



**Rutgers** Center for  
State Health Policy

*The Institute for Health, Health Care Policy and Aging Research*

## **Discussion Brief:**

# **Advancing Medicaid HCBS Policy: From Capped Consumer to Consumer-Directed**

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## **Discussion Paper:**

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#### **Introduction**

The evolution of state and federal long-term care policy over the last century sets the scene in the new millennium for the hugely diverse group of long-term care consumers who will opt for services at home instead of care in a health facility. Over the last eight years, federal, state, and local governments have re-envisioned how to deliver and pay for an ever-growing caseload of elderly individuals and persons with disabilities who need services at home, in the workplace, or in more costly nursing facilities. State and local program administrators have joined with advocates and family caregivers as they struggle to avoid expensive institutional stays by making services in community settings more available and accessible. Federal policy makers are providing technical help and financial incentives to states that want to reduce public expenditures associated with Medicaid-funded institutional long-term care.

The US Supreme Court's *Olmstead* decision, the *Americans with Disabilities Act*, and the more recent *Deficit Reduction Act of 2005* provide consumer and political momentum to "rebalance" long-term care spending and promote reforms in local service delivery. In recent years, states have launched initiatives for retooling much-preferred home and community-based services (HCBS). However, state and federal Medicaid HCBS policy has not emerged uniformly for all long-term care users.

There are two reasons for the resulting policy and HCBS system gaps: First, political capital and the ability to influence legislation and state and federal funding decisions vary by advocacy group. For example, by Federal Fiscal Year 2005 advocates for those living with traumatic brain injuries were able to obtain Medicaid HCBS waivers in 21 states, and AIDS advocates had obtained waivers in 16 states. Necessary forces to obtain waivers for those same users in other states either did not exist or were not successful. For users without influential advocate groups, inpatient facility stays remain the only option.

Secondly, the development of local service delivery models has divided rather than coalesced local service delivery systems. Local networks typically were organized around a specific user profile; for example, developmental disability or mental illness. Local providers and community organizations have specialized in serving very specific subgroups of long-term care users, resulting in screening procedures that screen out those who don't meet the profile. Other individuals with certain chronic conditions and physical disability who depend on services and supports can be without dedicated

networks and have difficulty finding community supports that are the right fit. Moreover, one size or model for home care plans does not fit all. A younger person living with a physical disability often does not want or need the same protective services that are designed for a senior with dementia.

Public policy issues have emerged as consumers and governments shift away from highly regulated institutional care to offering consumer-based home care. However, ensuring quality in highly individualized and intimate home and community settings is complex, given the diversity of the long-term care population and especially considering the personal nature of consumer decisions. Service providers, unions, and local population-based networks add to the mix by competing for scarce public funding and preserving the status quo.

This discussion provides a vision and a context for HCBS reform consistent with CMS' vision for reforming post-acute care that focuses on addressing system barriers and informing and empowering health care consumers. The historical context reminds policy makers of lessons learned from deinstitutionalization initiatives in the past, and the vision calls for raising the quality bar for HCBS provider performance by embracing the diversity of consumer preferences and needs.

The broad deinstitutionalization initiative, as envisioned by the *Deficit Reduction Act Money Follows the Person (DRA MFP) Rebalancing Demonstration*, provides the opportunity for HCBS reform and the challenge to retool and rebalance. The discussion presents the challenges of such an ambitious agenda and identifies opportunities to raise the level of sophistication of HCBS networks and providers so they are technically prepared for the diversity of consumer decisions and the numbers of users that will be seeking HCBS in the coming years. The technical discussion about consumer preference is informed by experience under a *Real Choice Systems Change* grant in California.

### ***Major Points***

- Deinstitutionalization initiatives in recent history have been focused on meeting the needs of targeted subgroups of the long-term care population.
- HCBS policy and service networks have evolved to accommodate the needs of narrowly defined subgroups in limited pilots, waivers, or demonstrations.
- The *Olmstead* decision shifted focus from population-based HCBS models to a person's civil right to exercise personal decisions about his/her least restrictive and most integrated setting.
- Deinstitutionalization initiatives in the past provide lessons to guide broad HCBS reforms.
- Traits of long-term care users and costs have changed as medical science, public health, and demographics have changed.

- Generalizations are scarce about planning services for individuals who, in the facility, are referred to as “custodial care” residents.
- Individuals adapt to disability and chronic conditions in a way that is highly personal, involving decisions about risks.
- Facilitating consumer-based decisions is at the core of reforming and retooling responsive and capable HCBS provider networks.
- The DRA MFP demonstration provides the opportunity to not just rebalance long-term care spending, but also to reform and retool HCBS systems.

### **Envisioning the Future of Home and Community-Based Services**

Dialog about the high costs of health care appears daily in newspapers, radio, and television. Presidential and gubernatorial candidates float ideas about how to reposition and reframe health care policy and financing hoping to discover the public’s tolerance for either small changes or sweeping reforms. The aging demographic lends urgency to how best to restructure federal and state budgets to pay for over 12 million older Americans who will likely need long-term services starting in 2010.<sup>1</sup> In 2007, the pending increase in long-term care users is now called a “silver tsunami” stirring just off the horizon.<sup>2</sup> WWII Baby Boomers are turning 62. They are retiring and withdrawing their Social Security allowances. Instead of contributing the majority of tax dollars to Social Security, Medicare, and Medicaid, they are using publicly funded services and cash benefits. Policy makers are struggling to shore up public systems to accommodate the flood. But the numbers are only part of the picture.

Aging Boomers make up only a portion of the long-term care user profile. In fact, with healthier lifestyles, aging alone is not a reliable predictor for needing long-term care services. In 1996, Fernando M. Torres-Gil made it clear that the need to refine long-term care policy was not solely an aging issue. Compelling demographics call for streamlining delivery of Home- and Community-Based Services (HCBS).<sup>3</sup> Torres-Gil also advised decision makers to attend to the pressures of families and caregivers and to use limited resources to find the common needs of those requesting services. He advised against launching even more distinct and separate delivery systems. Policy discussions have ebbed and flowed over the last ten years as advocates, stakeholders, and consumers position their favorite services and argue over the best mix of public financing and community service models.

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<sup>1</sup> US Health & Human Services website: <http://www.medicare.gov/LongTermCare/Static/Home.asp>

<sup>2</sup> Smith, D. (2007).

<sup>3</sup> Torres-Gil, F. M. (1996).

This paper calls for a reaffirmation of urgency and a renewed vision. Drawing on history, promising practices, and academic work across the nation, this paper offers the following vision:

- ❖ HCBS information, screening, and assistance will be available and accessible to any potential users and their families, friends, and supportive others.
- ❖ HCBS service planners will facilitate consumer decisions and will work with them on a service plan that is unique to each individual's living situation and circle of support.
- ❖ HCBS options will be available and accessible to consumers before facility options are considered.
- ❖ Clear and understandable information about a person's disabling and chronic conditions will be part of service planning so that conditions can be managed at their highest level of dignity, function, and comfort.
- ❖ HCBS policy and benefits will evolve with medical advances and technological improvements.
- ❖ HCBS policy will embrace and value formal and informal caregivers.
- ❖ Individual service plans will favor self-management and lesser intrusive interventions whenever possible.
- ❖ Consumers will have the opportunity to assert their unique vision of quality of life along with plans to minimize risk when they exist.

## **Long-Term Care in Retrospect**

### ***1900 Through 1930***

A retrospect through history is rich with the voices of those who have, for years, debated and enlightened policy makers about providing care for those who can't or won't care for themselves. Historical trends away from institutional care can be traced back to the early 1900s and the de-population of poor houses, alms houses, and government run asylums. In 1926, Harry Evans published *The American Poor Farm and its Inmates*, with hopes of putting the spotlight on unhealthy and abusive conditions and calling for reforms. Evan's report exposed a system that sent hospital cases, the feeble-minded, the insane, the deaf and dumb (sic), the blind, criminals, and children to poor farms.<sup>4</sup> The local

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<sup>4</sup> Evans, H. (1926).

responsibility for the care of the poor originally developed in England during the 1500s (e.g., Acts of the English Parliament in 1531, Henry VIII's laws in 1536, and the Elizabethan Poor Laws of 1572) and was elaborated upon during the 1600s and 1700s. This system was transferred to the new world and was incorporated into colonial law and practice. For example, in 1723 Parliament permitted local parishes to establish poorhouses and to refuse aid to the poor who would not enter them. Evans and other reformers at the turn of the century exposed the problems in local institutions and set the stage for the federal programs that emerged in the 1930s.

