the case of *Olmstead v L.C.*, Justice Ruth Bader Ginsberg stated: "We confront the question of whether the proscription of discrimination may require placement of persons with…disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes." (Donlin, 2002, p.1) In a 6-3 decision, the Court ruled that states must "provide community-based treatment for persons with mental disabilities when the [s]tate's treatment professionals determine that such a 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 [s]tate and the needs of others with mental disabilities." (Toland, 2008, p. 1)

3 Reasonable Modification vs. Fundamental Alteration

In developing an effectively working plan to address the *Olmstead* requirements, states were required to make 'reasonable modifications', but not 'fundamental alterations' to their state long term care programs. States had difficulty distinguishing between the two, so the Court offered the following approach:

If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified individuals with…disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met (*Olmstead*, 527 U.S. at 605-06).

The condition of the Court's judgment referring to reasonable accommodations provides states with some protections. The Court ruled that the requirement that states provide services in the community is neither absolute nor limitless. With that said, there are exceptions in which a state would be allowed to discriminate according to the reasonable accommodations parameter. The Court provided that under the reasonable accommodation clause of Title II of the ADA a state would be allowed to discriminate if the suggested change would result in a fundamental alteration of the program (Desonia, 2003). In response to this ruling, the Court also had to develop parameters that would determine a fundamental alteration. For example, a proposed modification (e.g., a transition from an institutional placement into the community) would need to be extensive or costly enough to fundamentally alter the program. If it is

determined that a proposed modification constitutes a fundamental alteration, a state would, therefore, be relieved of the requirement to provide said services (Desonia, 2003). Given these considerations, the Court decided that in determining the existence of a fundamental alteration the decision will be made considering the state's need to serve others with disabilities, as well as the resources available to the state (Mathis, 2001). If, for example, a move towards community placement would result in a destabilization of the state's institutional structure, then the fundamental alteration defense would be plausible. Evidence of a destabilized institutional structure would be increased expenditures that could decrease services available to others in the state (Zendell, 2007). The interpretation of what constituted a fundamental alteration has led to the most litigation thus far.

4 Cost: How Much is Too Much?

The Medicaid program is the primary payor of long term care services and supports. Medicaid is a public assistance program that provides medical and long term care to low income individuals. The Medicaid program was created in 1965 and is financed by both the federal and state governments. Medicaid covers many health related expenses such as physician, hospital and prescription costs (Miller, 2003). The Medicaid program has an embedded "institutional bias", such that the provision of institutional placement to eligible individuals is a mandatory benefit, while the provision of home and community based services is an optional benefit. Spending on home and community based services has increased in recent years; however, institutional care still makes up 53 percent of the Medicaid long-term services and supports budget, whereas spending on home and community based services totaled 30.8% of the Medicaid budget (National Health Policy Forum, 2012).

The expansion of community-based programs under the Medicaid program is often at the center of the *Olmstead* debate. Medicaid allows states flexibility in service provision, but *Olmstead* requires that states expand their community-based services in a way that the Medicaid program does not require. This has led to a number of lawsuits in which states have argued that altering the flexibility that they have within their Medicaid program should be considered a fundamental alteration (Mathis, 2004). However, a significant majority of lawsuits have determined that cost alone does not amount to a sufficient fundamental alteration defense. In determining whether a plan for community integration would be too costly, a state's 'available resources' must be taken into consideration; that is, any resources or services that could be provided to an individual to ensure appropriate placement in the community. The *Olmstead Decision* does not place any limits on available resources; therefore, this could include all of the resources that the state has available to use. Resources beyond an agency's budget may be used as long as they may contribute to the ability to safely thrive in the community, including housing, health services, meals, and so forth (Mathis, 2004).

The determination of cost was essentially vague and led to the most ambiguity in the interpretation of the reasonable accommodations clause. Since state budgets vary so extensively in the provision of services to the disabled population, it is difficult to develop a uniform methodology for determining cost effectiveness (Desonia, 2003). As previously stated, Justice Ginsberg determined that there must be alternative ways for states to demonstrate their compliance with *Olmstead* requirements. The plans had to be comprehensive and emphasize placement in less restrictive settings. Further, if there are waiting lists for particular community-based services, it is required that these lists move at a 'reasonable pace', which should not be affected by the state's efforts to keep its institutions stable and populated (Desonia, 2003, p. 9).

