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Single Point of Entry for Long Term Care and *Olmstead*: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations

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How can I stay in my home?

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Executive Summary

Since the early 1990s, states across the U.S. have been implementing or considering single points of entry for long term health care. These points of entry (POEs) vary greatly in scope and implementations. However, as the name implies, they generally involve the development of a single entry point through which consumers in the state are able (and generally required) to use to access the care they need. Functionally, a POE generally provides one place for information and referral, one place to find out about and apply for services, and one place to evaluate and provide service recommendations.

In addition to the national trending towards POE implementation, the Supreme Court ruling in *Olmstead v. L.C.* laid the foundation for monumental change in long term care access and delivery in the U.S. *Olmstead* established that the unjustified institutional isolation of people with disabilities is a form of discrimination under Title II of the Americans with Disabilities Act (ADA) of 1990. In effect, this means that, unless necessary, the institutionalization of individuals eligible for publicly funded programs is prohibited. Since two out of three nursing home residents in the U.S. have their care paid for by Medicaid, it is easy to see how significant the impact of *Olmstead* will be.

In order to learn about POE & *Olmstead* developments nationally, and gain insights into their successes and/or failures from a consumer perspective, we studied POE and *Olmstead* implementation across the U.S. and conducted a survey of groups that work to improve care for consumers in the states that have implemented a POE. Below are highlights from our study of POE implementation, our survey and our study of Olmstead implementation with recommendations for policy makers and consumers:

Highlights From National Report on POE:

- Almost half of all states have a POE for long term care.
- Five principal issues drive states' development of a POE for long term care:
    - *to decrease state spending on long term care;*
    - *to reduce system fragmentation;*
    - *to increase knowledge and coordination of available services;*
    - *to respond to consumer demand for community based services;*
    - *to respond to dictates of the Olmstead decision.*
- There are two basic philosophies guiding POE design:
    - *One-Stop Shop: Consumer-centered information system providing comprehensive information and support on long term care services and benefits in one place.*
    - *No Wrong Door: Focuses on the delivery of information to consumers regardless of where they first enter or encounter the system.*
- Most POEs determine financial as well as functional eligibility for services.
- Most POE states also provide Older Americans Act services such as personal care, homemaker services, home-delivered meals, and transportation assistance.
- Funding sources for POE programs are diverse.

- The Report concludes with case studies of two diverse states with POE: New Jersey, with a densely populated and highly diverse population, and Colorado, with a more rural and homogeneous population.
    - *Colorado reports that since origination of its statewide POE system, "participation in home and community-based services has more than doubled while the number of nursing home residents has been stable." The major weaknesses identified in the Colorado system were a lack of coordination across the different county POE systems and, according to consumer surveys, dissatisfaction with case managers not arriving on time or missing appointments.*
    - *The New Jersey program provides a toll-free number. Consumers can get information about public or private assessments services in their area, which are done at no cost, but are not assessed by the POE itself. Since implementation of the POE, New Jersey has doubled the amount of public resources used for home and community based services. However, long wait lists are one of the major weaknesses identified in New Jersey.*

<u>Highlights From National Survey of Community Groups:</u>

Summary of Benefits Reported by Survey Participants:

While there are a range of problems and issues for consumers faced with a single point of entry for long term care, it is clear that the consumer groups and ombudsmen we spoke to believe that the POE has had a generally beneficial impact on long term care consumers. The benefits reported to us include: greater choice for consumers, access to more appropriate services and care, more community placement and less institutional placement.

Recommendations on POE:

- Only thirteen out of the eighteen groups agreeing to participate knew anything about the POE program in their state: indicating a need to better educate and inform consumer and community organizations.
- The five groups that were involved in the development of the POE in their states listed a number of important ways that community groups can and should be included. States developing and implementing a POE program should consider these.
- Only four groups stated they were involved in the implementation. Since they are the groups that are involved in a daily basis educating consumers, it only makes sense for the state to involve them.
- The variety of communication methods being utilized, coupled with the vulnerability of long term care consumers as a group, indicate that further research is needed to determine the effectiveness of the different methods and identify best practices to ensure that those who are in need of long term care do not "slip through the cracks."
- Although the general consensus was that waivers have been beneficial by helping many consumers receive the services they need, POEs are a relatively recent phenomena. Almost half of the respondents to this survey did not know of a Medicaid waiver in their state. It might be too early to say what the long term impact on

consumers will be. This is an important part of POE programs that will need to be carefully evaluated as time goes by.
- As POE programs progress, there is a need to conduct research related to consumer benefits and negative outcomes related to reducing Medicaid costs and changing Medicaid eligibility in addition to waivers.
- A number of the respondents reported that alternative services were lagging behind the POE implementation. This indicates that capacity building – ensuring that appropriate services and housing are available in the community – will be critical.

Highlights from National *Olmstead* Compliance Report:

- States have been slow to take concrete steps to comply with the *Olmstead* decision. The tension between compliance with *Olmstead* and state efforts to control and/or cut costs has often slowed proposals to implement *Olmstead*.
- Olmstead compliance within the Medicaid program is primary focus of the states.
- There are key barriers to more community based services: Medicaid's institutional bias and lack of affordable, accessible services in many communities.
- Litigation has been key to getting states to implement *Olmstead*. However, it is no magic bullet. Enforcing rulings and expanding the benefits beyond the designated class of plaintiffs has proven difficult, thus litigation should be viewed as a last resort.
- Elderly consumers are often unable to benefit from *Olmstead* litigation. Most judicial decisions have been directed toward those with mental & developmental disabilities.
- Use of Medicaid waivers by the states has resulted in many consumers receiving home and community based services. However, due to capping of available funds and other constraints, consumers frequently face long waiting lists. Many policy makers are worried that expansion of home and community-based services will create even longer waits. The expansion may produce a very expensive "wood work effect" triggering many long term care users relying upon informal care to switch to government subsidized services.
- Several states are exploring single points of entry (POEs) to disseminate information and assist with assessment, referrals, and case-management to help comply with *Olmstead*.
- To successfully ensure proper placement in the least restrictive setting and address the growing demand for home and community-based services, local, state and federal governments will have to face the realities of an aging population, decreased supply of female informal care givers and long-term care workforce shortages along with many other barriers that reinforce an institutional bias.

Recommendations on Olmstead compliance:

- Future efforts to comply with *Olmstead* should include stakeholders such as consumers, family members and advocates to guarantee access to the most integrated setting possible. Planning should be based on need, utilization and quality assurance.
- Examining and adapting best practices used throughout the country can provide valuable information in developing, revising and implementing an *Olmstead* Plan.
- Policy makers and consumers must make sure that any POE program fulfills the mandate of the *Olmstead* decision.

Single Point of Entry for Long Term Care and *Olmstead*: An Introduction and National Perspective for Policy Makers, Consumers Organizations

Introduction

Since the early 1990s, states across the U.S. have been implementing or considering single points of entry for long term health care. These points of entry (POEs) vary greatly in scope and implementations. However, as the name implies, they generally involve the development of a single entry point through which consumers in the state are able (and generally required) to use to access the care they need. Functionally, a POE generally provides one place for information and referral, one place to find out about and apply for services, and one place to evaluate and provide service recommendations.

In addition to the national trending towards POE implementation, the Supreme Court ruling in *Olmstead v. L.C.* laid the foundation for monumental change in long term care access and delivery in the U.S. *Olmstead* established that the unjustified institutional isolation of people with disabilities is a form of discrimination under Title II of the Americans with Disabilities Act (ADA) of 1990. In effect, this means that, unless necessary, the institutionalization of individuals eligible for publicly funded programs is prohibited. Since two out of three nursing home residents in the U.S. have their care paid for by Medicaid, it is easy to see how significant the impact of *Olmstead* will be.