### ***1930 Through 1990***

Public welfare programs for specific subgroups in need were developed in the early 1900s. Privately funded pensions developed as a way to bargain away older workers so that factories could retain higher-producing younger workers and maintain high production rates.<sup>5</sup> Private pensions gave rise to public relief for older public employees such as teachers, firemen, and policemen. The elderly became the country's most effective lobby for social insurance in a climate mired in public and private policy issues: industrial expansion, unionization, and (in retrospect) age discrimination. In 1935, *Old Age Assistance* (OAA) cash grants were established but were available only to those who were not "inmates" of public institutions. Subsequently, OAA cash grants could go to elderly inpatients, giving rise to the growth of today's nursing facility industry.<sup>6</sup>

In 1965, President Lyndon Johnson signed the Social Security Act in the Truman Library in Independence, Missouri, and President Truman became the first Medicare enrollee. Medicare and Medicaid provisions required a distinction between post-acute and ongoing supportive services, resulting in two distinct tracks for the home care industry.<sup>7</sup> The home care provisions resulted in the distinction between intermittent skilled nursing care and ongoing long-term services needed by individuals who live with non-specified chronic conditions.

The *Omnibus Reconciliation Act* (OBRA), passed in 1981, created HCBS waivers. As federal Medicare and Medicaid policy evolved, states established corresponding policy and distinct waiver systems that served the largest subgroups of long-term care users. OBRA 1987 required that states implement *Pre-Admission Screening and Resident Review* (PASRR) evaluations prior to institutionalization of those living with mental illness or developmental disabilities. Mandates for screening other subgroups of long-term care users (e.g., those with dementia or traumatic brain injury) were not included in PASRR requirements. The PASRR requirements created distinctly separate service referral procedures for two groups of consumers but did not require states to divert other long-term care users from institutional care. The federal Office of Inspector General, in 2001, found that even though the PASRR system was intended to

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<sup>5</sup> Katz, M. (1986).

<sup>6</sup> Vladeck, B. (1980).

<sup>7</sup> Hudson, R. (1996).



divert two specific subgroups of users, it was not adequately implemented in all states.<sup>8</sup>

Initiatives that focused on deinstitutionalizing those who are mentally ill and developmentally disabled have been interwoven over the years, as state and federal policy makers reacted to scientific advances and public demand for reforms. Public health, better access to health care, and public financing provided additional overlays that enabled states, local communities, and families to care for individuals who lacked social and financial supports. From 1955 to 1980, resident populations in mental hospitals fell from 559,000 to 154,000. Unfortunately, there was not a corresponding and concurrent improvement of community supports until about 1993, when states allocated more dollars to community mental health programs.<sup>9</sup> Community programs were sparsely implemented and were rarely evaluated. Successful model programs were not systematically identified as standards of excellence for replication on a broader scale.

In 1993, President Clinton attempted to bring policy recommendations to fruition by including in his health care reform proposal a national system of HCBS based not on age but on levels of disability. Clinton's proposal included flexibility for states to include social services, transportation, and meals, without which no home services plan is meaningful or sustainable. The proposal was not embraced, but the policy debates were productive and created the momentum that continues today.

### ***Olmstead (1999) and Beyond***

In 1999, the US Supreme Court's *Olmstead* decision and the Americans with Disabilities Act shifted the focus of HCBS policy and service delivery. A person's civil right to make decisions about long-term care services in his/her least restrictive and most integrated setting is now driving policy discussions and creating a tension about population-based policy assumptions of the past. Subsequent to *Olmstead*, the combined voices of government, consumers, and advocates called for a reversal of the Medicaid bias embodied by the public entitlement to institutional long-term care and the limited or capped access to home and community-based services. The US Supreme Court found basis for that reform in the *Americans with Disabilities Act (ADA)*. The *Olmstead* decision challenged states to re-examine service delivery systems across the board to ensure that individuals were not institutionalized unjustly and that they could access services in the least restrictive environment and the most integrated setting. Policy makers can no longer assume that they know the best quantity and type of services needed based on diagnoses or specific disabling conditions. The consumer's civil right to decide changes the HCBS policy landscape from separate population-based profiles to a broad and diverse customer base.

Under *Olmstead* initiatives, states and their respective provider networks have shifted their attention from distinct service delivery systems to broader-based consumer information about services at home, in the workplace, and in the community at large. States such as Texas, New Jersey, Kansas, and Pennsylvania are re-organizing at the state

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<sup>8</sup> DHHS Office of the Inspector General (2001).

<sup>9</sup> Koyanagi, C. (2007).

level. New collaborations are taking place in local communities to capitalize on successful service delivery models and to achieve efficiencies in providing information about community-based supports. Aging and Disability Resource Centers,<sup>10</sup> Centers for Independent Living, non-profits, and Area Agencies on Aging are building single entry point concepts and leading local collaborations between the networks providing services for seniors and those experienced in serving younger persons with disabilities. In this mix of public policy shifts and population growth, states are repositioning both state agency organization and local service delivery systems to better accommodate a wider range of consumer requests for supports in community settings.

The forward momentum on health care reform and *Olmstead* has resulted in opportunities and flexibilities for states under the *Deficit Reduction Act* (DRA) of 2005, which focus on broad deinstitutionalization efforts as a method for long-term care reform. Financing and policy initiatives under the DRA include incentives for cost reduction strategies and increasing access to HCBS for Medicaid's highest cost users. Although some infrastructure exists for deinstitutionalizing the two largest subgroups of the long-term care population, long-stay facility residents who don't meet those profiles often remain in the institution by default or choose an HCBS option that doesn't quite fit their needs.

## **Long-Term Care Facility Users and Their Costs**

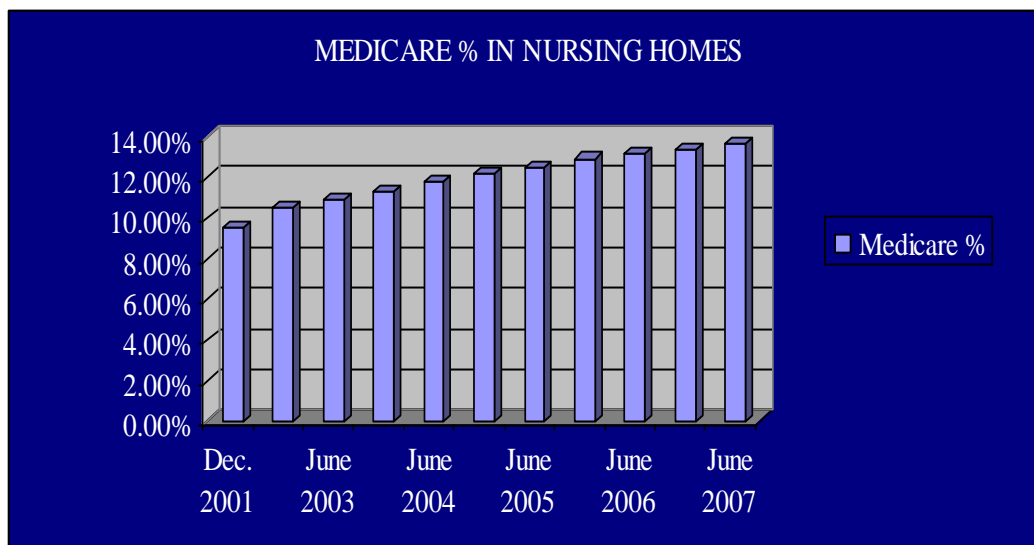
### ***Numbers and Needs***

Medicare and Medicaid policies have been intertwined and interrelated from the beginning. With changes in Medicare and the numbers of aging boomers, reimbursement opportunities favor short acute hospital or rehabilitation facility stays for those recuperating from an acute episode. Because Medicare is perceived to be a better payer than Medicaid, nursing facility providers have increased their emphasis on rehabilitation and have positioned themselves as lower cost service providers, compared to specialized rehabilitation hospitals. The table below, from Medicare's Online Survey, Certification and Reporting (OSCAR) shows the growth in the percentage of Medicare patients served in nursing facilities.