The economic crisis that has affected the United States within the last several years has significantly worsened. There are budget shortfalls in every state across the country. Therefore, states have claimed it necessary for them to focus on low cost or cost neutral solutions in the move towards community integration. This is also a primary reason that states cite for their slow response to the *Olmstead Decision*. Many states have argued that home and community based services are more costly than institutional placement. Opponents of the expansion of home and community based services are concerned about the aggregate costs of this movement. There is further concern about the potential for a "woodwork effect", in which large numbers of individuals who are not currently receiving services may begin to seek services if they are offered in the community, leading to an overall increase in costs. Kaye, LaPlante, and Harrington (2009) conducted an analysis of state data on Medicaid Long Term Care spending between 1995 and 2005 in an effort to determine if home and community based services truly are more costly than institutional care on an aggregate level. States were classified in three ways according to their long term care spending patterns – states that spend under the median amount on home and community based services were identified as "low HCBS" and the remaining states as "high HCBS". Those states that were classified as "high HCBS" were further divided into two additional categories – "expanding HCBS", or states in which HCBS spending has doubled during the timeframe, and "extensive HCBS", or states which have traditionally been spending more in the area of home and community based services. The results found that states classified as offering extensive home and community based services experienced reductions in overall long term care spending relative to the other states. States that expanded their home and community based services during the study timeframe experienced an initial expense, which was eventually reduced as reliance on institutional services decreased, thereby reducing expense in this area. The study suggests that there is no additional cost associated with the expansion of home and community based services; in fact, there may be an eventual cost savings.

5 States Slow to Respond

The *Olmstead Decision* required that states must provide community-based alternatives to individuals when: (1.) the individual has been deemed eligible to live in the community by the state's treatment professionals; (2.) placement in the community is not opposed by the individual; and (3.) the placement can be reasonably accommodated, taking into consideration the resources available to the state as well as the needs of others (Kaiser Family Foundation, 2004).

States have been slow to respond to the Olmstead Decision, which has led to litigation as a means to achieve desired change. Per the Court's direction, states were mandated to comply with the *Olmstead Decision* by demonstrating an effectively working plan to transition individuals from institutions to the community (Kaiser Family Foundation, 2004). In the years following the *Olmstead Decision*, many states still had yet to develop or implement a plan to move disabled consumers out of institutions and into the community. Several states have spent a significant amount of time and effort developing *Olmstead* task forces and corresponding plans for community integration with little advancement. This is primarily a result of the lack of specific timeframes with regards to program implementation. (Mathis, 2004). Furthermore, some states claimed that they already had plans in place, while some argued the fundamental alteration clause of the *Decision*.

Another ambiguous term in the implementation language of *Olmstead* was 'reasonable pace'. For example, there were several lawsuits brought to the lower courts by individuals claiming that a state violated the 'reasonable pace' requirement of *Olmstead*, due to the fact that they

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had waited several years for community placement. The courts often ruled in favor of the states in these cases, as long as the state was demonstrating active and ongoing efforts to achieve community integration for persons with disabilities. The reason for the courts' majority rule in favor of the states is due to the overall inability to quantifiably define 'reasonable pace', which leaves them unable to require a specific action to be taken within a specific timeframe (Rosenbaum and Teitelbaum, 2004). Political analysts, Rosenbaum and Teitelbaum (2004), offer the follow explanation,

"(w)hen courts see forward motion – even if the forward motion is slow – they are more inclined to defer intervention. Furthermore, where courts are convinced that the issues they confront amount to a program redesign rather than program administration, their deference also is apparent." (p. 15)

At present, twenty seven states have developed formal Olmstead Plans and eighteen states have developed an acceptable alternative plan for transitioning people with disabilities into the community. However, there still seven states that have yet to develop an Olmstead Plan – Washington, D.C., Florida, Idaho, New Mexico, Rhode Island, South Dakota, and Tennessee (Ng, Wong, and Harrington, 2012). Political researchers have argued that, even though *Olmstead* has had a positive influence on policy development at the state level, there are still challenges that remain as states continue to work on implementing a plan that will truly address the intent of the *Olmstead Decision* (Hornbostel, 2005).