In order to learn about POE & *Olmstead* developments nationally, and gain insights into their successes and/or failures from a consumer perspective, we studied POE and *Olmstead* implementation across the U.S. and conducted a survey of groups that work to improve care for long term care consumers in the states that have implemented a POE. The following report is divided into three sections: Section I addresses POE implementation across the country; Section II presents our survey of consumer groups in states with a POE and Section III addresses implementation of the *Olmstead* decision across the country.

Section I
Single Point of Entry for Long Term Care: A National Overview and Perspective

Introduction

State policymakers have been considering and/or implementing single point of entry (POE) systems for long term care since the early 1990s. These systems, which are also known in different states as "single entry point," "aging single access point," "options for long term care," and "single point of contract system,"[1] share a common, fundamental attribute: to require consumers to access long term and supportive services through one agency or organization. However labeled, POE consideration focuses policymakers on recognizing that services are commissioned and purchased, not just provided.[2] Functionally, a POE generally provides one place for information, referral and advocacy, one place to find out about and apply for services, and one place to evaluate and provide service recommendations.[3] Additionally, a POE can:

> Perform a range of activities that may include initial screening, nursing facility preadmission screening, assessment of functional capacity and service needs, financial eligibility determination, care planning, service authorization, monitoring, and periodic reassessments. A [POE] may also provide protective services.[4]

Currently, 43 states have a POE system for various service categories, 24 of those states have a POE system for long term care. [Long term care may in most states include individuals age 65+, while a few states include individuals age 60+.] Additionally, another four states are in long term care POE development stages with plans for near future implementation.[5] The experiences in the states that have developed or are beginning to develop such a system provide information and insights into relevant state processes and the disparate costs and benefits of POE systems. Below is a detailed account of POE implementation across the country. It is followed by our survey of consumer perspectives in the 24 states with a POE system for long term care (Section II).

Origins of POE

States' motivations (whether officially acknowledged or undeclared) for developing a POE vary, but can basically be attributed to five distinct issues: 1) The desire to reduce money spent on long term care or prevent health care costs from rising; 2) The problem of

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[1] Department of Health and the Office for Aging. "Request for Information: NY ANSWERS: A Point of Entry System for Long Term Care in NYS." May 2004. NYSDOH.
[2] Simpson, Dennis, Specialist; Advisor to Department of Health. Speech: "The Future of Health & Social Services for Older Adults in Great Britain." May, 1998. UC Berkley Campus.
[3] Reinhard, Susan C. and Scala, Marisa. "Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States." 2001. Institute for the Future of Aging Services, Washington D.C.
[4] Eiken, Steve and Heestand, Alexandra. "Promising Practices in Long Term Care Systems Reforms: Colorado's Single Entry Point System." December 18, 2003. Medstat Research and Policy Division, Baltimore, MD.
[5] Mollica, Robert and Gillespie, Jennifer. "Single Entry Point Systems: State Survey Results." August 2003. The Institute for Health, Health Care Policy, and Aging Research.

fragmentation of services and funding sources; 3) Lack of coordination and knowledge about long term care services; 4) Consumer demand for community based services, rather than institutional care; and 5) The U.S. Supreme Court's *Olmstead* decision, which requires states to provide long term care in the least restrictive setting for each individual.[6] Additionally, Medicaid programs "pay for almost half of long term care expenditures – 38 percent in 1998[7] – and therefore play a major role in shaping access to and the quality of these services."[8] Hence, policymakers have trended towards POE systems to restructure and streamline service access and delivery.[9]

POE systems are generally founded on one or both of the following philosophies:

- "One-Stop Shop" consumer-centered information system. This provides comprehensive information and support to encourage informed decision making on long term care services, supports and benefits. Coordination, integration, and linkages of care services are seen as necessary to service the diversity of consumers; *and*
- "No Wrong Door." This evolved from one-stop shop and is focused on the delivery of information to consumers regardless of where they first enter or encounter the system. This type of system tends to rely heavily upon technology that brings together services and funding streams.

Today's POE programs combine these philosophies in varied amounts and create systems that: 1) Provide information and assistance; 2) Streamline the application process; 3) Address eligibility; and 4) Monitor/oversee services.[10]

General POE Characteristics

In 43 states, POE systems provide services to the various populations including: the elderly (24 states); people with disabilities (22); people with mental retardation or developmental disabilities (20); traumatic brain injury patients (13); children with special needs (7); HIV/AIDS patients (6); mental health patients (6); and others (3). Some states serve multiple populations, while others only offer services to a specific population. State field offices, county offices, community-based nonprofits, Area Agencies on Aging, or even case management subcontractors provide services individually or in conjunction with other agencies, dependant upon a state's legislatively determined structure.[11]

Over seventy percent of the 24 states providing a POE for the elderly population determine both financial and functional eligibility. Elder care services are often needed during times of crises, thus the ability to determine both elements of eligibility in one step rather than

[6] See Section III on *Olmstead* implementation in this report.
[7] Kaiser Commission on Medicaid and the Uninsured. *Facts*. March 2001, Washington D.C.
[8] Mollica, Robert and Gillespie, Jennifer. "Single Entry Point Systems: State Survey Results." August 2003. The Institute for Health, Health Care Policy, and Aging Research.
[9] Aging and Disability Resource Centers. "Streamlining Access to Long Term Care" July 11, 2004. 29th Annual n4a Conference. Atlanta, Georgia.
[10] Dize, Virginia; Associate Director, National Association of States Units on Aging. Speech: "The National Perspective on Long Term Care Reform," November 30, 2004. Albany Marriott, Albany, NY.
[11] Mollica, Robert and Gillespie, Jennifer. "Single Entry Point Systems: State Survey Results," August 2003. The Institute for Health, Health Care Policy, and Aging Research.

multiple steps can be a comparative advantage over alternatively structured programs.[12] However, as reported by some program administrators, prospective consumers and their families may be unable to properly assess their needs during a crisis due to the traumatic nature of the event. Therefore, appropriate outreach and marketing is necessary to capture these individuals before their crisis occurs.

Along with POE services, fifty-four percent of the states provide Older Americans Act services, which may include personal care, homemaker services, chore services, home-delivered meals, adult day care, and transportation assistance.[13] As with any program, unsuccessful implementation may lead to ineffectiveness. Thus, POE effectiveness, from a system-wide perspective, is predicated upon the ability to properly and sufficiently inform consumers, family members, professionals, and associated stakeholders of its existence and of its appropriate, functional options.

POE Funding

Funding for POE systems and the services provided to consumers comes from multiple sources, including (in order of prevalence across states): Medicaid Home and Community Based Services waivers; Medicaid State plans; Older Americans Act; Social Services Block Grants; State General Revenues; County funds; and fees from those who are not eligible for subsidies. Various states have explored and implemented controversial funding practices. For example, Texas and Vermont use rebalanced funding to aid in shifting funds from institutional to community services.[14] Oregon,[15] and Washington,[16] employ pool funding to shift funds between nursing facilities and home and community based services (HCBS) programs. Alaska[17] has experimented with an individual budget program, where participants are trained to select and manage their personal assistance services.

Case Studies

Due to the varying scope of POE systems, as well as variations in populations and regions served, there are significant distinctions among states' POE origination and activities, as well as their individual strengths, weaknesses, successes and failures. In order to provide insights into the range of POE possibilities, following are in-depth accounts of the POE programs in two states, Colorado and New Jersey.[18] Colorado was chosen because it is representative of more rural and homogenous states and its POE, widely considered to be highly successful, has been in place for over a decade, and is continually altered to better deliver POE services.