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<sup>10</sup> Read about Aging and Disability Resource Centers at [http://www.aoa.gov/prof/aging\\_dis/aging\\_dis.asp](http://www.aoa.gov/prof/aging_dis/aging_dis.asp)

**Figure 1: Growth in the Percentage of Nursing Facility Resident Stays Paid for by Medicare December 2001 – June 2007<sup>11</sup>**



In post-acute care (PAC) settings, Medicare generally pays as long as the individual demonstrates progress on treatment plan goals. To date, Medicare’s PAC benefits and payment policies have focused on a phase of illness (e.g., acute, post-acute, rehabilitation) as defined by the setting in which services are delivered, rather than on the care needs of the consumer. Medicare provider payments across PAC settings can differ even when the clinical characteristics of consumers are the same and services delivered are similar. Additionally, each provider setting has a different prospective payment rate based on separate and distinct assessment tools and data sets.<sup>12</sup> After a hospitalization, providers and consumers alike must navigate a confusing maze of Medicare service coverage depending on where PAC services are to be delivered. Coordination and communication between treatment settings and providers is challenging even for informed care managers. A transition from Medicare to Medicaid and/or coordination between the two sets of eligibility criteria and benefits adds to consumers’ dilemmas.

When rehabilitation efforts have not resulted in increases to a person’s abilities and daily functions, Medicare ceases coverage. Medicare also has a cap on the number of days it will pay for nursing facility care. Those who are not progressing and have been assessed to need continual assistance with activities of daily living are often referred to as “custodial care” facility residents. Who are these long-stay residents? What are their needs? What brought them to the nursing facility? What assumptions can be used by policy makers to tailor transition services and HCBS systems? This is the very population that is the focus of the DRA MFP demonstration.

Long-stay facility residents are those who no longer have Medicare coverage and whose source of payment shifts to private out-of-pocket payments, private insurance

<sup>11</sup> Medicare Data available at <http://www.resdac.umn.edu/Medicare/Index.asp>

<sup>12</sup> CMS Policy Council Document (2006).

coverage, or Medicaid. These long-stay institutional residents are included in descriptions and counts of Medicaid's highest cost users. Along with payments for facility stays, these individuals incur costs for physician visits, equipment, drugs, and supplies associated with long-term disabling diseases and conditions. Medicaid spending for institutional care is well documented as providing the impetus for state and federal policy initiatives to reduce spending.

However, details of the ideal cost containment policy remain a chicken-and-egg conundrum. Do you build it (adequate HCBS) before they come or will building it result in even more users and higher costs than planned? In 2001, 1.1% of Medicaid users spent more than \$50,000 per year, and this segment accounts for over a quarter (25.7%) of all Medicaid spending, or \$46.2 billion.<sup>13</sup> Within elderly users, 14% were institutional residents who used 54% of the total expenditures for all elderly Medicaid enrollees. This same 2001 study showed that overall, 48% of spending for high-cost users was attributable to long-term institutional care, including care for those with mental retardation (including developmental disabilities) and individuals with mental illness. In 2004, Medicaid spending for institutional care grew to \$64.8 billion. The urgency and reasons for cost containment strategies are clear. How those costs are contained through HCBS reforms is less clear.

Efforts to control costs by tightening restrictions on outpatient care have not been effective and can drive up costs unnecessarily when providers seek higher reimbursement incentives. Limits on post-acute and in-home services (such as flat rates or other limits) have resulted in unnecessary, prolonged, and costly facility stays with increased costs to the taxpayer (through Medicare and Medicaid) and increased costs to insurance companies, which are passed on to privately covered consumers in the form of higher premiums.<sup>14</sup>

Virtually all high-cost Medicaid users are elderly or disabled, but this information is still too general to inform HCBS policy makers. Long-term care users are not exclusively seniors or those who have always been in poverty or in need of public assistance. Catastrophic illness such as cancer, trauma caused by accidents (motor cycle, skiing, motor vehicle, etc.), near drowning incidents resulting in brain injuries, and multiple chronic conditions such as heart disease and diabetes can result in the need for long-term supports and dependence on Medicaid coverage. A Kaiser Commission paper<sup>15</sup> describes six long-term care user profiles and the conditions that cause them to need high cost Medicaid benefits. They are:

- Children who are born prematurely;
- Children receiving foster care;
- Adults and children with spinal cord and traumatic brain injuries (near death drowning, motor vehicle accidents, ski, diving and skateboard accidents, and others);

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<sup>13</sup> Sommers, A., & Cohen, M. (2006).

<sup>14</sup> Hall, M. & Owings, M.F. (2002).

<sup>15</sup> Crowley, J. & O'Malley, M. (2006).

- Adults and children with mental illness (schizophrenia, bi-polar, major depression, paranoia, and others);
- Adults and children with intellectual and developmental disabilities (autism, cerebral palsy, mental retardation, and others); and,
- Adults with Alzheimer's disease and other dementias.

Additional groups of long-term care facility users can include:

- Primarily adults with co-occurring medical conditions, including mental retardation, substance abuse-related conditions, and/or mental illness;
- Adults who develop secondary conditions when aging with physical disability;<sup>16</sup>
- Liver transplant recipients, depending on health and follow-up care;<sup>17</sup>
- Adults and children with AIDS and related conditions;
- Primarily adults with degenerative neurological disorders such as multiple sclerosis and Parkinson's disease; and,
- Seniors who are victims of crime.<sup>18</sup>

This is not a comprehensive list. In the years to come, greater numbers of persons will be limited by one or more chronic conditions.<sup>19</sup> The American Academy of Home Care Physicians, focusing primarily on Medicare coverage, presents a position that single disease patient education and care management approaches will not work for this high cost population. About 20% of Medicare beneficiaries have five or more chronic conditions, account for over two-thirds of Medicare spending, see about 14 different physicians in a year, and have almost 40 office visits annually.<sup>20</sup> Additionally, the number of chronic conditions has more influence than age on health care spending, at least in the Medicare population. In 1990, direct medical costs for persons with chronic conditions were found to be approximately \$425 billion, with over half of those costs going for hospital and nursing facility care.<sup>21</sup> Of the 88.5 million individuals with chronic conditions, 44% had two or more conditions (co-morbidity), with women having more co-morbidities than men.

Physicians assert the need for active involvement of themselves and their teams if improved outcomes and lower costs are to be achieved.<sup>22</sup> However, the role of physicians in planning HCBS is subject to debate. Additionally, there is an uneven physician interest in, and availability for, involvement in chronic care and physical disability management. Clinical literature is plentiful on disease-specific profiles of this costly population (e.g., congestive heart failure and diabetes) but there is little agreement and even less public education for consumers who want to manage their chronic

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<sup>16</sup> Kemp, B. et.al. (2004).

<sup>17</sup> Levitsky, J., & Cohen, S.M., (2006).

<sup>18</sup> Lachs, M. (2006).

<sup>19</sup> Hoffman, C. & Rice, D. (1995) using 1993 National Health Interview Survey data.

<sup>20</sup> Berenson, R. (2004).

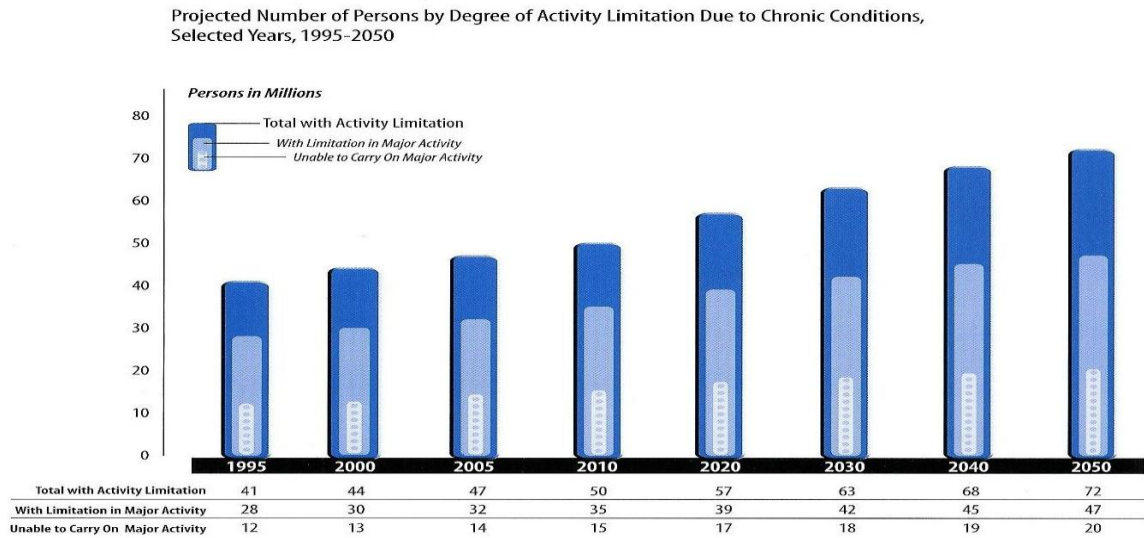
<sup>21</sup> Hoffman, C. & Rice, D. (1995) using National Medical Expenditure Survey 1987 data.

