



Californians for Olmstead



# A Blueprint for Advocates:

Recommended Next Steps to Advance  
California's Implementation of the Supreme  
Court's Olmstead Decision

*By Laurel Mildred, MSW*

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## ▶ Background

Californians for *Olmstead*, a project of the California Foundation for Independent Living Centers (CFILC), is a cross-disability coalition whose members include disability organizations representing people of all ages: children, youth, adults and older adults. The coalition promotes public policies that advance the implementation of the 1999 Supreme Court *Olmstead* decision and create meaningful community living options for people of all disabilities.

In 2009, the California State Independent Living Council (SILC) identified *Olmstead* implementation as a key priority and began groundwork to include it in their upcoming State Plan for Independent Living. In response to the SILC's goal, the California Department of Rehabilitation structured three critical projects under the American Recovery and Reinvestment Act to build community capacity on *Olmstead* implementation. One of these projects focused on public policy; another provided training for Independent Living Centers as providers of transition services through the California Community Transitions program. A third provided peer counseling and mentoring for people seeking assistance to successfully transition from nursing homes and institutions into the community.

CFILC was awarded the 23-month *Olmstead* public policy grant, and launched the Californians for *Olmstead* project. The project has employed several key strategies: 1) Working in concert with a broad array of individuals with disabilities and representative organizations to provide policy coordination and support; 2) Developing and implementing strategies to advance *Olmstead* public policy; and 3) Providing training and technical assistance to local advocates to assist in their efforts to educate decision-makers, providers and the public about *Olmstead* implementation and community-living options.

In order to assess the views of stakeholders themselves about the progress of *Olmstead* implementation, one of the initial project activities was to conduct a survey of stakeholder views. The findings of the survey suggested that many stakeholders felt that the State had made only limited progress in implementation activities in the previous 10 years since the Supreme Court decision. They identified appropriate funding of home and community-based services (HCBS), support for the In-Home Supportive Services (IHSS) program and access to affordable and accessible housing high among their priorities and concerns (Californians for *Olmstead*, 2010).

Using these and other experience and literature-based findings, the project's initial assessment of the previous implementation activities identified a series of barriers:

- Lack of specificity and accountability in California's *Olmstead* Plan.
- Almost two decades of recommendations to improve long term care, with little progress implementing those recommendations.
- Lack of a "system" in the long term care system, characterized by fragmentation of services and funding, with implications for the individual consumers and the overall budgets for services.
- Policymakers' acknowledgement of the effectiveness of the IHSS program in reducing dependence on nursing home services, juxtaposed with policymakers' decisions to reduce funding for IHSS.
- State policies and practices which impede moving people out of institutions, including a dearth of nursing facility waiver slots,
- under-funding of the Multipurpose Senior Services Program and other home and community-based waivers and alternative programs, and a limit on the Home Upkeep Allowance which makes it ineffective.
- Lack of progress in diverting people from nursing homes and other institutions and getting people out of institutions.
- Lack of data to transition providers to allow them to find and support nursing home residents to move to the community.
- Progress towards deinstitutionalization in the Department of Developmental Disabilities and the Department of Rehabilitation, with less progress in other departments.
- Small federally-funded pilot programs, but no overall system-wide expansion of those programs to other areas or other populations.
- Increases in spending for nursing homes, while reducing funding for cost-effective HCBS.
- Lack of legislative knowledge and leadership on *Olmstead* and community integration, as compared to legislative initiatives in other states.

With those identified barriers as a backdrop, the Californians for *Olmstead* project began to organize and provide policy support for change. Since the project's inception in November, 2009, extremely significant developments have taken place, including the ongoing economic

recession, the passage of the Patient Protection and Affordable Care Act (ACA), and the initiation of the Obama Administration's Year of Community Living, with an unparalleled commitment by the United States Department of Justice to utilizing legal means to redeem the promise of the *Olmstead* decision.

The purpose of this final report and blueprint for future action is to take stock of recent events and to recommend future strategies to advance *Olmstead* implementation and options for community-living that will allow people with disabilities to live successfully in their homes and communities instead of being forced to live in nursing homes and other institutional settings.

## ▶ Economic Recession and Recurring Budget Cuts

According to the California Budget Project (CBP), the economic downturn that California has experienced is the most severe since the 1930s, and California lawmakers have responded to large budget shortfalls with repeated cuts to state spending. State General Fund spending was reduced from \$103.0 billion in 2007-08 to \$87.3 billion in 2009-10, a drop of 15.3 percent. The CBP (2011) states that "In 2010-11 General Fund spending is estimated to be lower as a share of the State's economy than in 33 of the prior 40 years" (p. 1). The current-year budget assumed that revenues would grow during the year, but included a number of "trigger cuts" that will further reduce programs if these expectations lag. Over half (52.8%) of the spending reductions in the current year targeted health and human services programs (California Budget Project, 2011).