[12] *Id.*
[13] *Id*.
[14] Crisp, Suzanne et al. "Money Follows the Person and Balancing Long-Term Care Systems: State Examples." September 29, 2003. Medstat: Research and Policy Division, Washington D.C.
[15] Center for Medicare and Medicaid Services. "Promising Practices in HCBS: Oregon - Maximizing Participant Control Over Services." January 2002. Baltimore, MD.
[16] Center for Medicare and Medicaid Services. "Promising Practices in HCBS: Washington – Facilitating Nursing to Community Transitions." June 2004. Baltimore, MD.
[17] Coleman, Barbara et al. "State Long-Term Care: Recent Developments and Policy Directions, 2003." July 2003. National Conference for State Policy Legislators.
[18] Other informative and comprehensive assessments can be found for Indiana, Minnesota, and Wisconsin, and more limited information for other states on the Center for Medicare and Medicaid Services website: http://www.hcbs.org/browse.php/topic/.

New Jersey was chosen because we felt it is representative of more diverse and densely populated states; its POE was more recently developed and implemented. Together, we believe that they represent the range of populations served in the country as well as in our home state of New York, which has a densely populated and diverse downstate and a more homogeneous and rural upstate. Like a number of other states, New York is at the early state of planning for a POE.

Colorado

In the 1980's, Colorado long term care consumers reported a lack of information, varying eligibility requirements per program, varying service options, and a fragmented system. A policy group that included management from the Colorado Department of Social Services (which administered long term care programs) and information from a Long Term Care Advisory Committee – consisting of providers, county staff, county elected officials, Area Agencies on Aging (AAA) and advocates – recommended a reform plan in 1989, which included a provision for a POE (referred to as SEP – single entry point – in Colorado). Supported by a Long Term Health Care Task Force, developed by Colorado's General Assembly, a law was passed in 1991 to establish a POE system.

Implementation of the POE was incremental, but by 1995, every Colorado County had a POE for consumers to enter in order to qualify and gain access to all long term care services provided under Medicaid as well as programs solely funded by the state. The Colorado Division of Aging & Adult Services (AAS) oversees this system, and it sets statewide rules and coordinates the activities of 25 local agencies across Colorado. These agencies are county departments of social services, county health departments, or private non-profit organizations. Colorado counties administer three Medicaid waiver and two state-funded programs. The state had encouraged the formation of multi-county districts in order to promote efficiency and achieve economies of scale. In addition, the state contracted with an economist to determine where counties must break even in order to avoid increasing state payments for assessment and case management.[19]

Eligibility for services is based on a person's functional capacity score, as determined by assessing their ability to participate in activities of daily living (such as bathing, walking, eating or using the toilet), instrumental activities of daily living (such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework or using a telephone), and cognitive measures. In addition, a person must require help at least five days a week. Other issues are considered as well, such as the need for skilled treatments, therapies and rehabilitation services. Care managers (who are usually social workers) working in the POE agencies conduct the assessments and send them to the Colorado Foundation for Medical Care (CFMC), where a licensed health professional, usually a registered nurse, determines and recommends the level of care needed by the individual.[20] The determination/recommendation is returned to the care manager who then

[19] Paragraph was paraphrased from: Eiken, Steve and Heestand, Alexandra. "Promising Practices in Long Term Care Systems Reform: Colorado's Single Entry Point System." December 18, 2003. Medstat, Research and Policy Division, Baltimore, MD.

[20] Stevenson, David G. and Wiener, Joshua M. "Long-Term Care for the Elderly: Profile of Thirteen States." August 1, 1998. Urban Institute's Health Policy Center.

meets with the consumer to develop a care plan and to set up services. Their case manager contacts consumers who remain in the home, at least quarterly, in order to identify any potential changes in their needs. The case manager, aside from being available to be contacted by the consumer, must perform a face-to-face evaluation with the consumer at least once every six months.[21]

Since the POE's inception, Colorado has employed a system of continual process evaluation. Evaluation is made by two different entities – through the Medical Advisory Committee (which consists of providers and consumers) and through Community Advisory Committees (made up of county commissioners, county staff, medical professionals, providers, consumers and representatives from AAA and the Long Term Care Ombudsman Program).

As reported by Colorado, since origination of the statewide POE system, "participation in home and community-based services has more than doubled while the number of nursing home residents has been stable." Their combination of functional and financial eligibility tasks enables the program to manage care closely, to ensure that it is appropriate and to control spending. Importantly, the state's contractual relationship with POE agencies allows for quality control of case managers and providers and gives the state authority to fire or fine those providing poor service. Additionally, based on previous utilization, the Department of Health Care Policy and Financing (HCPF), limits payment to POE agencies, thus inhibiting manipulation of the payment system.[22]

From a program implementation assessment perspective, state staff reports indicate no increase in HCBS program administrative costs due to transition to a POE, and a reduction of duplicative services. Colorado officials continue to further integrate services, expand capacity, and strive to improve assessment and case management.

The major weaknesses identified in Colorado's system are the lack of coordination across the different county POE systems and dissatisfaction with case managers not arriving on time or missing appointments, as indicated most frequently by consumer surveys.[23] Lastly, Colorado's POE system and its development have continually been identified in the Centers for Medicare and Medicaid Service *Promising Practices* series.

<u>New Jersey</u>

New Jersey's proportion of older adults to total population is slightly higher than the national average.[24] In 1994, New Jersey's Governor Christine Todd Whitman began to explore ways to redesign and rebalance home and community-based services and the delivery of information about long term care to consumers. The goal was to address consumer frustration with the present system (rather than respond to the growing needs of an

[21] Eiken, Steve and Heestand, Alexandra. "Promising Practices in Long Term Care Systems Reform: Colorado's Single Entry Point System." December 18, 2003. Medstat, Research and Policy Division, Baltimore, MD.
[22] *Id.*
[23] Center for Medicare and Medicaid Services. "Promising Practices in HCBS: Colorado – Simplified Access to Nursing Home Alternatives." June 2004. Baltimore, MD.
[24] Reinhard, Susan C. and Fahey, Charles J. "Rebalancing Long-Term Care in New Jersey: From Institutional Toward Home and Community Care." March, 2003. Milbank Memorial Fund.

increasingly elderly population), which was identified as confusing, fragmented, multi-tiered, and duplicative. As a result, New Jersey Easy Access, Single Entry (NJEASE) was created. This POE system, which was implemented, according to the state, "to offer older adults of all income levels and their families 'one-stop shopping' for health and social service needs."[25] Program service responsibilities were designated in a manner similar to Colorado. Each county was responsible for creation of their individual model and received state support for training and technical assistance. The state's active involvement is limited to activities like spearheading development of computerized systems for assessment and resource collaboration, including Helpworks, "a web-based software that will computerize the benefits screening process," and Factors, "care management tracking software for care managers."[26]

As mentioned above, NJEASE functions on a county level. Consumers call the NJEASE nationwide toll-free number, which recognizes where the consumer is calling from and automatically transfers the consumer to the appropriate county agency. Live representatives are available from 8:30am – 4:30pm and any calls received at other times are answered by recording with instructions for operating hours or emergency services. For example, Union County serves 48 different language-speaking consumers who are serviced by assistance/outreach specialists. Consumers receive general information about public or private services and/or agencies and may have their needs assessed by the specialist who uses a Comprehensive Assessment Tool (CAT) - a uniform evaluation method. Additional options include the ability to be visited at home by a care manager, more intensive care manager assessment, and arrangement of services.

All assessments are free of charge and available to consumers of all income levels. However, NJEASE employees do not assess either financial or functional eligibility. There is a wide range in elapsed time for financial eligibility determinations, thus, wait lists for public programs are known to have been created. To service these consumers as well as middle and upper income consumers who do not financially qualify for Medicaid, Jersey Assistance for Community Caregiving (JACC) was implemented in 2000. As a state-funded, sliding scale home care program, JACC allows these older adults, in a consumer-directed model, the ability to hire family members and friends. Lastly, to expedite eligibility determinations conducted by the County Board of Social Services, NJEASE provides a list of documentations that consumers will need.[27]

An impact assessment of NJEASE has not been formally conducted at this time, yet there are preliminary reported findings that indicate a positive movement towards community based services. Since the arrival of NJEASE, public resource reliance on nursing homes has been reduced from 92.7 to 84.7 percent, while public resources dedicated to HCBS more than doubled, 7.3 to 15.3 percent. Also, the number of people on Medicaid in nursing homes dropped ten percent between fiscal year 1997 to fiscal year 2002.[28] From an activity level,

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[25] *Id.*

[26] Reinhard, Susan C. and Scala, Marisa. "Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States." 2001. Institute for the Future of Aging Services, Washington D.C.