6 Defining Community Integration

One of the more essential tasks of developing an effectively working plan for community integration is to establish a clear understanding and/or definition of community integration. For example, a disabled person who is residing in an institution may have a particular idea of what they consider to be a community placement that could differ from what is considered appropriate or what is available. As part of their decision, the Courts ruled that states must provide community placement when the state's treatment professionals determine that such a placement is appropriate (*Olmstead*, 527 U.S. at 587). In order to determine appropriateness for community placement, these treatment professionals would be required to conduct a thorough assessment of the individual requesting such placement. Rosenbaum and Teitelbaum (2004) determined that treatment professionals should conduct two separate types of assessments: "liberty assessments" and "coverage assessments". Liberty assessments are necessary when an individual residing in a state-operated institution requests community placement. Coverage assessments are required when the individual is requesting the resources or benefits that are necessary to live in the community. Liberty assessments require the acknowledgement of basic due process. Moreover, these assessments tend to consider evidence that is more objective, such as observations by clinicians and reliable, valid assessment tools. Coverage assessments require a process that involves fact-finding to determine what resources or benefits an individual would need to live in the community and whether or not the state either provides or has the capacity to provide such services (Rosenbaum and Teitelbaum, 2004).

Situations do exist where a particular individual may not want community placement, in which case, states are not required to provide it. For instance, an elderly individual may prefer the socialization environment of a nursing home to the potential isolation that they could possibly experience in the community (Zendell, 2007).

7 Barriers to Community Integration

Fiscal Constraints: A primary component of the requirements of the *Olmstead Decision* is that it provides the states with the responsibility of implementing a plan at their own discretion. Throughout the history of long term care, the federal government has exhibited a bias towards institutional care. The Medicaid program involves two realms of services – those that are mandatory and those that are optional. States are required to offer mandatory services such as nursing home care, but can choose whether or not to provide optional service such as personal care. States disagree with the requirement to fund nursing home placements, while they have to apply for a waiver to provide home and community based care. A majority of states, along with the National Governor's Association feel that this requirement should be reversed – that Medicaid should fund home and community based services, while requiring a waiver for institutional care (Hornbostel, 2005).

It will be important for federal and state policy makers to determine an appropriate balance between home and community based and institutional care (Hornbostel, 2005). According to former director of the Medicaid program, Tim Westmoreland, as cited in Mulligan, "[W]aivers are a bad thing for people with disabilities because they allow keeping eligible people out, forming waiting lists at the door...and also allow very limited services to be provided [despite the fact that federal funds are used]" (2004). However, the *Olmstead Decision* did not require a change in Medicaid law that would end the existing institutional bias. As such, if community integration became a mandated service, it would result in significantly increased costs for state, which would be difficult for states to handle, due to recent economic constraints (Kaiser Family Foundation, 2004).

Workforce Shortages and Caregiving: The expansion of home and community based services will result in a greater demand on the current long term care workforce. There has been a history of frequent staff turnover and shortages in the human services workforce. These workers are often underpaid, poorly educated, without insurance, and are without many professional advancement opportunities (Zendell, 2007). As a result, positions in this field are not lucrative for those entering the workforce. The aging baby boom population will place a significant increase in demand on the long term care system. The area of personal care and home assistance was the fourth fastest growing occupation in 2006, increasing by 84.7 percent. Despite this considerable increase in need, it is not expected that the labor force will grow at a pace even close to that rate. This expectation becomes more daunting when considering that a majority of the current workforce is made up of middle aged women who will soon be retiring (Stone and Wiener, 2001).

Unpaid informal caregivers provide the majority of long term care services in the United States. This group is likely to reach 37 million in 2050, an increase of 85 percent from 2000. A significant proportion of caregivers are also working full or part time. Among baby boom aged caregivers, an estimated 60 percent are employed. The caregiving responsibility is also time-consuming. It is estimated that approximately one in five caregivers provide 40 or more hours of care per week. In a 2003 study it was determined that the average caregiving experience lasted four years. Caregiving responsibilities can lead to burnout, evidenced by physical and mental distress. There can also be a significant loss of finances, due to the high travel and out-of pocket expenses associated with caregiving (Selected Caregiver Statistics, Family Caregiver Alliance).