Specifically, since Fiscal Year 2008/09, California's legislature and Governors have approved approximately \$15 billion in cuts to health care and social services, and as a result the State has lost nearly an additional \$15 billion dollars in matching federal funding (Health and Human Services Network of California, 2011). Approximately \$9.7 billion of those State General Fund reductions were direct cuts to services for seniors and people with disabilities, including cuts to Supplementary Security Income-State Supplementary Payments (SSI/SSP), reductions to health and Medi-Cal services, cuts to mental health and substance abuse funding, reductions in services for people with developmental disabilities, and cuts to IHSS, senior services and senior nutrition programs. These cuts included the total elimination of a number of programs, including Adult Day Health Care, Alzheimer's Day Care Resource Center, Brown Bag, Linkages, Respite Purchase of Services and the Senior Companion program.

Many of these reductions to different programs are born by the same individual. For example, the same person may have lost dental, vision, podiatry and other medically necessary services,

been required to pay increased co-payments for medical visits, while at the same time having reduced personal care services hours through IHSS, lost Adult Day Health Care program services, nutrition services, or case management services, and all of this while also losing direct income by having his or her SSI/SSP payments reduced.

## ▶ Reconciling Differing Visions

Underlying these steep ongoing cuts to services for seniors and people with disabilities are fundamental questions of the social contract, the responsibility of government to its citizens with disabilities. In the past, services and supports were seen as acts of public generosity or charity. This view was based in exclusionary policies that segregated people with disabilities as unworthy to participate in public life. However, with the advent of the disability rights movement, advocates have successfully fought to replace those policies with democratic and integrationist policies, based in civil rights and self-determination.

Historian Dr. Paul Longmore (2010) has written that a key principle of disability rights is *“the claim that people with disabilities have a right to the means necessary for them to participate in the community. This principle redefines services and assistive devices, accessibility and reasonable accommodations as, not ways of caring for those who are fundamentally dependent, but alternative modes of functioning and the necessary means for social participation and integration. Disability rights advocates also have campaigned for the establishment of these means as enforceable rights, rather than dispensations of public or private charity.*

*Advocates have sometimes argued that funding community-based living and in-home support services is less expensive than institutionalization or nursing home placement. But more important than that pragmatic argument, they have asserted not only the right of people with disabilities ‘to live in the world,’ but also their right to the means to make that right effective”* (pp. 6-7).

The landmark advancements of the 1975 Individuals with Disabilities Education Act, guaranteeing children with disabilities the right to education; the 1990 Americans with Disabilities Act, the world’s first comprehensive prohibition of discrimination on the basis of disability; and the 1999 *Olmstead* decision, finding that unnecessary segregation and institutionalization is a type of discrimination, were among the important advancements that memorialized these human rights as the law of the land.

Disability advocates largely see funding of community services and supports through an *Olmstead* filter. They believe that the *Olmstead* decision provides an underlying choice to live in the community rather than being forced to live in an institution. But they also believe that living

in the community does not imply poor healthcare, substandard housing and homelessness, or social isolation due to lack of personal care assistance or transportation. Without the means to live in the world, advocates argue, people with disabilities are “at risk” of institutionalization, and so the protections of *Olmstead* would also protect the services that they rely upon to live, and rightly extend to the community.

However, the State of California does not fully share this view. As recently as July 26, 2011, in the Adult Day Health Care suit of Darling, et al. v. Douglas, et al., California Attorney General Kamala Harris argued on behalf of the State that disabled plaintiffs must demonstrate more than a “risk” of institutionalization, and that the *Olmstead* ruling does not demand that states provide people with disabilities the opportunity to remain out of institutions.

The State of California (2011) argued in this case that “*translating Olmstead’s ‘unjustified isolation’ to cases involving a state’s reduction or elimination of medical or social services to those already living in the community raises interpretive problems*” (p. 13). The State went on to say that “... DHCS submits that the ADA cannot properly be read so broadly. Virtually all government action directly or even indirectly affecting eligibility for, or the scope, level or availability of health or social services could, depending on each beneficiary’s unique circumstances, have the effect of increasing the risk or even serious risk of causing a deterioration in their physical or mental condition. An ADA violation, however, must rest on the necessary impact of a state’s action, not the impact to an individual based on their unique personal, social and economic circumstances. Requiring that any change or reduction in services avoid any ‘risk’ of institutionalization would turn the ADA into an affirmative mandate to the states to maintain ‘a certain level of benefits,’ contrary to *Olmstead*. *Olmstead* does not demand states to provide the disabled ‘with the opportunity to remain out of institutions.’ *Rodriguez v. City of New York*, 197 F.3d 611, 619 (2nd Cir. 1999)” (p. 13-14).