<sup>22</sup> American Academy of Home Care Physicians position papers can be found at <http://www.aahcp.org/publicpolicy.shtml>

conditions and disabilities in a community setting. Consumers are left to their own devices to piece together their medical and service provider team.

“Chronic conditions” serves as a catch-all phrase that causes frustration for both medical professionals and the consumer because it implies a persistent state that requires a degree of acceptance of a maintenance regime instead of a cure. After a short rehab period to see if conditions respond to therapies, for example, chronic conditions may stabilize or be manageable for periods of time. They may also become acute again, especially when there are multiple interacting conditions and treatments. Between acute episodes, chronic care patients typically have an ongoing need for assistance with daily living.

**Figure 2: Projected Number of Persons by Degree of Activity Limitation Due to Chronic Conditions, Selected Years, 1995 - 2050**



**What is “Custodial Care?”**

Nursing facilities serve two general populations of users. Some are there for short stays associated with rehabilitation, and some are there for long-term stays related to ongoing chronic conditions and assistance with daily activities.<sup>23</sup> Long-term facility users who have reached a plateau and are no longer benefiting from rehabilitation are described as having ongoing “custodial care” needs. The definitions for custodial care vary and are less than helpful in describing the specific service needs of this growing and costly population. Definitions for custodial care and the sources of the definition include:

US Health and Human Services: Medicare doesn’t pay for this type of care called custodial care. Custodial care (non-skilled care) is care that helps with activities of daily living. It may also include care that most people do for themselves, for

<sup>23</sup> Korbin L., et al. (1994).

example, diabetes monitoring.

US Veterans Administration: Treatment or services, regardless of who recommends such treatment or services, or where such treatment or services are provided: (1) that can be rendered safely and reasonably by a person who is not medically skilled; (2) that is designed mainly to help the patient with the activities of daily living.

Rupp's Insurance & Risk Management Glossary (2002): Assistance with activities of daily living, whether in a residential care facility or at home, including help in walking, bathing, preparing meals and special diets, and supervising use of medications. These services normally do not require trained medical professionals, though residential care facilities often must be state licensed. Custodial care is usually not covered by health insurance plans.

Investopedia Website: Non-medical care that helps individuals with his or her activities of daily living, preparation of special diets, and self-administration of medication not requiring constant attention of medical personnel. Providers of custodial care are not required to undergo medical training.<sup>24</sup>

Senior Health Website: Generally, care is considered skilled when a trained professional must do it, because the care is changing frequently and there is a need for professional assessment of efficacy or condition. Care is considered to be custodial when the patient is stable and the care needs have not changed, nor are they expected to change much, and the care is routine enough to teach any competent adult to perform this care.<sup>25</sup>

North Carolina Health Plan: Custodial care is care designed essentially to assist an individual in his activities of daily living, with or without routine nursing care and the supervisory care of a doctor. While some skilled services are provided, the patient does not require continuing skilled service 24-hours daily. The individual is not under specific medical, surgical, or psychiatric treatment to reduce a physical or mental disability, to the extent necessary to enable the patient to live outside an institution providing care, nor is there reasonable likelihood that the disability will be reduced to that level even with treatment.<sup>26</sup>

The definitions of custodial care paint a bleak picture of the assistance available to these high-cost users, especially in light of analyses that show they have ongoing complex chronic conditions, dementia, chronic and intractable pain, co-existing disabilities, and conditions that are not expected to improve or be “cured.” This population is clinically complex, high-cost, and is subject to recurring acute episodes. According to home care physicians, the definition of custodial care does not seem to

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<sup>24</sup> See : <http://www.investopedia.com/terms/c/custodialcare.asp>

<sup>25</sup> See: <http://seniorhealth.about.com/library/FAQ/blqa10.htm>

<sup>26</sup> This is one of the more detailed discussions of custodial care. The definition goes on to describe the policy for coverage [http://statehealthplan.state.nc.us/pdf/IN0250\\_12.05.pdf](http://statehealthplan.state.nc.us/pdf/IN0250_12.05.pdf)

adequately describe this growing population or the types of services they will need in a community setting. This lack of specificity further marginalizes this group of health care users.

Prospects to transition back to community living from a facility are made even more difficult when state-designated criteria for admission to limited Medicaid HCBS waivers requires HCBS applicants to meet specific diagnostic requirements and specific skilled nursing needs. Medical and social service professionals disagree about whether they need more, less, or more diverse types of HCBS services. Individuals with non-specific custodial care needs can get virtually and literally stuck in the long-term care system, especially when they can remain in the nursing homes for years without ever having their functional eligibility reassessed.

Transition prospects are also minimized in the 30 states that use a Medically Needy program for nursing home financial eligibility. If the state does not also use a Medically Needy program for home and community services, then it is possible for a person who has been Medicaid-eligible in the nursing home for years to lose eligibility upon leaving the home for an HCBS setting. Such persons are “over income” in the community because there is no corresponding Medically Needy program for HCBS services. This setting-based eligibility creates an economic coercion that circumscribes freedom of choice.

### ***Psychological Impact of Long Institutional Stays***

Custodial care residents are affected in other ways by living in a health care facility for a long-stay. Even if facility placement happens with informed consumer consent, it impacts a person’s psychological and social wellbeing, affecting how he/she might respond to transition opportunities. Institutional residents adapt with “learned helplessness and instrumental passivity.”<sup>27</sup> Advocates have made clear that the longer a person resides in an institution, the longer the process for providing information and making all the decisions that lead up to transitioning back to community living. Depression impacts a person’s interest in any change, let alone a life-changing decision to relocate. Depression among nursing facility residents can run as high as 25%. Institutional living erodes self-confidence and the ability to envision a future in the community, even with supports.<sup>28</sup>

### ***Longer Lives, More Life Decisions***

Older Americans have become a highly diverse group; younger populations of users will be even more so.<sup>29</sup> The diversity of long-term care users goes beyond ethnicity and economics and includes unique expressions of giving and receiving care within social groups. Living longer increases the time that individuals must deal with a multitude of chronic conditions and disabilities that place those individuals, including children, at risk

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<sup>27</sup> Voelkl, J. E. (1985).

<sup>28</sup> Gruber-Baldini, A. L, et al. (2005).

<sup>29</sup> Day, J.C. (1992).



for needing an even broader array of services and supports from others.<sup>30</sup> With improvements in medicine and general health practices, as individuals age they do not all experience a downward trend of function and wellness. Rather, it is more typical to have health transitions across provider types, settings, and experiences with an array of interventions, rehabilitation, medical, and social supports over a lifetime.

Improvements of public health and access to health care have resulted in longer lives and dramatic changes in the characteristics of long-term care users. New users of long-term care services have emerged as those individuals are living longer with a wider variety of chronic conditions and disabilities. Medical advances that blur boundaries between acute hospital care and the need for new forms of long-term care include the emerging treatments for cardiovascular disease, congestive heart failure, osteoporosis, cataracts, gastritis, ulcers, and End Stage Renal Disease.<sup>31</sup> Advances in antibiotics, emergency response, the use of technical equipment, and other new interventions have had direct impact on length of stay in facilities and how community-based supports can be delivered. Improvements in public health policy have increased the general life expectancy; better drinking water, avoidance of toxic substances, improved nutrition, etc. Diseases that were at one time death sentences can now be controlled or at least managed to some degree with medications, therapies, and preventive treatments; for example, diabetes, multiple sclerosis, and others. Disabilities, which were in the past sources of shame and discrimination, are overcome with pride and determination. Technological advances, synthetic materials, and electronics have resulted in improvements to prosthetics, ventilators, and custom wheelchairs. Information on assistive devices is becoming more available through the assistive technology libraries and the Internet.