Service Availability, Accessibility, and Acceptability: The increasing fervor towards home and community based services may lead to a loss of focus on the importance of quality of care. In

determining the appropriateness of community placement, states and treatment professionals should not focus solely on justification, but also on service improvement. The long term care service delivery system has long been criticized for a lack of service coordination. Since an individual's functional capacity can vary throughout their involvement in the long term care system, it is essential that there be a continuum of care that exists. However, there are often service gaps present, which lead to eventual fragmentation (Wallace, 1990).

Many times an individual is found to be capable of living in the community; however, the particular service(s) that they may require is not available or accessible to them. Service availability, or lack thereof, is often attributed to state resources, workforce issues, waiting lists, and so forth. Service accessibility is generally related to the individual's personal finances or assets and their overall knowledge of long term care. A particular service may not be accessible to an individual because they cannot afford to pay for it and are also unable to rely on public funding.

Knowledge of the long term care system is of significant importance in regards to service accessibility. When many people think of long term care, they often think of nursing homes, or institutional care. Many are unaware of the availability of home and community based services; therefore they do not seek these services as alternatives to institutions (Wallace, 1990). Moreover, poor communication among providers contributes to further accessibility issues. Communications between hospital discharge planners, case managers, and other providers is essential in providing the necessary program linkages that individuals need to ensure an appropriate continuum of home and community based services. Communication problems often lead to a failure to disseminate the appropriate information about available services. A study of home and community based service delivery, conducted by Steven Wallace (1990), found that there was a great deal of variation in regards to the degree of knowledge concerning available home and community based services among professionals. If professionals in the field of long term care are unaware of the service options that exist in the community, it can be expected that it will be difficult for consumers and families to make informed decisions regarding care needs.

Finally, a consumer needs to be accepting of a particular service after they begin receiving it in order to ensure continued participation. Wallace's (1990) study also found several reasons that an individual might not be accepting of a service, which were typically related to the consumer's relationship with the worker providing the service. The primary reasons identified were: fear of theft, worker turnover, fear of dependence, and racial prejudice (Wallace, 1990). In regards to worker turnover, the relationship between the consumer and the worker appeared to be essentially important as it relates to acceptability. If worker continuity is not ensured, the consumer must rebuild trust with another worker every time there is a change. Often times the stress and vulnerability involved with this change leads a consumer to refuse further services. Many consumers feel that personal care is just one step closer to institutional care and, therefore, they deny services in order to avoid a perceived dependence. Further, they may view a reliance on a particular service, such as housekeeping or bathing, as a loss of independence, which they have yet to acknowledge. This is particularly true for the elderly populations, who have never relied on 'hired help' (Wallace, 1990).

Wallace's 1990 study on home and community based availability, accessibility and acceptability determined that social care needs, rather than medical, were most essential in avoiding institutionalization. However, the only place where an individual can access public

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programs that cover all of their supportive and basic needs is in the medically-based setting of a nursing home.

8 Suggestions for Change

Public Education: The definition of long term care is often ambiguous. Those in the professional field often have difficulty determining what services encompass long term care – are they generally acute services, or can they be social services, such as home modifications? The public tends to view long term care as care that is provided in a nursing home. Sometimes even professionals become acculturated to nursing homes as a first option. As described in Wallace's study (1990), this is often simply because there is a lack of knowledge about the existence of services within one's community. It will be important to change the perception of long term care and continue to combat the bias towards institutional care that exists within the consumer and provider worlds. To counteract this stigma and promote advocacy in favor of person-centered service opportunities and availability in the community, it is necessary to educate the community and providers alike on the new opportunities for community integration (Zendell, 2007).

Public education will also help reduce public stereotypes and prejudices, which often accompany community integration for those with disabilities. The mental health population is often confronted with these prejudices in the community. This is particularly due to the negative media attention that this population has received in recent years. The public is often exposed to cases in which this population presents a threat to the community. This fear results in the concept of 'not in my backyard'. Continued education is essential in order to redefine long term care as including community integration (Zendell 2007).

Ensuring True Community Integration: Sometimes community based settings, such as large apartments or supportive living environments, can promote segregation and prevent a true 'community' experience. On the other hand, some disabled individuals prefer this type of setting, since they are able to access necessary services on-site. These types of settings can also provide more opportunities for companionship and socialization (Coalition, 2003). With this in mind, it is important that states avoid creating segregated communities in their attempt to comply with the *Olmstead Decision*. It is also important to promote consumer choice and self determination in determining the type of setting most appropriate for an individual (Zendell, 2007).