There are many steps that the State of California and advocates concerned with *Olmstead* implementation can take together to advance community living options and conditions for citizens with disabilities. Some of those strategies are mentioned here. However, while these fundamentally different views of the State’s responsibilities under *Olmstead* persist, it is likely that community services that provide the means for people with disabilities to live will be considered acts of public charity that may be removed whenever the State faces financial constraints. Continuing to educate policymakers about these issues, and ultimately reconciling these conflicting visions, will be necessary to achieve serious progress on *Olmstead* implementation in California.

## ▶ Health Care Reform

One of the most significant developments that will impact *Olmstead* implementation was the passage of the Patient Protection and Affordable Care Act (known as the ACA) on March 23, 2010. The ACA reformed both private and public health insurance systems, increased coverage for people with pre-existing conditions, and provided an extraordinary expansion of health insurance coverage to over 30 million Americans. It also stimulated creation of state health insurance exchanges to provide more affordable coverage, launched improvements for people who are dually eligible for Medicare and Medicaid services, and created a Center for Innovations to foster new approaches and partnerships with patients for better health, better care and lower costs (Claypool, 2011).

Within this vast reform legislation, Congress specifically addressed *Olmstead* and state systems of long-term services and supports (H.R. 3590--111th Congress: Patient Protection and Affordable Care Act, 2009):

*“In 1999, under the United States Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), individuals with disabilities have the right to choose to receive their long-term services and supports in the community, rather than in an institutional setting. Despite the . . . *Olmstead* decision, the long-term care provided to our Nation’s elderly and disabled has not improved. In fact, for many it has gotten far worse . . . Although every State has chosen to provide certain services under Medicaid home and community-based waivers, these services are unevenly available within and across States, and reach a small percentage of eligible individuals”* (Section 2406).

Eleven million Americans need long-term services and supports (LTSS), and a total of \$200 billion dollars a year is spent on these services. Medicaid pays for more than half of this cost (Howard, 2011). In order to address the shortcoming of this system, the ACA included a number of specific LTSS improvements and innovations. These provisions included:

- Creating the Community First Choice Option for Personal Care Services, offering a 6% enhanced federal match to cover community-based attendant services and one-time transition costs.
- Extending the Money Follows the Person Rebalancing Demonstration (in our state, called the California Community Transitions Program), and improving the program rules, to assist people to transition from nursing homes to community settings.
- Expanding Aging and Disability Resource Centers to provide information and assessment, long-term options counseling, short-term service coordination and care transition services.

- Creating the Medicaid Health Home Program, with a 90% federal match for physician practices to care for persons with chronic medical and mental health conditions.
- Creating the Community Living Assistance Services and Supports (CLASS) LTSS insurance program, a voluntary, federally-administered program (the future of this program is uncertain as of this writing).
- Creating the Community Care Transition Program, intended to reduce hospital readmissions, test sustainable funding streams for care transition services and improve cost-effectiveness and quality of care.
- Expanding the 1915(i) state plan option, to provide HCBS services statewide to more individuals.
- Making workforce investments.
- Giving authority to the Secretary of Health and Human Services to emphasize HCBS.

These reforms are intended to address system fragmentation, better align incentives to coordinate care, increase access to HCBS and create new tools to finance individual LTSS services (Steenhausen, 2011). Along with the fundamental reforms to the larger health systems enacted through the ACA, they are rapidly driving an unprecedented move on the part of state LTSS systems toward integration and managed care.

## ▶ Integration and Managed Long-Term Services and Supports

Addressing fragmentation of services, eligibility, funding and other system constructs that negatively impact quality of care for the individual is a high priority for advocates, who have long argued that more effective and integrated systems would result in a better investment of public dollars, as well as better outcomes for people. Advocates have also emphasized the importance of integrating social services and supports into medical model programs. Finally, they have pointed out that many people need services but do not have access, with results that are expensive in both human and fiscal terms.