### **The Current HCBS Policy Environment**

States and local communities have responded over the years to federal funding opportunities and to consumer demand for HCBS with multiple Medicaid HCBS waivers, privately funded pilot projects, local volunteer programs, and community-based collaborative systems. Medicaid HCBS waivers are limited: targeted to a narrow user profile, used with enrollment caps that lead to wait lists, capped for costs, targeted to geographically distinct areas, or planned for only a temporary demonstration, similar to the patchwork of community mental health programs of the past. By 2006, there were 329 waivers spending \$25.6 billion in state and federal Medicaid dollars.<sup>32</sup>

The cumulative impact of these capped and targeted waivers is to balkanize eligibility into limited “target groups” and create more complicated state regulatory environments for state and local workers. In the midst of this waiver complexity, whether driven by local leadership, state initiatives, or federal funding opportunities, states are actively reworking HCBS policy to embrace a broader mix of users who prefer

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<sup>30</sup> Kingson, E. R. (1992).

<sup>31</sup> Manton, K. G., Stallard, E., (1996).

<sup>32</sup> Information retrievable from HCBS.org at <http://www.hcbs.org/files/122/6068/HCBSWaivers2006—Table1.xls>

to transition from facility care, or ideally to avoid facility placement before it happens. Consumers, advocates, providers, and other stakeholders are coming to the table to advance HCBS policy agenda. Concurrently, old practices and existing programs are defended by vested interests, making it difficult to adopt new assumptions and new technology that can keep costs in check.

Lessons for deinstitutionalizing a diverse resident population, as envisioned by the DRA, are presented in a Kaiser Commission on Medicaid and the Uninsured issue paper.<sup>33</sup> HCBS alternatives can come to scale if Medicaid, Medicare, and other programs are coordinated to provide high quality services in community settings. Savings may not be realized until there is a reduction of institutional beds. Sustained momentum for change is critical due to the technical and policy issues that arise with services provided at home or in the workplace. Unfortunately, now that there is more technical information about HCBS programming, the political will for long-term care reforms lags or gets overshadowed by Medicaid managed acute care programs or proposals to reduce the number of persons with transitory or no health insurance.

When HCBS reforms are initiated at the state level, state policy leaders depend on assurances that flexibility will be provided to accomplish state goals. The current strategic plan adopted by the CMS Disabled and Elderly Program Group provides policy touchstones that will guide federal approval of state HCBS reforms. Those principles, applicable to multiple federal programs, also call for focus on consumer choice, self-direction, and the consumer's responsibility for informed decision making.<sup>34</sup>

### ***Critical Leadership***

Discussions about living independently with chronic conditions or disabilities have new dimension and meaning when policy makers are also users, who can testify first-hand to the value of long-term supports. These policy leaders are changing the landscape and the climate for developing sane and sustainable HCBS policy. For example, Richard Devylder, a highly respected California government official, has chosen to make public his story of living independently without arms or legs.<sup>35</sup> The late Mary Ann Jones was executive director of the Westside Center for Independent Living in southern California. She had been a quadriplegic since the age of 23, having broken her neck diving off the end of a dock while on a family camping trip in 1967. She died on Sept. 23, 2007, as a result of pulmonary embolisms. She was 63.<sup>36</sup> Christopher Reeve raised public awareness of his spinal cord injury and his motivation to stay connected to his world. His story also raised the technical and political issues associated with the pursuit of research using embryonic stem cells to advance treatment and cure options for those with spinal cord injuries, Alzheimer's, Parkinson's, diabetes, and other conditions.<sup>37</sup> Old assumptions about why a person can only be safe in a health care

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<sup>33</sup> Koyanagi, C. (2007).

<sup>34</sup> CMS Disabled and Elderly Program Group 2007-2009 Strategic Action Plan.

<sup>35</sup> Download video at [http://www.rehab.cahwnet.gov/rd\\_video.htm](http://www.rehab.cahwnet.gov/rd_video.htm)

<sup>36</sup> Full story available at <http://www.latimes.com/news/printedition/california/la-me-jones1oct01.1.7993468.story?coll=la-headlines-pe-california>

<sup>37</sup> CNN/Health (2001).

institution no longer apply. Advocates call for what most of us take for granted: the opportunity to assert the right to make informed decisions and to accept responsibility for any risk that is associated with those individual life decisions.

### ***More Political Players***

The array of stakeholders in long-term care debates has expanded from nursing home trade associations to a broader assortment of home health industry providers, community organizations, local governments, managed care plans, personal care worker unions, as well as specific philanthropic organizations and advocates for emerging problems. New entities want to contribute their perspectives to the dialog on long-term care as states implement *Olmstead* initiatives. Some are calling for change, while some are defending the status quo. Industry competition and unions play an increasingly active role in long-term care<sup>38</sup>. Along with cost neutrality calculations come comparisons between facility provider payment and home health agency services payments calling for equity and a “level playing field.” States that implemented bed tax payment methodologies for nursing facility providers may be asked to implement similar payment methodologies for other provider groups, such as home health. Bed tax initiatives are major state budget initiatives that enable higher provider reimbursements and increased opportunities for states to leverage valuable federal funding.<sup>39</sup> Debates also occur around acuity-based reimbursements for facility and HCBS providers. Reforms, even if viewed as positive consumer-based reforms, get bogged down in political wrangling.

The focus on consumer access to HCBS quickly migrates to a discussion about available licensed and unlicensed workforce, wage and benefit issues, union representation, preserving family caregivers, training programs for nurses, reimbursement, and other infrastructure and financing issues. States vary on the factors that are driving the HCBS policy debates, depending on which advocates have the loudest voices or which leaders have the largest following. Certain states have focused on service delivery by launching high-level Governor’s initiatives, and others are going about incremental system changes by improving educational opportunities for nurses.<sup>40</sup> Single Points of Entry or No Wrong Door systems rally local resources to uniformly inform consumers of HCBS choices and at the same time eliminate duplicative administrative overhead.<sup>41</sup>

## **The Challenges that Come with Choice**

Broadly based deinstitutionalization, as envisioned by the MFP Rebalancing

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<sup>38</sup> The Service Employees International Union (SEIU) SEIU is the largest union of long-term care workers in the United States with 350,000 home care and 150,000 nursing home workers. See: [http://www.seiu.org/about/fast\\_facts/](http://www.seiu.org/about/fast_facts/)

<sup>39</sup> National Conference of State Legislatures (2007).

<sup>40</sup> View the report on the California Nurses Initiative at: <http://www.labor.ca.gov/CNEIAnnualReport100406.pdf>

<sup>41</sup> For example, see South Carolina’s work on a state wide telephone system described at the Rutgers Center for State Health Policy’s site: <http://www.cshp.rutgers.edu/cle/Products/7480.pdf>

Demonstration, requires widely available consumer-friendly information about HCBS alternatives. States implementing the MFP Demo are grappling with determining what type and amount of information is needed for a consumer with ongoing chronic care needs and disabilities to make meaningful and informed decisions about long-term care services.<sup>42</sup> Federal policies for HCBS service delivery emphasize the importance of informed consumer decisions that require states and HCBS providers to retool intake and screening procedures and to offer consumer-friendly service planning. HCBS service delivery, that in the past was designed to protect, is now viewed by contemporary users as overly paternalistic, restrictive, and unnecessarily focused on medical conditions and functional deficits. Advocates for younger persons with disabilities are quick to point out that every HCBS recipient does not want a high-level of intervention by others managing their care. HCBS providers are faced with accommodating choice, while at the same time being held accountable for health and safety. Providers need contemporary administrative tools for the today's HCBS customer.

### *Quality*

While HCBS service planning models are widely available, they have not been fully evaluated or incorporated as standard practices.<sup>43</sup> Analyses of quality and consumer outcomes have been focused on narrowly defined target populations,<sup>44</sup> specific service delivery models (e.g., cash and counseling),<sup>45</sup> or a financing strategy (e.g., managed care).<sup>46</sup> Quality protocols for HCBS waivers are required but are currently designed for a narrowly targeted population and may not translate to the broader array of today's HCBS user groups, let alone those with custodial care needs. States are investing in formal evaluations to identify what works well and what doesn't, under Medicaid waivers, but broad evaluations of quality HCBS in the home or workplace are still under development. The HCBS Clearinghouse for the Community Living Exchange is a vital hub of information sharing, training, and technical assistance for more than 180 recipients of Systems Change Grants for Community Living in all 50 states, two territories, and the District of Columbia.<sup>47</sup> Technical models and tools for identifying high quality HCBS are available for states to use on a broader scale and for system-wide application.