[27] Paragraph was paraphrased from: Reinhard, Susan C. and Scala, Marisa. "Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States." 2001. Institute for the Future of Aging Services, Washington D.C.

[28] Reinhard, Susan C. and Scala, Marisa. "Navigating the Long-Term Maze: New Approaches to Information and Assistance in Three States." 2001. Institute for the Future of Aging Services, Washington D.C.

county managers report increased consumer choices; increased familiarity of service options amongst specialists and care managers; creation of stringent policies for interactions with consumers and their families; and increased specialist sensitivity towards consumers.

Less positive reported results included: NJEASE experienced difficulties in coordinating the telephone system; appropriately preparing for the increased demand, including experiencing a lack of manpower; limited establishment of web-based information; and the need to improve promotion of the system in the community. Finally, the development of a lengthy wait list has created debate whether it is a positive indicator of resident use of NJEASE or a negative indicator of inefficiency and is merely a substitute for pre-program system frustrations.[29]

While New Jersey's POE program has improved the landscape for consumers, future challenges, which New York and other states can learn from in developing their own systems, include: 1) implementation problems of NJEASE; 2) inconsistent policies among Medicaid waivers, services, and caps; 3) states' economic constraints; 4) continued fragmentation of some home care programs; and 5) the need for stronger tracking and accountability systems.

Conclusion

A single point of entry system has been introduced and used across the country in various states and settings. Literature supplied by the New York State Office for the Aging (NYSOFA) and the New York Department of Health (DOH) indicate that New York State is planning to implement its own POE. Therefore, consumers and their advocates should focus now, not on whether it is a good idea to have a POE or not, but on determining the activities and functions of a POE system that best ensure quality and cost effective care that provides the most independence possible. We recommend that consumers actively seek to be part of the process, which the NYSOFA and NYSDOH expect will include widespread stakeholder consultation.

Once part of the process, consumers and their advocates may want to focus their efforts on making certain a POE system is: administrated locally by one agency, including either single or multi-counties; providing multiple access points to all information and assessment; and using a consistent, state determined evaluation/assessment tool. A system that includes a form of Colorado's contractual relationship with its administering agencies may provide NYS consumers with established protocols for maintaining delivery of unbiased, comprehensive, and efficient information and assessment. In developing such a system, we can allow local agencies to work with local consumers, autonomously, thus providing consumers with information and assessment that is more relevant and sensitive to their needs. At the same time, these local agencies will ultimately also be responsible to the State, its agencies and legislators and therefore are encouraged to achieve program goals of delivering unbiased, comprehensive, and efficient services.

[29] Paragraph was paraphrased from: Center for Medicare and Medicaid Services. "Promising Practices in HCBS: New Jersey – Single Access Point for Information on All Services for Older People." June 2004. Baltimore, MD.

If the POE is to significantly affect delivery of long term care then another recommendation is needed. It is important to develop a well-marketed and publicized system that is available to consumers in multiple languages and formats and can easily transfer information across the state to various local agencies and/or care managers, possibly through a web based data management system similar to New Jersey's. Lastly, consumers and their advocates should continue to encourage their states to address serious long-term staff shortages and the quality of care being delivered. POE implementation should be a phase of system reform and improvement rather than the sole component.

Section II
National Survey Of Advocates And Ombudsmen on POE for LTC

In order to gain insight into long term care single point of entry (POE) systems from a consumer perspective, the Long Term Care Community Coalition conducted a nationwide survey of state Long Term Care Ombudsman Programs and Citizen Advocacy Groups in states identified as having a POE for long term care recipients. The survey focused on ascertaining the perceptions and experiences of these community groups and gaining insights into how these groups were – or were not – involved in the planning and implementation of POEs in their states. This section of the full report adds a unique perspective from people who are dealing with these issues on a day to day basis. The other sections, our studies of POE and Olmstead implementation, include data and are focused on legal and policy analysis

We focused on these two groups because we believed that they would provide the most consistently consumer-oriented voice across the United States. As described on the ombudsman page of the National Coalition for Nursing Home Reform (NCCNHR) Website, "An Ombudsman is an advocate for residents of nursing homes, board and care homes, and assisted living. Ombudsmen provide information about how to find a facility and what to do to get quality care. They are trained to resolve problems…. Under the federal Older Americans Act, every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long term care system."[30] Citizen Advocacy Groups are, of course, by their very nature consumer-oriented.

The foremost goal of this study was to learn from a consumer-oriented perspective whether these programs are serving consumers well. In addition, we hoped to gather information on best and worst practices which would be instructive for other states, particularly our home state of New York, that have begun planning a POE for long term care, or other related long term care policy changes. Delivery of long term care is currently undergoing significant changes on both the federal and state levels, due to such varied (though often intersecting factors) as compliance with the Olmstead decision[31] and changes to the Medicaid and Medicare programs, etc….

Background of Study

As reported in the first section of this report, we identified 24 states as having a POE for long term care. We referred to the NCCNHR Website[32] to get contact information on CAGs and LTCOPs in the 24 states. Using the NCCNHR data, we were able to identify 24 state Long Term Care Ombudsman Program offices and 14 Citizen Advocacy Groups for possible participation in the study.

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[30] http://www.nccnhr.org/static_pages/ombudsmen.cfm.
[31] *Olmstead v. L.C.,* 527 U.S. 581 (1999), established that the unjustified institutional isolation of people with disabilities is a form of discrimination under Title II of the Americans with Disabilities Act (ADA) of 1990. For more information, see Section III of this report.
[32] NCCNHR's Website, www.nccnhr.org, is home to the National Long-Term Care Ombudsman Resource Center.

In order to maximize response rate, prior to conducting the survey we asked NCCNHR to issue an announcement about the survey via e-mail to advocates and ombudsmen groups. We subsequently called each group to set up a time for a phone interview. Those who agreed to be interviewed were sent a copy of the questionnaire by fax or mail prior to the interview. State or regional AARP offices were contacted to help find survey participants in states where there were no data available for organizations or the contact information we had did not yield results.

In all, we identified twenty five active organizations in the states having a POE for long term care. Of those, eighteen groups agreed to participate in our survey.

Survey Protocol

As mentioned above, participating ombudsmen and advocates were given an appointment for a telephone interview as well as advanced notification of the survey protocol and were sent copies of the survey questions prior to their prearranged survey appointment. If a telephone appointment could not be arranged, a copy of the survey was mailed or e-mailed for completion by the advocate or ombudsman. The survey instrument[33] consisted of seventeen questions, some requiring yes/no responses and the balance being open-ended questions. In order to obtain the most forthright responses possible, survey participants were promised anonymity. *Even though there were limited responses to some of the questions, they echo the findings detailed in the other sections of the report.*

Survey Results

Following is a report on the survey results. Because the participants, who represented statewide ombudsman agencies or community organizations, were assured anonymity, any information that would identify particular states has been removed. Below each question is a summary of the answers.

Are you familiar with the POE in your state and do you know when it was implemented? Only thirteen of the 18 respondents were familiar with the point of entry system. This indicates a disconnect between the state policy implementation of essential services and community groups who often play an essential role in informing consumers. When those who were familiar were asked to relate when the POE was instituted in their state, a 1984 pilot project was the earliest date given for implementing a point of entry. Several respondents reported that the POE in their state was instituted piecemeal, a few counties at a time. A majority reported that their state POE was instituted in the 1990s.