Understanding the best practices involved with integrating LTSS systems has been a major focus of the Californians for *Olmstead* project, with the goal of promoting systems change at the state level that would lay the foundation for an effective state LTSS system such as the Washington

or Oregon systems. Research identified a number of common elements that comprise good long-term living programs. These include a philosophical commitment to providing HCBS, and a belief by policy makers and budget staff in their cost-effectiveness. Strong data and analytics to substantiate cost-effectiveness, aid in forecasting and manage the program are also an essential component. Uniform assessment, comprehensive eligibility (serving all populations, not just those who are Medicaid-eligible), efficient and timely eligibility determinations, no wrong door access to services with single point of entry eligibility, and access to institutional and HCBS services on an even footing, are all important elements (Reed, 2010).

Effective LTSS systems also offer a broad array of services (especially HCBS); require a fair rate setting and contracting process, a care coordination system with capacity to provide appropriate assistance to recipients, good transition and diversion services, and budget flexibility to transfer funds between accounts to purchase the necessary mix of appropriate services. An important organizational feature of effective systems is a single unit in state government responsible for the program, or at least the functional equivalent. Finally, assuring quality oversight throughout the system is also essential (ibid).

Articulating and advocating for these elements seemed like an effective strategy in 2009/10. However, the pressures of the ongoing recession and subsequent budget deficits, paired with the implementation of health care reform, have fundamentally altered the conversation. While it may have seemed that California would improve its long-term living system incrementally, developing a step at a time toward a Washington-like system, there is mounting evidence from across the country that a new model is becoming pre-eminent: a system based on managed long-term services and supports.

Managed LTSS is a plan in which a contractor (a managed care organization) is responsible for providing beneficiaries with a defined set of services in exchange for a pre-paid capitation payment. A capitation payment is a set amount paid for each enrolled person, whether or not that person seeks care, per period of time. The amount of the payment is based on the average expected utilization of services, as well as factors such as age, gender and other characteristics. In most states that utilize Managed LTSS the plans are inclusive of acute care and often behavioral healthcare, as well as LTSS. Services in a Managed LTSS plan might include care management, personal care services, home-delivered meals or other classic HCBS services.

As states across the country continue to struggle with budget deficits, long-term services and supports are big targets for budget deficit reduction (Woodcock, 2011). The National Governor's Association and the National Association of State Budget Officers report that in fiscal year 2012, thirty-three states will have a combined projected budget gap of *\$75.1 billion* dollars. Spurred

by the incentives and requirements of the ACA, states are using 1115 waivers, dual eligible demonstration grants, and other means (such as California's mental health and substance abuse consolidation) to rapidly integrate care and, with increasing frequency, to move to managed care models for LTSS. In 2009, there were just 15 states with Managed LTSS programs. However, many states are now experimenting with a variety of different Managed LTSS models. New Mexico already had Managed LTSS for Medicaid, but is now exploring an 1115 waiver that encompasses all of Medicaid and would further promote Managed LTSS. New Jersey and Rhode Island are also pursuing 1115 waivers that encompass all of Medicaid, including LTSS. CMS reports that every day they are receiving new applications from states for Managed LTSS – states are widely using it as a strategy to close budget gaps (ibid).

National long-term care expert Cynthia Woodcock noted at a recent Alliance for Health Reform conference that while mature Managed LTSS systems can demonstrate good outcomes, such as Minnesota's top-rated system, they were carefully developed over many years with extensive planning and evaluation (ibid). The current wave of development is happening very quickly, as a means to close budget gaps. She identified several key questions that should be addressed as states develop Managed LTSS:

- How can consumer choice and person-centered care be preserved in a managed care environment?
- How do you align incentives across payers?
- How do you ensure that incentives are correctly aligned in a managed care environment to effectively manage across systems of care (such as primary and acute care, behavioral health, and care transitions)?
- How do you ensure effective service delivery, so that the right person gets the right amount of services?
- How do you preserve and grow existing provider networks?
- How do you properly forecast the demand for services?

Along with many other states, California is now embarking on a number of new systems designs that integrate services and/or utilize managed care. These initiatives are complex, rapidly evolving and are changing the landscape of LTSS service delivery in California, and they all present both extraordinary opportunities and great challenges for advocates concerned with developing a quality system of care:

- **1115 Waiver** - As of November 2010, the State has undertaken an 1115 Demonstration Waiver to expand coverage to more uninsured adults as well as to move seniors and people with disabilities to managed health care. California's stated goals in this project are to preserve the safety net, improve care coordination for vulnerable populations, and promote transformation of the public hospital delivery system. It is important to note that the State may submit an 1115 waiver at anytime it wants to, may amend an existing 1115 waiver anytime it wants to, and can have more than one 1115 waiver at a time.
- **Dual Eligible Demonstration** - The State was recently awarded a \$1 million planning grant by CMS to develop a Dual Eligible State Demonstration to integrate care for persons who are eligible for both Medicare and Medicaid services. The State plans to launch four pilot projects and to enroll up to 150,000 dually eligible individuals into integrated care over the next two years. CMS has very specific requirements for these Dual Eligible pilot projects, including global budgeting, consumer protections, and requiring full integration of services such as personal care and behavioral health along with the full array of traditional services. The design and implementation of these pilot projects is likely play a significant factor in systems integration efforts statewide.
- **Community First Choice** - The State is also in a planning process for implementation of the Community First Choice Option for personal care services. Currently focused on integrating the assessment process for just part of the LTSS system (state-level HCBS) the State's working concept for this program is to develop a Home and Community-Based Care Continuum that includes a single point of entry for services, a uniform assessment, and consolidated access to six of the State's current HCBS waivers.
- **Consolidation of Mental Health and Substance Abuse Services** – Specialty Medi-Cal for these services, along with the other functions previously administered by the Department of Mental Health and the Department of Alcohol and Drug programs, are being moved to the Department of Health Care Services. The State has completed planning for Phase 1 for this process and plans for the remainder will be developed and implemented over the upcoming year.
- **A New Program "Realignment"** – There has been discussion of a new integration of programs at the county level that may be developed for the Governor's January budget proposal, but as of this writing, no clear details have yet emerged. Any new realignment proposal may likely be designed through negotiation between the State and the counties, and the ability of advocates to influence the design may be limited without active assertion of their role.

Advocates, who have waited for 12 years since the *Olmstead* decision for systems change, may well feel overwhelmed by the unprecedented scale of the change that is taking place. On the one hand, advocates are experiencing important successes - many of their ideas are being implemented. Coverage is being expanded; medical services are being required to incorporate the whole person and his or her social and human services needs; prevention is being emphasized; fiscal incentives can be designed to reduce institutionalization and instead fund HCBS. For populations currently under-served by existing systems of care, such as people with dementia, traumatic brain injuries, or psychiatric disabilities, there are important opportunities for expanded access and improved quality of care. It is hard not to appreciate the opportunities of the moment. However, it is also true that budget deficits are driving the change; that important programs and services have already been lost, and that the timelines are incredibly rapid for thoughtful planning and input. Advocates typically have less staff and technical capacity than lobbyists of for-profit interests, and familiar service delivery systems may be disrupted or displaced. An extremely important concern for advocates is that years of hard-fought advances for the importance of the social model could be diminished or lost as they become “absorbed” into medical systems.

In the face of such large-scale change, advocates may want to consider their highest priorities and focus on making a significant difference on those issues. Determining priorities will be done on a case-by-case basis by each organization and entity, but we offer three high-impact strategies for consideration:

1) Promoting consumer direction and protection; 2) Preserving the non-profit, community-based safety net provider network; and 3) Focusing on fiscal incentives and advocating strongly for them to be aligned to support HCBS.

## ► Strategy 1: Ensuring Consumer-Direction and Protection

In June of 2011, Californians for *Olmstead* sponsored a webinar about the implementation of health care reform. The webinar featured several experts including Henry Claypool, Director of the Office of Disability for the U.S. Department of Health and Human Services (HHS). Claypool serves as the primary advisor to the HHS Secretary on disability policy and oversees the implementation of all HHS programs and initiatives pertaining to Americans with disabilities. Claypool is himself a person with a disability and has previous experience working in an Independent Living Center.

In preparation for and presentation of this training, Claypool encouraged Independent Living Centers and consumer-driven organizations to be flexible and open to the many changes that

are occurring under health care reform. He emphasized that there are significant opportunities for improvements, including expanded services and coverage, higher quality, better access, and the potential for new investments in HCBS (Claypool, 2011).

According to Claypool (personal communication, June 3, 2011), many of the changes that are occurring are being driven by the Affordable Care Act, and advocates would be better served if they do not spend their energy just resisting managed care. He suggested that advocates need to be deeply involved in the design and implementation of new programs and that they bring forward a strong consumer voice and represent the social needs of the person by working in partnership with medical systems, programs and providers.

One strategy for implementing these suggestions is to focus on strong consumer direction and protection in all of the systems redesign efforts underway. Seniors and people with disabilities have successfully advocated for strong consumer direction in social programs, notably the In-Home Supportive Services program. This principle of consumer-directed care is a key asset and strength that advocates may wish to focus on protecting, as well as extending to other programs and services, in any systems redesign efforts. According to the Center for Health Care Strategies (A. Lind, personal communication, August 29, 2011), New Mexico has implemented IHSS-like consumer direction within its Managed LTSS program. Finding relevant models and advocating for strong consumer direction as a key principle in the design of new programs may be one of the most important upcoming opportunities.