While deinstitutionalization initiatives have a long history, establishment of HCBS excellence, best practices, and financing models on a large scale are just now emerging as core mainstream public long-term care policy. States are only now beginning to view self-evaluations of HCBS as a source for formalizing and improving HCBS systems.<sup>48</sup> Policy makers are reasonably hesitant to broadly implement initiatives

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<sup>42</sup> See the State of Minnesota's (2007) Department of Human Services, Continuing Care Administration, Request for Proposals: *To Study and Report on Housing with Services, Assisted Living and In-Home provider services*. Retrieved 12-13-07

[http://www.dhs.state.mn.us/main/groups/business\\_partners/documents/pub/dhs16\\_139472.pdf](http://www.dhs.state.mn.us/main/groups/business_partners/documents/pub/dhs16_139472.pdf)

<sup>43</sup> Koyanagi, C. et al. (2007).

<sup>44</sup> Read about quality at <http://www.nasddd.org/StateHCBSWaiverQualityManagementStrategies.shtml>

<sup>45</sup> Applebaum, R., Schneider, B., Kunkel, S., & Davis, S. (2004).

<sup>46</sup> Read about quality at: <http://www.ncqa.org/some2001/>

<sup>47</sup> Find information about other states at: <http://www.hcbs.org/>

<sup>48</sup> Booth, M. et al. (2005).

that have not been validated for quality and evaluated for costs. Widely accepted indicators that demonstrate HCBS users are happier and healthier in the community setting are difficult to replicate because of the multiplicity of factors that make up a successful home or workplace focused service plan.

Quality standards for nursing facilities have evolved over years as have state and federal mandates for licensure, Medicaid and Medicare certification, complaint handling, and quality. For facility residents there are federally required protocols and regulations that are intended to safeguard resident outcomes. HCBS quality protocols have not evolved to that same level of sophistication and oversight. The public and advocates are calling for a shift from facility care, but they do not agree on what success looks like. What gold standards apply to community-based care for a broad and diverse consumer public? A one-size fits all HCBS system will not meet the needs of the diverse group of users.<sup>49</sup> The Centers for Medicare & Medicaid Services (CMS) requires that states ensure global HCBS quality, but there has been little in the way of specific expectations. Instead of the traditional monitoring and sanction methods of oversight, HCBS alternatives are conducive to operating models and quality measures that afford the individual consumer the opportunity to be a co-producer of quality.<sup>50</sup>

### ***Case Management or Self Management***

Federal HCBS requirements have evolved to keep pace with current and evolving HCBS practice. For example, state requirements that a doctor approve admission to Medicaid waiver services are now seen as unnecessary, especially given that the federal Medicaid regulations do not require a doctor's authorization.<sup>51</sup> Care planners are expected to work as partners and navigators instead of being the chief engineer. For example, a Real Choice grant enabled the Support and Techniques for Empowering People (STEP) initiative in Montana. The STEP initiative is geared toward families of children with developmental disabilities and provides training in self advocacy and service planning. The Empowering Parents curriculum asserts that parents can acquire the information, skills, and tools to make decisions about services that meet the family's preferred quality of life.<sup>52</sup> The New Jersey Association of Centers for Independent Living website provides resources dedicated to information and skill building for individuals wanting to transition from facility to community living.<sup>53</sup> These two examples empower consumers and their circles of supports no matter the specifics of age or disability.

Advocates in California have made clear that not everyone wants a case manager. Decisions about who manages services goes hand-in-hand with the notion that individuals seem to prefer the highest level of self-determination and control for as long as possible, provided they have the information and will to do so. HCBS systems can

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<sup>49</sup> Angel, R. J. & Angel, J. L., (1996).

<sup>50</sup> Auerbach, R. & Hamilton, T. (2003).

<sup>51</sup> Mollica, R. & Reinhard, S. (2005).

<sup>52</sup> Moore, D. (2007).

<sup>53</sup> Welcome Home website <http://www.nursingfacilitytransition.org/>

focus on a person's "right to flourish"<sup>54</sup> and right to be in charge of life decisions. In the broadest sense, self-determination is "a combination of attitudes, beliefs and skills that enable people to gain control over their lives and work toward personal goals."<sup>55</sup> Long-term care users seem to vary widely on how much and what types of formal supports they need or want, regardless of their "assessed" frailty. The questions need to be asked and information provided in order for consumers to make sound decisions.

Policy that guides discussions with consumers about the degree of intervention by HCBS service providers offers an opportunity to streamline and tailor HCBS systems. Screening and assessment procedures that assume incapacity and frailty can undermine an already marginalized consumer population. Interventions by social workers, nurses, attendants, and others can be modulated based on informed consumer decisions so that the consumer retains the greatest degree of control and self-management for as long as possible. If formal supports and comprehensive case management is the norm and the only model available, an HCBS system can actually increase dependency and increase costs unnecessarily. An inventory of case management models across HCBS waivers and provider networks typically includes differing characteristics of case management.<sup>56</sup> Additionally, case management interventions can be very narrowly focused on single sub-sets of services resulting in confusion rather than help when individuals have numerous, duplicative, and expensive case managers.

### **Risk**

Consumers intending to maintain decision control may choose to assert their right to accept a degree of risk in order to remain engaged with their home and community. *Revisiting Choice* points out that just as preference is personal, so is risk.<sup>57</sup> Stories come to light daily about successful persons living with disabilities, managing assistive services and devices, and accepting a degree of risk that comes with leading a lifestyle that is meaningful.

States have been assessing and addressing risk under HCBS programming for decades.<sup>58</sup> However, formal assessments of risk are often buried in procedures that assess medical conditions and functional deficits. Risk is personal. In New York, service planners use a *Plan for Protective Oversight* when arranging HCBS for those living with traumatic brain injuries.<sup>59</sup> Vermont has an agreement called *The Informed Consent and Negotiated Risk Policy*. It commits the consumer, the surrogate decision maker if there is one, and the service provider to a negotiation process and outcome. Written negotiated risk agreements are not without controversy.<sup>60</sup> The element of risk is presented in this discussion as a reminder that, as in the domains of medical conditions, functional deficits and behavioral challenges, risk is highly personalized. It entails highly personalized

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<sup>54</sup> Cohen, E. (2003).

<sup>55</sup> Text available at Wisconsin Council on Developmental Disabilities website: <http://www.wcdd.org>

<sup>56</sup> Scharlach, A., E., et al. (2001).

<sup>57</sup> Smull, M.W. (1995).

<sup>58</sup> Galantowicz, S., et al. (2003).

<sup>59</sup> Galantowicz, S., et al. (2003).

<sup>60</sup> Carlson, E. (2003).

planning discussions that seek out consumer decisions and supply whatever information is needed to make those decisions.

When consumer decisions and preferences are the driving principles for service planning, it is logical to have service plans that identify and address the risks that accompany those preferences: not that it is simple. In each case, the user's right to make informed choices competes with the state's responsibility to ensure health and well-being. Especially in the case of transition to the home, caregivers and providers often focus on the risk when the consumer may focus on independence and freedom. In the case of elderly persons or persons with terminal illnesses, the discussion may reflect how an individual wants to spend his/her remaining years, months or days. Discussing risks and documenting how each risk is addressed adds additional dimension and time to monitoring and revising plans as situations and risks change. Where facility regulations have mandated protocols for patients at risk (e.g., falls, seizures, drug interactions, etc.) the same universal requirements for HCBS are not universally applied. Identifying and mediating risks in a community setting apply only to certain provider types such as licensed and certified home health agencies. Safeguards are inconsistent, leaving consumers at a risky disadvantage.<sup>61</sup>

### **The Vision and How to Get There From Here**

Whether under state *Olmstead* initiatives or under the DRA MFP Demonstration, states have the opportunity to advance HCBS policy that spans broadly available HCBS alternatives to costly institutional care. The challenges are many, resources are slim, but the pay-off has potential to be the proverbial win-win situation; lowering health care costs while at the same time, supporting consumers' preferences and motivation to remain independent and engaged in community life. The challenge with approaching HCBS reform across populations includes preserving the general policies that are universal to all HCBS users and eliminating population-based assumptions that screen out individuals who don't fit user profiles. Tools that other states have used to accomplish uniformity are shared through the Clearinghouse for the Community Living Exchange Collaborative.<sup>62</sup> Consistency with CMS strategic plans and reforms for Medicare PAC services underscores the important components of this vision.