Did you have input into how the POE was instituted? Of the thirteen groups who were familiar with their state's POE, five groups had been participants in the development of their respective POE systems. Following are their descriptions of participation in the POE:

- A coalition of consumer advocacy groups, representing both seniors and the disabled, developed the legislative language and succeeded in getting it passed;

[33] The questionnaire may be viewed on the POE/Access to Care section of our Website, www.ltccc.org.

they then helped to institute a pilot program in three counties. This subsequently developed into a state program.

- Another participant reported that they helped pass a legislative package, a process that included stakeholder participation.
- An ombudsman program reported that they were involved in a consultation capacity in their state's development of a gateway-information/referral system that centered on connecting consumers with the services they need. This group also reported that they served as advisors for a new grant, which incorporated delivering to services to those who are developmentally and/or physically disabled.
- One advocacy group reported that they served on advisory committees and on state stakeholders planning teams for the POE development in their state.
- An ombudsman group reported that they had headed a council that designed the POE in their state. Half of the members of this council were consumers.

Were you or other consumer oriented organizations directly involved its implementation? Four groups reported involvement in the implementation of the point of entry system, while six groups said they did not participate in the implementation. Three of the survey participants were not able to answer this question for their organizations. Of the four groups who participated when the state implemented the point of entry, all were involved in an organizing activity which furthered the cause of the point of entry, such as: holding consumer focus groups or setting up task forces. Following are highlights of some of the implementation activities survey participants described:

- One ombudsman group participated in negotiations with their state. An advisory board of consumers was created as well as a coalition task force to represent consumer interests.
- Other groups were involved in planning and establishing ways for consumers to obtain information about services, such the development Websites and call centers for consumer information and referral.

Describe how the plan works in your state. There was a great deal of diversity among participants' response to this question, indicating that the development of POEs across the country is not developing monolithically but, rather, appears to be determined to a great extent by the political environment in the individual states.

- A few groups mentioned that their states had instituted a "no wrong door" policy. Under such a policy every participating agency can provide the same consumer information which eliminates the need for the consumer to make multiple calls in order to obtain comprehensive information about their care options. This type of policy can help minimize consumer confusion and frustration.
- One survey participant reported that in his/her state entry to long term care services took place in the consumer's home. For instance, public health nurses and social workers perform nursing home assessments at clients' homes. Some assist the consumer in gathering the records needed for the Medicaid application. To the survey participant, this was a very user-friendly way of implementing the POE: Sending a representative into a client's home with a laptop computer to make an assessment and perform a functional screening (to see what services are needed) along with a

financial screen (for waiver programs) makes it very easy to obtain needed services, especially for the physically challenged consumers.

- As mentioned earlier, several respondents reported that their states had instituted a system to facilitate consumer access to information, such as special telephone numbers for people to get information and/or Websites with information and resources to help people obtain the care they need.

Do you think the plan made it easier or harder for people to get the services they need? Ten participants responded to this question. Nine of them reported that it was easier for clients to get the services they needed since the point of entry was instituted. For instance, they reported that there are now shorter wait times to obtain services and clients can often be provided with immediate knowledge of what services he or she is entitled to receive. Often, it was reported, information can be provided easily, quickly and accurately in one location. The respondent who reported that his/her state's POE made it more difficult for people to get services attributed this to the belief that consumers had to wait until someone on Medicaid drops out of the program before another consumer can access services.

Do you think the plan has led to more appropriate services for people? Twelve of the survey participants responded to this question. Eight respondents indicated that they thought that consumers were receiving more appropriate services; four respondents replied that the plan was not providing more appropriate services. In the past, nursing homes were often the only choice available to those in need of long-term care; now community-based solutions are being emphasized instead of institutionalization. According to the responses to this question, this appears to be the case in the states that have developed POEs for long term care.

Survey respondents who stated that consumers were getting more appropriate services with a POE reported that community agencies are developing other resources, such as mental health services and food banks to help keep people in the community. In some communities, we were told that those who are able to leave the nursing home and live in the community with assistance have been able to do so and continue to receive Medicaid money to pay for services and equipment to meet their needs. This type of program is often referred to as "money follows the person" or , in a variation, "cash and counseling." It is an increasingly popular idea among advocates, particularly advocates for the disabled.

One of the problems with this type of program that was identified by several respondents is that some states are finding that consumers are experiencing long waiting lists and lack of services. This indicates that capacity building – making sure that appropriate services and housing are available in the community – will be critical for the idea of "money follows the person" to become a reality.

Has the POE made it easier or harder for consumers to get appropriate care? Nine participants responded to this question. Six indicated that appropriate care was made easier for their constituents. This was attributed to greater information being made available to consumers, the availability of age specific services, and streamlined processes for receiving care. One participant reported that adaptive equipment for the disabled helped provide appropriate care for individuals with special needs. Three participants responded that it was too early in the life of the program for them to make a judgment about appropriate care.

Have the changes resulted in more or less consumer choice? Nine respondents answered this question. All stated that consumer choice has increased under the POE. In particular, respondents noted that it was now easier for consumers to know what options were available to them. For instance, instead of being put into a nursing home, many consumers are discovering the services available to them in their homes.

Has the general public been informed about the available services? While all thirteen of the respondents who knew of the POE in their state said that the general public was being informed, the extent of public education varied widely. Methods cited by the study participants included: telephone outreach, web sites, hotlines, television ads, public hearings, informational brochures, magazine articles, notification by mail, networking (especially in rural areas), and information provided at medical clinics that are frequented by elders.

Are you seeing more consumers staying in the community under this plan rather than being institutionalized? Nine of thirteen groups responded positively to this question. "That is our goal" replied a respondent who reported that his/her group was seeing a thirty per cent decrease in nursing home care. One state has reportedly sent 3,200 nursing home residents back to the community, under a POE that operates under a "money follows the person" arrangement On the negative side, a couple of respondents noted that if there is a long wait for services, elderly clients have no other choice than to enter nursing homes.

Do you know if your state has applied for Medicaid waivers under the POE? Eleven participants answered this question. Seven reported that they were aware that their states had applied for Medicaid waivers while four were not aware of an application for their state.

If waivers have been approved and implemented, do you think the use of waivers has benefited or harmed consumers? All of the seven respondents who reported that their states had applied for waivers to the Medicaid program felt that the waivers had benefited consumers, though one of those respondents said that s/he felt the waiver had both costs and benefits for consumers.

Do you think the use of the POE led to reduced Medicaid costs? If yes, have cost reductions helped, harmed or had no effect on consumers? Six participants responded to this question; four of them felt that Medicaid costs had been reduced while two did not. Reported perspectives on whether the cost reductions helped, harmed or had no impact on consumers were inconclusive: of the six respondents who answered this question one said yes, one said don't know and the remaining four said it was too early for them to determine.

In your opinion, has the POE led to changes in Medicaid eligibility? If yes, do you think that these changes have helped, harmed or had no effect on consumers? Eight respondents answered this question, with six saying that the POE had not led to changes in Medicaid eligibility in their states and two stating that it had. On the negative side for consumers, one state extended spousal impoverishment; eligibility levels for Medicaid were raised in another. Both resulted in less people able to qualify for Medicaid, thus having a clearly negative impact on consumers. On the positive side, personal assets allowed to qualify for Medicaid

in one state increased from $2,000 to $8,000, enabling more consumers to become eligible for benefits.

Has the state instituted any changes or incentives to increase capacity, especially in settings other than nursing homes? Seven survey participants answered this question. Six participants reported that their states had instituted systemic changes to increase capacity for long term care and one participant reported that his/her state had not made such changes. Means for increasing capacity included increasing availability of housing and community services, enabling increased use of personal care providers rather than institutionally based providers and making assisted living more affordable to lower and middle income consumers.[34] However, some services have been depersonalized and a need was expressed for more community based residential facilities for the poor.