Consumer protection is also critical. The National Senior Citizens Law Center has developed ten essential consumer protections for the design of dual eligible integration models:

- The right to choose how, where and from whom to receive care, beginning with a truly voluntary “opt-in” enrollment model.
- Inclusion of all Medicaid and Medicare services as well as enhanced benefits, especially those designed to keep individuals living at home and in the community.
- Continuity of care, allowing access to current providers and services, treatments and drug regimes during the transition process.
- The ability for enrollees to appeal decisions and file complaints about problems they encounter.
- Meaningful notices and other communications about all aspects of the plan.
- Services that are culturally and linguistically appropriate and physically and programmatically accessible.

- Adequate access to providers with appropriate specialty experience.
- Comprehensive oversight and coordination to ensure contracted duties are performed and high-quality services are delivered.
- Payment structures that promote delivery of optimal care and do not reward the denial of needed services.
- Thoughtful and deliberative integration efforts that take into consideration the structures and readiness of existing service delivery systems.

(Prindiville & Burke, 2011)

***ACTION STEPS TO IMPLEMENT THIS STRATEGY:***

- *Educate policymakers about the importance of consumer-directed services and consumer protections in any service delivery system.*
- *Explore models for consumer-directed services within managed care models from other states.*
- *Advocate for the inclusion of all consumer protection standards within any managed care contracts.*

## ▶ Strategy 2: Preserve the Non-Profit Community Provider Network

As integration efforts and Managed LTSS plans are rapidly driven forward by state budget deficits and the implementation of the ACA, preserving the network of non-profit, community-based organizations (CBOs) which provide services, supports and leadership is becoming an urgent priority. This network by-and-large operates from person-first, mission-driven philosophies, and often better understands and provides the services that are most valued by and useful to recipients. CBOs serve as incubators for system leaders and innovative practices, push for enlightened systems change, and hold government accountable for ultimate outcomes. Much of the power of direct consumer concern and voice comes into the planning, programmatic and political processes by means of CBOs, including Independent Living Centers, aging service networks and providers, and mental health and developmental disability providers. However, despite the importance of their formal and informal contributions, CBOs find themselves engulfed in a series of sweeping and rapidly evolving systems redesign initiatives that could dramatically

diminish or even potentially eliminate their role in the system of care for seniors and persons with disabilities.

For example, New Jersey's new comprehensive 1115 waiver, mentioned above, will usher in a whole new era for all of that state's providers. Under this new waiver, which encompasses all of Medicaid, contracts with community-based providers will end as of July 1, 2012, nine months from now. CBOs will have to compete for contracts with four designated managed care providers. Some of that state's managed care plans have already indicated that they plan to provide services in-house, and do not intend to contract with CBOs. Programs of All-Inclusive Care for the Elderly (PACE) will not exist under the health plans – the plans will include “PACE-like” services instead, and the state's PACE programs have been given a two-year bridge of financial support to expand beyond their current model and re-invent themselves in such a way that they can continue to exist in the new environment (State of New Jersey, 2011). Here in California, managed care plans presenting at a Dual Eligible Integration stakeholder conference sponsored in August, 2011 by the California Department of Health Care Services were generally vague in answering questions about the role they envision for CBOs as partners in Managed LTSS.

It is essential for California CBOs to begin now to prepare for changes in the service delivery system and to explore new business models, partnerships and roles that will provide a platform for them to continue to influence policy and practice and to deliver person-centered and mission-driven services within new integrated systems and models of care.

Some of these new roles may arise naturally from the long-standing expertise located within CBOs, including the capacity to deliver diversion services, assessment, transition, peer services and care management. Working with the state Department of Health Care Services, CBOs can continue to develop and support new and existing diversion and transition programs. Working with hospitals, managed care organizations and accountable care organizations, CBOs can also provide a range of services such as assessment and care management that can assist in supporting successful community living.

A discussion brief by national long-term care consultant Roger Auerbach and Henry Claypool (2008) specifically explored ways that Centers for Independent Living (CILs) are experienced local partners for Medicaid HCBS, and laid out approaches that can assist CILs to develop new or existing HCBS in partnership with government, hospitals, health plans or other providers. The brief stated that “Centers have proven to be effective partners in helping government comply with the Americans with Disabilities Act and save money by supporting individuals with disabilities to live in less-costly community settings.” CILs have a “rich understanding of the community living infrastructure used by individuals with significant personal assistance needs,”

and provide “a unique understanding of the strengths and weakness of the current HCBS system and help Medicaid agencies build more effective services for enrollees with long-term service needs” (p. 20).