#### ***Refocus on Consumer Decisions***

Standards for facilitating consumer decisions about HCBS have not had the same broad application as health care decisions in institutional settings. Consumers need to be assured that their rights to make decisions about their personal living situations are preserved, especially considering the number of health care episodes and transitions made by a person with long-term, chronic, or disabling conditions. In 1991, facilities and other long-term care providers were required to comply with the federal *Patient Self-*

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<sup>61</sup> A MEDSTAT report, *Risk Management and Quality in HCBS*, is a wealth of information on this subject and includes references for very specific and helpful administrative tools. See Galantowicz, S., et al. (2003).

<sup>62</sup> The Clearinghouse for Community Living Exchange Collaborative is found at <http://www.hcbs.org/>

*Determination Act*, which has at its core the intent and responsibility to inform individuals about their rights to assert advanced health care directives and to have those directives respected and implemented.<sup>63</sup>

Institutional providers are required to have procedures to implement resident decision making, even when there are mental capacity issues. On the other hand, HCBS providers across the board may not have the same level of experience with facilitating and documenting health care decisions, with the exception of certified home health agencies that are subject to federal Medicare and Medicaid requirements. Services providers such as case managers, personal care services attendants, and community organizations vary in their level of sophistication and experience in dealing with complex and emotional health care decisions, advance directives, and end-of-life events.

Consumer decisions about HCBS are based on how a person views his or her disability and level of dependency on others for assistance: a humbling situation for anyone who values independence. Active adults living with physical disability do not lose decision-making capacity; they simply cannot do for themselves what a non-disabled individual can do.<sup>64</sup> How individuals feel about planning and receiving help from others depends greatly on a personal vision of quality of life and their history of giving and receiving care over a lifetime. Sustainable and broad HCBS policy incorporates a renewed focus on the rights of individuals to have power over their own lives.<sup>65</sup> After the *Olmstead* decision, states reminded policy makers of this right through legislative resolutions or Governor's initiatives. For example, the Kansas legislature renewed its commitment to the inherent dignity of an individual by passing a bill that asserts that individuals needing long-term care are entitled to enjoy health, honor, and dignity. The Kansas bill sets forth principles that guide future HCBS policy in the state.<sup>66</sup>

HCBS providers and service planners must also be prepared to conduct planning activities with surrogate decision makers. Under a Real Choice grant, the state of California initiated a *California Pathways* project. Its team encountered reactions from facility residents, from authorized surrogate decision makers, and from concerned family members when discussing the subject of transitions back to home. Surrogate decision maker responses ranged from being interested in learning more, to being resistant and even hostile to any change in the status quo. How and to what degree should transition coordinators challenge the dynamics of a family and the person's relationships with concerned others? There is no pat answer, of course. The point being that HCBS policy discussions can prepare service planners for an infinite range of family anecdotes. Even more complex situations arise when there is reduced mental capacity (e.g., dementia) but there has been no prior designated health care agent. In other situations, an individual may be mentally competent and able to make decisions, but defers voluntarily to others. The complexity of individual family and social dynamics argues for renewed technical attention to procedures for identifying authorized decision makers so that there is

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<sup>63</sup> Winn, P. & Cook, J. (2000).

<sup>64</sup> Wyoming Independent Living Rehabilitation: <http://www.wilr.org/sdc.html>

<sup>65</sup> Wisconsin Council of Developmental Disabilities: [http://wcdd.org/07stateplan/self\\_determination.cfm](http://wcdd.org/07stateplan/self_determination.cfm)

<sup>66</sup> Kansas AARP Long-term Care Bill of Rights, SB 490, statutes of 2006



consistency between what the consumer wants and what HCBS service planners plan.

At the federal level, it may be useful to rethink how waivers are used. Is it possible to build a wavier program that focuses on the services that persons want and need rather than the target group they are within? For example, a recurrent situation across nursing home transition programs is a that a nursing home resident with some mental health problems will be stuck in the nursing home, since aged and disabled waiver policies often say a person with mental health issues is not eligible for their waivers and should get mental health services from some other state department. However, the transition worker finds that there are little or no community mental health services available for this person. Can a renewed federal waiver policy deemphasize “target groups” and emphasize the services that eligible persons think they need? What statutory or federal regulatory changes are necessary to do away with “target groups”?

### ***Identify Personal Preferences***

Under *California Pathways*, the state and the project team opted for a proactive approach to identifying transition candidates. The project team went directly to facility residents with a direct question about their preference to return to community living. The California project relied on a consumer’s own stated personal preference for a less restrictive and more integrated setting. The absence of direct questions to consumers leaves decision making in the hands of treating professionals instead of with the consumer. Indirect questions impose assumptions of frailty instead of empowering individuals, even though the interview process may later reveal reduced capacity. Personal preference, where it is assessed, is often buried in formal client assessment processes or assessed indirectly.<sup>67</sup> Where preference is discussed, it is sometimes an interpretation or judgment made by the assessor. CMS is conducting a review of this concern in the context of developing federal instructions for conducting the MDS. In the past, the MDS assessment of a person’s “discharge potential” has been made by facility staff assessors. Recommendations have been made to federal policy makers for a consistently applied *Resident Assessment Protocol* (RAP) so that there is required follow-up action to a facility resident’s stated interest in, and preference for, community living.<sup>68</sup>

In 2003-04, the California Department of Health Care Services and the Department of Rehabilitation worked with researchers at the University of California Los Angeles and the University of Southern California to determine how to assess residents’ preference to stay or leave the facility. Under *California Pathways*, the goal was to develop and test a protocol that proactively identifies any nursing facility resident who prefers to return to the community with services and supports. The technical design and test of the interview tool and protocol is pending publication in the January volume of the *Journal of American Geriatrics Society*.<sup>69</sup>

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<sup>67</sup> Schnelle, J. F., Wilber, K., & Osterweil, D. (2003). California Department of Health Care Services, *California Pathways* Final Report Pending (2003-2007).

<sup>68</sup> Reinhard, S. & Hendrickson, L. (2007).

<sup>69</sup> Nishita, C. et.al, (2008).

Under *California Pathways*, each individual was approached directly unless there was a health care decision surrogate designated in the patient record. The private interview with each facility resident or surrogate took about 30 minutes. The project team found that there were difficulties contacting surrogates and differences between the frequency of preference to transition among residents and surrogates. Interviews were repeated as a procedural substitute for an assessment of mental capacity to make health care decisions. Those who did not express a stable preference to transition did not advance to the next step. Individuals who expressed a stable preference to pursue transition were asked for HIPAA permissions to begin gathering assessment of need data from the MDS and to make a referral to a HCBS provider network. Project experience revealed nuances of consumer decision making that could be helpful in designing procedures for soliciting consumer decisions and preferences:

Surrogate Decision Makers, Guardians and Conservators: Contacting surrogates was time consuming and less productive than direct interviews with facility residents. Direct scripted telephone contacts were made to proxy decision makers who were often family members. Telephone contact was complicated by answering machines and call-back instructions. These contacts to proxy decision makers might have been more easily accomplished by a direct mail approach, presentations to family council meetings, or general outreach methods. Surrogates could then express interest by contacting the Transition Coordinator.

Stability: A stable consumer decision to relocate from the facility to the community was established as an indicator of whether or not to proceed with transition planning. Capacity to make decisions can fluctuate over time for certain individuals for a variety of reasons. The project team adopted a protocol to repeat the interview as a brief procedural substitute for pursuing medical assessments of capacity. When interview responses varied, the interviewee was considered to have expressed an unstable preference to relocate.

Feasibility: The preference interview incorporates direct questions about the individual's own perceptions about his/her needs for services and supports. This self-perception might be multi-dimensional, subtle, or obvious and may be influenced by others. The interview process allows for a resident to express a stable personal preference to relocate, but at the same time he/she may perceive that relocation is not feasible because of his/her needs for services or his/her understanding about the availability of supports in the community. This nuance goes hand-in-hand with discussing options and providing information that the individual needs to decide that transition is actually feasible.