Conclusion

While there are a range of problems and issues for consumers faced with a single point of entry for long term care, it is clear that the consumer groups and ombudsmen we spoke to believe that the POE has had a generally beneficial impact on long term care consumers. The benefits reported to us include: greater choice for consumers, access to more appropriate care, and greater flexibility stemming from Medicaid waivers (which, as noted earlier, have a potentially harmful impact as well).

Survey results indicate:

- The variety of communication methods being utilized, coupled with the vulnerability of long term care consumers as a group, indicate that further research is needed to determine the effectiveness of the different methods and identify best practices to ensure that those who are in need of long term care do not "slip through the cracks."
- The general consensus was that waivers have been beneficial by helping many consumers receive the services they need. This is promising from a consumer perspective, though, given the fact that POEs are a relatively recent phenomena and that almost half of the respondents to this survey did not know of a Medicaid waiver in their state, it might be too early to say what the long term impact on consumers will be.
- There are a number of ways that community groups can be involved in the development and the implementation of POE programs.
- As POE programs progress, there is a need to conduct research related to consumer benefits and negative outcomes in a number of areas: waivers, reducing Medicaid costs and changing Medicaid eligibility.
- There is a need to make sure that there are adequate alternative services to nursing homes.

[34] Increasing the affordability of assisted living, which is often prohibitively expensive for the elderly, is a growing consumer movement and is expected to be a significant part of our assisted living advocacy in the future. There are a variety of ways in which states are already facilitating affordability of this option, from utilizing Medicaid waivers to Section 8 housing funds.

Following are some noteworthy comments from the survey participants. They all relate to the goals of some of the states which have instituted a POE for long term care. While they came from individuals, we felt that they were representative of the issues encountered in many states.

- *A goal of the point of entry system was that consumers only have to tell their story once.*
- *A public goal is to equalize spending between home and community-based services and nursing home services.*
- *Medicaid is never discussed with clients; they only speak of Managed Care and Family Care.*
- *One roadblock is that the state government is incompetent and fearful about the funds going out of control.*

Section III
Olmstead Implementation in the United States: An Introduction and National Perspective for Policy Makers, Consumers and Advocacy Organizations

Introduction

The Supreme Court's 1999 landmark ruling in *Olmstead v. L.C.* (*Olmstead*) established that the unjustified institutional isolation of people with disabilities is a form of discrimination under Title II of the Americans with Disabilities Act (ADA) of 1990.[35] Title II of the ADA requires state and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities. The court declared that states are required to make reasonable modifications to publicly funded programs to accommodate qualified individuals who desire to live in the most integrated setting. The Supreme Court's majority opinion stated that "reasonable modifications" are met when a state has a, "comprehensive, effectively working plan," and, "a waiting list that moved at a reasonable pace."[36] Many states have used this statement as their cue to achieving *Olmstead* compliance, focusing more on prospective planning and formation of commissions than making the mandated systemic changes. Since the Medicaid program is the largest public financer of long term care services and provides either partial or full support for two-thirds of all nursing home residents, *Olmstead* compliance within the Medicaid program is the primary focus of each state.[37] The Court also stated that any changes determined to "fundamentally alter" the Medicaid program is out of the jurisdiction of the court and must be addressed through legislative reform.[38] This could further impede change.

Many individuals desire to remain in their homes rather than enter institutions. An estimated 15 to 30 percent of nursing home residents could be cared for at lower levels of care (such as that which is available in assisted living or in a community setting).[39] [40] Yet, there are many barriers to achieving care in the least restrictive setting. Some are specific to Medicaid and others are not. Medicaid has an inherent institutional bias since the provision of institutional care is a required benefit for all eligible beneficiaries. Community-based services are "optional" benefits, meaning that a state may choose to offer them to certain groups and receive federal matching funds. Some of the community-based services offered in this category include the home health care benefit, personal care, rehabilitation services, private duty nursing, physical therapy, and occupational therapy.

All fifty states have expanded coverage to include optional services to some degree. Most states have chosen to add amendments to their Medicaid programs to include these optional services and/or apply for home and community-based service waivers which provide states more flexibility in who, where, and what is covered. While spending on Medicaid home and

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[35] *Olmstead v. L. C.*, 527 U.S. 581 (1999)
[36] *Id.*
[37] Feder J, et al . 2000. Long-Term Care in the United States: An Overview. *Health Affairs* 19(3):40-56.
[38] *Olmstead* v. *L. C.*
[39] Spector WD, Reschovsky JD, Cohen JW. 1996. Appropriate placement of nursing-home residents in lower levels of care. Milbank Quarterly 74(1): 139-160.
[40] Ikegami N, Morris JN, Fries BE. 1998. Low-care cases in long-term care settings: Variations among nations. *Generations.*

community-based services has grown rapidly over the last decade, the majority of resources still go to institutional care. Beneficiaries using institutional care accounted for roughly half of total Medicaid long term care users, but 70% of long term care spending is devoted to institutional care, partially or fully supporting 2/3 of all residents.[41] [42] Eliminating Medicaid's institutional bias is difficult because of the financial constraints on the program and political pressure of invested institutions. Other key barriers to community integration include lack of affordable, accessible housing, transportation, labor shortage of support staff, and quality control.

Litigation

Over the last five years, more than 100 *Olmstead*-related lawsuits have been filed and over 400 complaints have been submitted to the Department of Justice in an attempt to implement *Olmstead*.[43] Legal advocates argue that, "where real progress has occurred, it is largely because states have been sued…it remains the single most effective way to combat the persistent segregation…"[44] Advocates have used arguments based on allegations that policies are discriminatory and that Medicaid law has been improperly applied by the state.

While the ADA most directly addresses discrimination, the courts ruled that individuals could bring cases under *Olmstead* when unnecessary segregation occurred even if there was no intentional or overt discrimination.[45] The interpretation of the Supreme Court's decision regarding "reasonable modification" versus "fundamental alteration" has been more mixed. One very influential case, *Alexander v. Choate*, determined that a new benefit required by disabled individuals would be a "fundamental alteration" because across the board treatment and universal limits on services are not discriminatory, despite a greater burden on the disabled.[46] But a benefit already existing somewhere in a state's plan has been considered by some courts to be part of a package of services and a change in administration was a "reasonable modification."[47]

Home and community-based services are received by many through Medicaid waivers. These have a designated number of slots that often have very long waiting lists. Some argue that these long waiting lists violate the "reasonable pace" requirement in both *Olmstead* and the Medicaid Act. Though disagreement continues, several decisions give insight into how optional waivers and wait lists have been viewed by the courts. When states choose an optional Medicaid waiver, it is still a part of the Medicaid program and subject to its rules. Under these rules, states are allowed to limit or "cap" the number of slots available and this

[41] Reester H, Missmar R, Tumlinson A. 2004. Recent Growth in Medicaid Home and Community-Based Service Waivers. *Kaiser Commission on Medicaid and the Uninsured*.
[42] O'Brien E, Elias R. 2004. Medicaid and Long-Term Care. *Kaiser Commission on Medicaid and the Uninsured*.
[43] U.S. Department of Justice. Delivering on the promise: self evaluation to promote community living for people with disabilities. Report to the President on Executive Order 13217.
[44] Legal advocate cites ongoing segregation on eve of *Olmstead* anniversary. *U.S. Newswire*. June 21, 2004.
[45] Kubo M. 2001. Implementing *Olmstead v. L.C.*: defining "effectively working" plans for "reasonably paced" wait lists for Medicaid Home and Community-Based Services Waiver Programs. *Hawaii Law Review* 23(731).
[46] Rosenbaum S, Teitelbaum J. 2004. *Olmstead* at five: Assessing the impact. *Kaiser Commission on Medicaid and the Uninsured*.
[47] *Id.*

cap has been interpreted to be another eligibility requirement. If there are open slots, eligible individuals are entitled to these services at "reasonable promptness."[48] This interpretation has been extended in some courts to mean that when the waiver slots are full, those on the waitlist are not entitled to these services and thus subject to indefinite waitlists.[49] It is important to note that lack of funding alone has been determined to be no defense for fundamental alteration or a proper reason for excessive waiting times to recommended services.[50] Several cases also address the shortage of homecare workers due to low state payment rates, which hinder many individuals from obtaining approved support.[51] This has been framed as an issue about unequal access to benefits. These cases have been brought in Minnesota, Arizona, and California, with mixed results. It should be noted that after the 2002 Supreme Court decision of *Gonzaga University v. Doe*, states have begun to argue that federal Medicaid law can only dictate overall administration and not individually enforceable rights. Decisions have gone both ways on this issue and it will be interesting to watch how the Medicaid program will be affected in the future.[52]