The brief noted that CILs have long provided vital “core” training and support services including information and referral, independent living training, peer counseling and individual and systems advocacy. Other high priority areas where ILCs are currently building skills and capacity include transition coordination for individuals who are institutionalized, transition services for youth with disabilities, housing, personal assistance services, assistive technology and home modification. The authors suggest that the long experience of CILs in delivering these services be developed in new business models with Medicaid and other entities, and that new roles in care management/support coordination, intensive community integration services, chronic care education and management, options counseling for primary, acute and long-term care services, assistive technology counseling and sales, and telemedicine equipment are also potential areas for development (ibid).

For Independent Living Centers and Area Agencies on Aging, another opportunity is continuing to swiftly move forward with development of a statewide network of Aging and Disability Resource Centers (ADRCs). Begun in 2003 by the U.S. Administration on Aging and the Centers for Medicare and Medicaid Services (CMS), ADRCs are programs that assist people of all ages, disabilities and income levels to access LTSS. ADRCs have received certain preferences under the ACA that tend to strengthen the likelihood that they will be part of developing care models. As a result, some states are utilizing ADRCs in prominent roles in their systems of care. New Jersey’s new 1115 waiver, for example, reinforced the “front-end” role of ADRCs, making them responsible for information and referral, general assessment, screening and referral, financial assessment for benefits qualification, and referral for clinical assessment under the state’s comprehensive waiver (State of New Jersey, 2011).

Global changes to the payment and service delivery systems pose significant challenges to the non-profit CBO network, which in California has traditionally been part of the backbone of “safety net” providers. Although CBOs are known for innovative, cost-effective strategies and nimble responses, Independent Living Centers in particular often lack the infrastructure and staffing necessary to participate in Medi-cal billing systems and reimbursement. These barriers need to be addressed in systems redesign efforts.

Rapidly adapting to the changes and developing new roles, partnerships and business models is essential for the long-term survival of these valuable organizations and the services that they provide to consumers of LTSS.

## **ACTION STEPS TO IMPLEMENT THIS STRATEGY:**

- *Understand how CBOs can play a role in Managed LTSS systems.*
- *Develop relationships with managed care organizations such as County Organized Health Systems, two-plan county-operated managed care, and geographic managed care plans.*
- *Explore partnership opportunities and new business models.*
- *Continue to develop the role of ADRCs.*

## ▶ **Strategy 3: Advocate to Ensure Fiscal Incentives Promote Home and Community-Based Services**

The implementation of health care reform and the rapidly evolving integration initiatives offer advocates a critical opportunity to re-set fiscal incentives that currently favor or result in institutional care, and instead incentivize the use of HCBS. In an integrated system rates should be structured to provide the appropriate fiscal incentives to ensure that people receive the right care, at the right pace, and at the right time, with access to services across the continuum. Advocates who delve into the State's integration initiatives will find that there is great complexity, sophistication and emphasis on rate-setting. Each entity with a stake in the cost or profit involved in delivery of services gives these issues the highest priority, and advocates should do so as well.

When fiscal incentives are misaligned, payment structures do not control the use of high-cost institutional services. Examples of misaligned fiscal incentives exist across systems:

- **Fiscal Incentives for Skilled Nursing Facilities** – Nursing homes have a fiscal incentive to hospitalize a resident who has both Medicaid and Medicare coverage, because after a three-day inpatient stay in a hospital, the resident may qualify for a special rate (under Medicare Part A) when transferred back to the nursing home, at three or four times the daily rate paid by Medicaid. This creates a financial incentive for a nursing home to hospitalize a resident briefly and then bring the person back to the nursing home at a vastly increased rate.
- **Fiscal Incentives for the County** – Another issue that complicates providing HCBS is the state/local/county program funding requirement. For IHSS services, counties pay 17.5%; the state pays 32.5%, and the federal government pays 50% share-of-cost. If individuals are instead placed in an institution, the counties typically bear no fiscal responsibility for their care.

Residents who are not receiving adequate HCBS may also create costs to the county through Adult Protective Services, the Public Guardian, and local police and fire services. There is a financial disincentive to providing HCBS that would address the person's needs in the community, and instead an incentive to shift the individual to a skilled nursing facility, where all of their costs are born by state and federal government. Any new "realignment initiatives" should be carefully considered to ensure that fiscal incentives reward delivery of HCBS and disincentivize the use of institutional care at every level.