Diminishing Service Fragmentation: To ensure a successful transition to the community there needs to be a holistic pattern of service delivery. A disabled person often requires an array of services, such as housing, personal care, social supports, transportation, and employment opportunities, in order to safely live in the community (Zendell, 2007).

A community also needs to be prepared for potential integration. States will want to avoid the adversity experienced when large numbers of state psychiatric hospitals began closing in the 1960's through the 1970's. The community was unprepared for these mass closures and, thus, individuals were unable to access the services that they required upon transition into the community. As a result, they ended up back in institutional settings that were inappropriate for their needs or homeless, without any services at all (Herbert and Young, 1999).

Professionals need to ensure that a disabled individual that is transitioning into the community has access to the appropriate ongoing services in the community. Many times they need to learn, or re-learn, the basic skills necessary for maintaining stability in the community, such

as cooking, cleaning, budgeting, and basic decision-making. It will be necessary to make certain that these services are available, or that they can be designed or advocated for under *Olmstead* (Zendell, 2007).

Assuring Adequate and Continuous Funding: Since Medicaid covers a majority of long term care services, it is critical that a balance between home and community based services and institutional care is established. Since the need for long term services and supports can be life-long, it is equally important to ensure funding through various developmental and care transitions. For example, when a child graduates high school, they make the transition from school-age services to adult services, both of which have different funding streams. Transitions from one funding stream to another often results in a risk of losing a particular service, thus affecting the overall assurance of ongoing community integration (Zendell, 2007). As a result of this fragmentation in funding streams across transitions, many states, along with the federal government, are advocating for a more person-centered, rather than service-centered approach to funding. A more recent approach has been a money follows the person system, in which funding is allocated to an individual based on their needs, such that it 'follows' them through their particular care transitions (Crispell, Eiken, Gerst, and Justice, 2003).

Comprehensive Assessments: This paper has discussed the importance of the assessment process in determining readiness and appropriateness for community placement. In the *Olmstead Decision*, The Supreme Court deferred the recognition of one's ability to live in the community to the state's treatment professionals. Since their assessment determinations are so heavily weighed, it is important to develop uniform assessment tools that can be used across discipline, disabilities, and age groups (Cohen, 2001). These assessment tools should be comprehensive and designed to determine whether an individual is capable of living in the community, as well as the consumer's goals relative to the various long term care options that may be available to them (Zendell, 2007).

Dealing with Workforce Shortages: One of the primary issues identified by professionals and consumers in expediting transition into the community is the current workforce shortage. In order to provide quality and continuous in-home care to people with disabilities, this issue needs to be addressed. As discussed, there are several reasons for the lack of a sufficient workforce and the retention difficulties that exist with the current workforce. These workers tend to be poorly educated, un- or under-insured, and underpaid, with no opportunities for advancement (Coalition, 2003). States have adopted several different strategies to deal with this issue. Some states have established "wage pass-throughs" in which a portion of the state's long term care budget is allocated towards increased wages or benefits for front-line workers. Consideration has also been given to the issue of insurance. A state-subsidized health insurance program would be a method of ensuring access to health insurance for staff. Further, some states are increasing fringe benefits, such as health insurance, for workers (Stone and Weiner, 2001). To increase opportunities for advancement, several states are offering certification programs, training programs, educational grants and student loan deferments. Some innovative solutions involve the reimbursement of non-immediate family members who provide services in the home or allowing consumers to hire their own staffing (Zendell, 2007).

Addressing the Need for Public Advocacy: It is essential that the *Olmstead Decision* be kept in the forefront of public policy issues for it to be successful in shifting the focus of long term care from institutions to home and community based care. This can occur through community

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organization and education. A focus on collaboration and partnerships with other advocacy groups, such as AARP, National Alliance on Mental Illness (NAMI), and ARC should be central when educating the public about *Olmstead* and developing an effective plan for its implementation. Public education efforts should focus on dismissing the myths and stereotypes that exist regarding people with disabilities. It will be important to obtain buy-in from politicians, special interest groups, providers, advocates and others regarding the plan for implementation. These groups should be educated on the various benefits of community itegration (Zendell, 2007).