Some decisions coming out of the courts have resulted in positive changes for consumers. These include: increased funding in Florida to reduce waitlists, change of Medicaid rules in Ohio to accelerate community re-entry, and forced the Laguna Honda Nursing Home in California to conduct screening, assessment, service/discharge planning and ongoing case management for residents.[53] [54] [55] Generally, courts have tried to encourage policy change and have been inclined to take into consideration a state's dedicated efforts at change, even if those changes are slow.[56] Sometimes the genuine threat or initiation of litigation is enough to induce a state to act.[57] But when a state ignores court mandated settlement agreements, it

[48] Rosenbaum S, Stewart A, and Teitelbaum J. 2002. Defining "reasonable pace" in the Post-*Olmstead* environment. Center for Health Care Strategies, Inc. Washington, D.C. citing *Boulet v. Cellucci*, 107 F. Supp. 2d61 (D.Mass. 2000).

[49] Kubo M. 2001. Implementing *Olmstead v. L.C.*: defining "effectively working" plans for "reasonably paced" wait lists for Medicaid Home and Community-Based Services Waiver Programs. *Hawaii Law Review* 23(731). cites *Makin v. Hawai'i,* 114 F.Supp. 2d (D. Haw. 1999)

[50] Kubo M. 2001. Implementing *Olmstead v. L.C.*: defining "effectively working" plans for "reasonably paced" wait lists for Medicaid Home and Community-Based Services Waiver Programs. *Hawaii Law Review* 23(731). cites *Olmstead v. L. C.,* 527 U.S. 581 (1999), *Helen L. v. DiDario* 46 F.3d (3d Cir. 1995) and *Makin v. Hawai'i,* 114 F.Supp. 2d (D. Haw. 1999)

[51] Yue S. 2001. A return to institutionalization despite *Olmstead v. L.C.* The inadequacy of Medicaid provider reimbursement in Minnesota and the failure to deliver home and community-based waiver services. *Law and Inequality* 19(307).

[52] Smith G. July 20, 2004. Status report: litigation concerning home and community services for people with disabilities. *Human Services Research Institute.* cites *Gonzaga University et al v. Doe,* 536 U.S. 273 (2002), *Sabree et al. v. Houston*, 245 F. Supp. 2d 653 (Penn., 2003), reversed in *Sabree et al v. Richmond*, 367 F.3d. 180 (US App, 2004) [against individually enforceable rights] and *Rabin v. Wilson-Coker,* 362 F.3d 190 (U.S. App, 2004), *Mendez v. Brown,* 311 F. Supp. 2d 134 (Mass., 2004) [for individually enforceable rights]

[53] Kubo M. 2001. Implementing *Olmstead v. L.C.*: defining "effectively working" plans for "reasonably paced" wait lists for Medicaid Home and Community-Based Services Waiver Programs. *Hawaii Law Review* 23(731).

[54] Soencer C. June 29, 2004. State's ongoing efforts for disabled become part of lawsuit settlement. *The Beacon Journal*.

[55] Hetter K. Advocates applaud Laguna Honda settlement. *The S an Francisco Chronicle*. December 24, 2003.

[56] Rosenbaum S, Teitelbaum J. 2004. *Olmstead* at five: Assessing the impact. *Kaiser Commission on Medicaid and the Uninsured*.

[57] Feltz M. 2002. Playing the lottery: HCBS lawsuits and other Medicaid litigation on behalf of the developmentally disabled. *Health Matrix* 12(181).

might be necessary to go back to court and/or use non-litigation methods such as media exposure and political pressure to induce state action.

Despite the positive results litigation has been able to produce, there are several important disadvantages to the lawsuit strategy. While the *Olmstead* decision applies to a wide variety of individuals with disabilities, most judicial action has been directed toward those with mental and developmental disabilities. Elderly individuals have often been overlooked as a group affected by unjustified institutionalization. The necessity to create distinct classes automatically excludes others, possibly leaving certain segments of the LTC community without services or protection. By working through coalitions, it is possible that consumers and advocates can overcome the problems associated with classification of different consumer groups and achieve widespread benefits.

State Planning and Implementation

One major strategy states have chosen to employ to comply with *Olmstead* is to create task forces or commissions to coordinate an "effectively, working plan." Almost all states have groups accessing long-term care systems and most have *Olmstead*-related plans or reports.[58] Many of these have been published on the web.[59] In many states the agency heads created the task force but governors and legislatures are also important initiators. Most task forces focused on all people with disabilities rather than a specific sub-group. Some created working groups based on individual populations while others examined cross cutting issues like barriers or quality. Many recognized the importance of gathering feedback from stake-holders and held meetings throughout the state.

The members of the task forces were varied. Some were made up entirely of state agency personnel, while others include every stakeholder in the state. For example, in Alabama, more than half of each 40 member workgroup consisted of consumers and advocates but the workgroups had difficulty getting buy-in from state agencies.[60] In Montana the task force included consumers, legislators, advocates, family members, state staff, and providers.[61] In many cases, budget shortfalls created planning barriers because there wasn't enough state staff to coordinate planning efforts.[62] To help alleviate state staff shortages, technical assistance was available from the Healthcare Financing Administration and the Centers for Medicare and Medicaid Services (CMS) to assist states in their development of a comprehensive plan. Yet even when a plan was successfully produced, an analysis by the National Conference of State Legislatures (NCSL) found that keeling the *Olmstead* plan relevant and useful was a major challenge to successful implementation. NCSL recommends that one of the most important tools to keep a plan useful is to include monitoring and evaluation, periodic revisions, and prioritized recommendations.[63] Most plans set goals and

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[58] Fox-Grage W, Coleman B, Folkemer D. 2004. The states' response to the *Olmstead* decision: A 2003 update. *National Conference of State Legislatures*.
[59] Examples: Virginia http://www.olmsteadva.com, Connecticut www.dss.state.ct.us/images/CommIntPlan.pdf, Arizona http://www.ahcccs.state.az.us/Publications/PlansWaivers/Plans/Olmstead/default.asp,
[60] Fox-Grage W, Coleman B, Folkemer D. 2004. The states' response to the *Olmstead* decision: A 2003 update. *National Conference of State Legislatures*.
[61] *Id.*
[62] *Id*.
[63] *Id*.

strategies after an initial assessment of existing services, barriers, and the number of unnecessarily institutionalized individuals and those at risk in the community. Some recommendations were low cost short term goals that could be implemented quickly and others were long term goals that addressed broader problems that are more complex. Main priorities for many states are to increase choice and strengthen consumer-directed care. This often involves expanding the capacity of existing services and creating innovative methods to increase flexibility.