- Fiscal Incentives for County Health Care Plans – Fiscal incentives under county health plans that serve those who are dually eligible for Medicare and Medicaid services currently are not aligned to encourage the use of cost-effective HCBS. In counties with County Organized Health Systems (COHS), plans have some "risk" associated with costs of residents placed in skilled nursing facilities – for the first 90 days, they receive a lower rate from the State for cost of nursing home care, and must make up the difference. But after 90 days the State pays a "pass-through" of the full "1629 payment rate," and so the COHS have no further risk. They may not "blend" their rate so that when they keep people out of nursing facilities, the savings can pay for HCBS. Therefore, COHS have limited risk when they place a member in a nursing home. Even worse from the perspective of advocates, counties with a "two-plan model" or "geographic managed care" – the majority of California counties – have no risk for placing a person in skilled nursing care. While the county remains responsible for the individual's medical services, the major expense of the skilled nursing facility is paid directly by the state and federal government.

In contrast, fully integrated plans such as the Program for All-Inclusive Care for the Elderly (PACE) are at full risk for the range of services across the continuum, including all acute and long-term services covered under the Medicare and Medi-Cal programs. They are responsible for the full "1629 rate" to a skilled nursing home not just for 90 days, but for the entire duration of the resident's length of stay, be it 10 months or ten years. Therefore, these programs have an immense fiscal incentive to keep participants out of nursing homes and instead invest in HCBS. Creating similar risk for institutional costs for all entities involved with LTSS should be a goal for advocates as they help to design new integration models.

Fiscal incentives involve complex formulas, parsing of populations by payer, and other labyrinthian details that are difficult to decipher. Rate setting methodologies and fiscal models are deliberately opaque in order to discourage providers from gaining unfair advantages or "gaming the system." However, asking questions until they get to the bottom of these matters may be one of the most important contributions advocates can make to redesign initiatives.

## **ACTION STEPS TO IMPLEMENT THIS STRATEGY:**

- *Engage the State on issues pertaining to how Managed LTSS plans would promote appropriate fiscal incentives, for example by asking:*
  - » What is the process for incentivizing the use cost-effective services instead of more expensive services?
  - » Who develops the financial models for integration initiatives like the dual eligible projects, mental health consolidation, etc., that arranges the different parts to deliver the most cost-effective services?
  - » To what extent do various providers have an incentive to control expensive institutional costs?
  - » What are the mechanisms that create incentives to save money by using the most cost-effective services?
  - » What is the process that encourages substituting lower-cost services for higher cost services, and allocates the money saved to fund more services for more people?
- *Engage in Rate-Setting Methodology Discussions*
  - » Peter Harbage, consultant working on behalf of the Department of Health Care Services dual eligible pilot projects, has promised advocates representing consumer-driven agencies and other CBOs a meeting with Mercer, the actuary responsible for rate-setting for the dual eligible pilot projects. This will provide the opportunity for the advocacy community to get a better understanding of the fiscal models that are being considered. Advocates should take advantage of this opportunity as well as any other stakeholder processes to ask as many questions as they need to understand the fiscal incentives that are being designed, and to advocate that at every turn they incentivize HCBS and create disincentives for the use of expensive institutional care.

## ▶ Conclusion

Sam Bagenstos, Principal Deputy Assistant Attorney General of the United States Department of Justice, has said that the disability community expected that the *Olmstead* decision would be as significant for ending the segregation of people with disabilities as the *Brown* versus the

Board of Education Supreme Court decision was in ending segregation for African-Americans (Bagenstos, 2010). Like that earlier landmark civil rights decision, however, implementation of *Olmstead* has been disappointingly slow from the perspective of advocates, who have eagerly anticipated a change for the better.

Nevertheless, over the past two years, especially with the passage of the ACA, the influence of the status quo has been dramatically reduced and doors have been opened to many opportunities for change. Coming at the same time as the greatest economic recession in 30 years, these changes are not all good news; they are often driven by State budget deficits and the State's efforts to close budget gaps by cutting services.

However, many of the ideas that advocates have long promoted have finally made it to center stage, and states are being incentivized to make positive changes to their systems that can significantly advance their implementation of *Olmstead*. Advocates must actively engage with this process to create new systems that are ultimately of service to the individual as well as cost-effective investments of public funds.

In contrast to *Olmstead's* first 12 years, the current moment is filled with opportunity for change. By focusing on consumer direction and consumer protection, creating new roles and business models to sustain mission-driven community-based provider networks, and by "following the money" to ensure that fiscal incentives promote HCBS, advocates can make major strides to advance *Olmstead* and community-living opportunities for Californians with disabilities over the coming years.

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