A Phased-in Approach to Implementation: An *Olmstead* implementation plan be incremental in its approach. The goals set forth in the plan need to involve measurable objectives that are delivered within a specific timeframe. The objectives and timeframe should be laid out according to the developments of the various barriers outlined in this paper. Those involved with plan implementation should be observant of the occurrence of any one of these barriers, such as ill-prepared community integration, as implementation proceeds. The planning teams and collaborations that were developed should be maintained to assist in identifying barriers and ensuring continued success (Zendell, 2007).

9 Positive Influences of Olmstead

Real Choice Systems Change Grant: The *Olmstead* requirement that states develop a plan to address deinstitutionalization led to a distinctive opportunity for disabled consumers to voice their opinions about service delivery and have an impact on the development of state policy. The federal government, through the support of activities such as the "Dear State Medicaid Director" letter writing campaign, encouraged this opportunity. Furthermore, the federal government provided opportunities for increased funding for states through specific grants, such as the Real Choice Systems Change grant. The Real Choice grant requires the development of consumer task forces that provide an arena for disabled consumer to be at the table and contribute towards policy development. This increased consumer involvement also resulted in a unification, bringing together disabled individuals of all ages and impairments (Hornbostel, 2005).

Increased Consumer Choice: In addition to the increased demand for home and community based services, there has also been a recent movement toward consumer-directed care. This method of care encourages consumer choice and empowerment over the types of services that they receive (Batavia, 2002). The consumer-directed care model, also referred to as the independent living model, is the preferred model of long term care among the disabled population, particularly the young and working-age population, since it gives them more control over their lives (Batavia, 2002).

Redefining Long Term Care: Long term care has consistently been difficult to define by professionals and consumers alike. It is unlike many other medical services, in that it often encompasses several aspects of a person's life, often for the rest of their life (Batavia, 2002). However, the shift in focus from institutional, medically focused care to home and community based care provides a more thorough view of long term care. This re-defined view of long term care recognizes that people with disabilities want to be integrated into the community with full access to employment, transportation, affordable and accessible housing, and consumer empowerment.

The Patient Protection and Affordable Care Act: In 2010 President Barack Obama signed into law the Patient Protection and Affordable Care Act (ACA), which expands access to

affordable, quality health care in the United States. The ACA contains several provisions to ensure that older adults and people with disabilities are provided the option to receive long term services and supports in the community. The legislation provides financial incentives to states to offer increased home and community based services options by allowing them more flexibility in funding home and community based care without the need for a waiver (Administration on Aging, 2010).

Money Follows the Person Program: The Money Follows the Person Program (MFP) was established in 2005 and was extended through 2016 as part of the ACA. The MFP allows Medicaid recipients residing in institutional settings to use their Medicaid to fund a transition into the community. This transition does not require the use of a state's waiver slot, which benefits both the individual and the state by freeing waiver slots and eliminating the need for the individual to be placed on a waiting list for an available slot (Floersch, Kramer, Nelson, Rosenthal, and Spira, 2011).

10 Conclusion

The *Olmstead Decision* was the primary catalyst in enforcing a shift in focus from institutional care to home and community based services. It has been heralded as the *Brown v. Board* of Education for the disabled community. The *Decision* provided the legal groundwork to ensure access to necessary programs and services that will support persons with disabilities right to live in the community, in order to support their dignity and independence.

This paper has provided an overview of the parameters of the *Olmstead Decision*, as well as suggestions for addressing existing barriers to implementation. Since the *Decision*, there have been several federal initiatives that support the delivery of long term services and supports in the community. Efforts to reinforce the importance of adhering to consumer choice and the provision of quality care in the United States are consistent with those of the United Nations (UN) and the international community. The UN has established the Convention on the Rights of Persons with Disabilities, which followed several decades of work to change attitudes and behaviors and approaches to care for persons with disabilities. Similar to the ADA, the intent of the Convention is to serve as a broad human rights instrument that protects and supports the rights of persons with disabilities (UN, 2013).

The issue of disability rights is universal; therefore, political advancements and reform efforts to support consumer access will have far reaching implications. If the values driving the *Olmstead Decision* continue to remain a priority to consumers, politicians, and providers, both in the United States and abroad, then it will be successful in enforcing the necessary change that will support an individual's right to live in their community for as long as possible.

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