One strategy to increase access to community services is to improve consumer information and outreach. Missouri created a very popular consumer guide, *Missouri's Guide to Home and Community-based Services,* and Florida set up a 1-800 number.[64] Several states, including Maryland and Connecticut, are exploring single points of entry to disseminate information and assist with assessment, referrals, and case-management. See our section on national POEs: *Single Point of Entry for Long Term Care: An Introduction and National Perspective for Policy Makers and Consumer Organizations.*

At least 25 states are trying to improve the transition process for institutionalized individuals to return to the community. Barriers frequently encountered include inadequate funding, housing, transportation and direct care staff. Many states are exploring the concept of "money follows the person" which allows funds used for nursing homes to be partially transferred with the person to their new setting. This concept has also been used to increase consumer-direction and personal control by allowing individuals to hire and manage their own staff, which can sometimes include friends and family members. While several demonstration projects are under way, it is unknown what the impact will be on the long term care system and those who still require institutional care. Iowa and Connecticut are increasing housing options for the elderly, Colorado has given several wage increases to support staff to expand their work force, and Indiana provides mini-grants to local communities to build partnerships to increase support for disabled people.[65] CMS and the New Freedom Initiative, an extensive multi-agency strategy in which CMS participates, have both produced resources that assist in sharing information about promising solutions.[66]

Federal Initiatives

While many states have created comprehensive plans, actual implementation has lagged behind. Major budget short falls have severely hampered states' efforts to improve or expand home and community-based options. But several federal programs have facilitated many of the reforms that have been successfully implemented. The New Freedom Initiative, issued by the Bush administration in 2001, provides a set of proposals to improve access and expand opportunities to community life for the disabled. Through The New Freedom Initiative, the Aging and Disabled Resource Center Grant Program was created to assist states with information and point of entry services. The "United We Ride" program assists

[64] Missouri's Guide to Home and Community-based Services can be found at http://www.gcd.oa.mo.gov/PIC/ServicesPamphlet/index.shtml

[65] Fox-Grage W, Coleman B, Folkemer D. 2004. The states' response to the *Olmstead* decision: A 2003 update. *National Conference of State Legislatures*.

[66] The Promising Practices Report in Home and Community-based Services can be found at www.cms.gov/promisingpractices and Delivering on the Promise can be found at www.hhs.gov/newfreedom/final.

states and communities in coordinating transportation. Partnerships with the Department of Human and Urban Development and the Department of Justice facilitate the construction of handicap accessible homes and grants to enable disabled and elderly individuals can stay in their homes. National Caregiver Support Programs help with informal care and demonstration grants enable states to try new strategies for recruiting, training, and retaining support staff.[67] A new Health and Human Services initiative called Independence Plus is aimed at helping states develop consumer directed services. The New Freedom Initiative also funds Real Systems Change Grants which can be used to create infrastructure and develop programs for improving community integration and increase quality assurance and improvement in home and community-based services. Many of the planning efforts are tied to the eight grant opportunities that comprise the System Change Grant. From 2001-2003 $158 million have gone to 49 states, Washington D.C., and two territories.[68]

<u>Olmstead in New York</u>

Though New York has a large network of home and community-based programs, the state has only recently begun the process of evaluating, planning and coordinating the current system's *Olmstead* compliance. New York's current system of home and community-based programs involves a much higher share of elderly receiving Medicaid home care than many other states, 5% versus 2%.[69] The New York Medicaid program spends approximately equal amounts on institutional care and home and community-base care, while nationally two-thirds of Medicaid funding goes to nursing homes and one-third to community care.[70] In addition, New York's Medicaid program also spends the most per capita for home and community-based services compared to the rest of the U.S.[71] New York's home care spending is comprised of three main programs: HCBC waivers (33%), Personal Care (44%), and Home Health (24%).[72] New York has the Nursing Homes Without Walls program and has sponsored several managed long term care programs with the aim of keeping individuals out of nursing homes if possible. Yet despite this, New York must still address its growing Medicaid costs and the challenges of meeting the different needs of its urban and rural communities.

Several steps to analyze the state's long-term care system have been to create committees to assess and recommend possible reforms. The Health Care Reform Working Group reviewed ways to control and reduce health care costs associated with long-term care. In its "Interim Report", recommendations were made to change the design and delivery of long term care services by creating a single-point of entry system (POE) called NY ANSWERS.[73] The implementation of NY ANSWERS is meant to provide information about appropriate long-term care options and promote use of the most integrated settings, primarily through remaining in the community. It should be noted recommendations for NY ANSWERS by the Health Care Reform Working Group seemed to be motivated primarily by cost saving

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[67] White House Domestic Policy Council. 2004. New Freedom Initiative: A progress report.
[68] Centers for Medicare and Medicaid Services. 2004. Factsheet: Real Choice Systems Change Grants.
[69] 1/27 LTC lecture notes.
[70] *Id.*.
[71] Gibson MJ, Gregory SR, Houser AN, Fox-Grage W. 2004. Across the state: profiles of long-term care: New York. AARP Public Policy Institute.
[72] Coleman B. 1999. Trends in Medicaid long-term care spending. AARP Public Policy Institute.
[73] Health Care Reform Working Group Interim Report. 2004. New York State Department of Health

potential and not necessarily *Olmstead* compliance. In 2002, the New York Legislature approved the formation of an *Olmstead* task force called the Most Integrated Setting Council (MISC). Commissioners from relevant state agencies and nine non-governmental members were appointed by Governor Pataki and the Legislature in 2003. MISC's first step was to assess community needs and best practices by holding four public forums throughout 2004. An ad hoc group of non-state agencies was created to review and comment on MISC's recommendations and an *Olmstead* Report is expected to be published by the end of 2005. Unfortunately, it is unclear the extent to which advocates for disability and long-term care consumers have been included in the decision making process. The governor has also signed the Nursing Facility Transition and Diversion law, which allows the New York State Department of Health to apply for a new Medicaid HCBS waiver to provide home and community-based services to individuals that would be cared for in a nursing home. If the waiver is approved by CMS, additional services may also be covered such as case management, independent living skills training and support for assistive technology.

Conclusion

- While states are taking advantage of the System Change Grants and other federal assistance, Medicaid home and community-based services waivers have become an essential strategy to states for improving community-based care. Unfortunately, since waitlists for such services are already long and growing, there is concern that expansion of home and community-based services will create even longer waits. The expansion may produce a very expensive "wood work effect" triggering many consumers who rely on informal care to switch to government subsidized services.
- The tension between compliance with *Olmstead* and state efforts to control and/or cut costs has often slowed proposals to implement *Olmstead*. Litigation has proven a catalyst for change but it is no magic bullet. However, enforcing rulings and expanding the benefits beyond the designated class of plaintiffs has proven difficult. Thus, litigation should be viewed as an avenue of last resort.
- To successfully ensure proper placement in the least restrictive setting and address the growing demand for home and community-based services, local, state and federal governments will have to face the realities of an aging population, decreased supply of female informal care givers and the likelihood of long-term care workforce shortages along with many other barriers that reinforce an institutional bias.
- Future efforts to comply with *Olmstead* to guarantee access to the most integrated setting possible should include stakeholders such as consumers, family members and advocates. Planning should be based upon need, utilization, demand and quality assurance. Examining and adapting best practices used elsewhere can provide valuable information in developing, revising and implementing an *Olmstead* Plan.

Useful Resources For More Information on *Olmstead*

Center for Personal Assistance Services, Introduction to *Olmstead* Lawsuits and *Olmstead* Plans: www.pascenter.org/olmstead/. Bazelon Center for Mental Health Law, *Olmstead v. L.C.* Online Resource Center: www.bazelon.org/issues/disabilityrights/resources/olmstead/. National Conference of State Legislatures, Olmstead On-Line NCSL Reports http://www.ncsl.org/programs/health/ONCSLrep.htm.

The Long Term Care Community Coalition (LTCCC) is a non-profit organization that works to improve conditions for long term care consumers, such as nursing home residents, assisted living and adult home residents, and people in Managed Long Term Care. We accomplish our goals through policy research and analysis, advocacy and education of the general public, the news media and policy makers.

The Long Term Care Community Coalition:

- Identifies shortcomings in the delivery of long term care;
- Researches issues impacting care delivery to the elderly and disabled;
- Develops recommendations for improvement;
- Advocates for laws and policies to improve care;
- Educates the general public, policy makers and the media on long term care issues and
- Actively engages government agencies and elected officials in discussion and action on the needed changes.

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