Motivation: Interviewers made note of one observation that was not a direct expression of interviewees. Based upon their observations, interviewers were asked to identify the interviewee's level of motivation to relocate. This observation did not alter in any way how the individual's request for referral to transition services was handled. Level of motivation was just an indicator of how

relocation seemed to be ranked as a personal priority. It could be implemented as a direct question.

Privacy: The privacy of the interview governed the whole process. Written permissions were obtained to access MDS data and to forward personal health information to HCBS providers who could continue the planning process.

A final report on *California Pathways* is expected in 2008. This discussion seeks not to repeat a description of the project but references early project concepts in order to advance the HCBS policy agenda that supports increased reliance on technically sound tools and procedures that can be broadly applied with any consumer.

### ***Embrace Family and Informal Caregivers***

Broadening access to HCBS shifts costs and responsibilities from facility-based work forces (possibly unionized) to community work forces (possibly unionized) and informal caregivers. Embracing informal caregivers and attending to state issues associated with delegating and shifting care giving tasks to workforces other than institutional workers is critical if efficiencies are going to be realized with increased access to HCBS. The pressures and burdens on those who provide “informal” care are evolving as the population ages and as medical science extends persons’ life spans

As focus shifts from facility-based long-term care to HCBS alternatives, costs and responsibilities for care shift. As a lesson from the past, families were the front lines of service provision when deinstitutionalizing persons with mental illness. The same will be true for the increasing numbers of seniors who grow frail and need supports. Under the *DRA Rebalancing Demonstration*, the count of institutional beds may stay flat or even decrease, but limited and capped HCBS options may result in overburdened workforce, overwhelmed families, and further marginalized or even abused consumers. Expanded HCBS brings with it workforce issues, union issues, and risks for overburdened, overextended caregivers, especially women, who already provide a significant contribution to financing long-term care.<sup>70</sup> The importance and the magnitude of the increasing demand for informal caregivers have been mapped out in *Health Policy: Crisis and Reform in the U.S. Health Delivery System*.<sup>71</sup> An AARP Public Policy Institute paper also lays out in great detail the value of embracing caregivers who volunteer their time to provide supports to someone they love.<sup>72</sup>

### ***Retool and Coordinate Assessments of Need***

Widely deployed Electronic Health Records (EHR) will play a major role in coordination of Medicare post acute care.<sup>73</sup> The same capability will support better coordination between Medicare PAC with Medicaid HCBS. The use of uniform assessment data and electronic health records will alleviate the need to reconfigure

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<sup>70</sup> Institute for Research on Women and Gender (2002).

<sup>71</sup> Harrington, C. et.al. (2004).

<sup>72</sup> AARP (2006).

<sup>73</sup> CMS Policy Council Document (2006).

consumer data every time an individual moves between post-acute and chronic care settings. The assessment of need has become the centerpiece of HCBS care planning just as the Minimum Data Set (MDS) is the centerpiece to facility care. Unlike the federal requirement that facilities use the MDS, HCBS providers across the board are not required to use a uniformly administered assessment instrument unless there has been a state initiative to make it so. The exception is the home health agency industry, which is subject to the federal requirement to implement the *Outcome and Assessment Information* (OASIS). If HCBS providers such as personal care service organizations or case management agencies deliver only a narrow slice of an individual's service plan and use varying assessment protocols, consumers are faced with multiple and often lengthy assessment procedures in order to obtain adequate service coverage in a community setting.

Assessment data, data elements, and phrasing of interview questions have become points of HCBS policy debate because of the number of provider types necessary to meet the needs of one individual with complex chronic conditions and disabilities. Data does not easily follow consumers from one setting to another, and taxpayers ultimately pay for multiple duplicative procedures for each HCBS client. To the individual whose life is being examined, an insightful and helpful process can be the difference between hope and despair. A uniform intake and assessment process can mediate these concerns and potentially save tax dollars. A plethora of assessment tools and procedures used by other states are available through the HCBS clearinghouse at [www.hcbs.org](http://www.hcbs.org).

### **The Opportunities Provided by the Deficit Reduction Act of 2005 (DRA)**

Opportunities for Medicare and Medicaid HCBS reforms, taken together, provide the basis for coordinating benefits and better informing consumers as they transition from one stage of chronic care to another, and from one treatment setting to the next. CMS is actively working on reforms for Medicare post-acute care services and payments. This vision for Medicaid HCBS reforms is consistent with the federal vision for PAC reforms. Section 5008 of the DRA requires a Medicare Post-Acute Care (PAC) payment reform demonstration. Under this provision, the federal Health and Human Services Secretary is to establish a three-year demonstration program by January 1, 2008. The demonstration is to use a comprehensive assessment at hospital discharge to:

- Focus on PAC consumer placement based on care needs and individual characteristics;
- Gather data on costs and consumer outcomes in various PAC settings; and,
- Use a standardized assessment instrument at discharge and across PAC settings.

The goal of the demonstration is to use data collected under this demonstration for comprehensive, site-neutral PAC payment reform. The PAC demonstration also coincides with CMS' focus on pay-for-performance for both the home health agencies

and the nursing facility settings.

The *DRA Money Follows the Person Rebalancing Demonstration* (2005) provides Medicaid incentives to states wishing to decrease expenditures for inpatient long-term stays in nursing facilities. Concurrently, it is an opportunity to take an up-to-date snapshot of today's diverse long-term care users. At last count, 31 federal grants have been made to states under the DRA MFP demonstration, and under these demonstrations 37,781 individuals will transition from health care institutions to community living. These individuals will be diverse in their chronic conditions and in their preferences and needs for services in the community. The DRA authorizes the federal Medicaid agency to pay a higher percentage of the subsequent HCBS costs for persons who have lived six months or longer in the nursing facility. These demonstration participants represent the highest-cost Medicaid users, presenting an opportunity to serve them at lower costs in a community setting. Success will be achieved through a merging of visionary HCBS policy, local infrastructure development, sophisticated HCBS service planning, and carefully applied cost containment measures that support rather than undermine consumer decisions about where and from whom they receive services. Gaining experience with successful transitions from facilities to community living will demonstrate the importance and worth of a state's HCBS networks.

*Real Choice Systems Change* grants and the more recent Rebalancing Demonstration enable states to adjust policy and administrative tools so that state HCBS policy reflects the intent of the *Olmstead* decision. A recurring theme for states doing *Olmstead* work is the comparison of institutional options with the supply and capacity of HCBS alternatives. While the supply of nursing facility beds is an easy count, taking inventory of HCBS alternatives is not as clear-cut, which makes the notion of "rebalancing" a real challenge. Shifting costs from institutional stays to HCBS assumes there are providers and other ready resources, whether home health agencies, home aides, attendants, or other service providers available and qualified to do the work. Even if a state has adequate HCBS waivers, successful transitions depend largely on the local availability of a wide array of paid providers and informal caregivers.

The *DRA Medicaid HCBS State Plan Amendment* (SPA) (section 1915(i) of the Social Security Act) creates an additional opportunity for states to remove the requirement that individuals meet the institutional level of care criteria to receive HCBS services and has clear applicability to mental health populations. Under the HCBS SPA option, states are required to set needs-based criteria for HCBS services and more stringent criteria for institutional services (e.g., hospital, ICF-MR and nursing home).<sup>74</sup> The HCBS SPA establishes clear state policy for considering HCBS alternatives prior to more costly institutional placements. Additional tools, forms, and analyses on related subjects are available at the clearinghouse at [www.hcbs.org](http://www.hcbs.org).

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<sup>74</sup> Mollica, R. (2006).

## Conclusion

Health care costs for persons with long-term chronic conditions, including those with custodial care needs, will continue to escalate unless Medicare PAC reforms are implemented and Medicaid HCBS alternatives are as available and as accessible as the Medicaid entitlement to institutional care is today. Controlling costs at both the federal and state level is at the core of the DRA initiatives. From a programmatic perspective, the DRA MFP Demonstration is a broad deinstitutionalization initiative for a diverse and growing population. Deinstitutionalizing a marginalized population whose needs are described in imprecise terms like “custodial” is the highest of challenges and will be the greatest achievement for any existing HCBS program infrastructure. Limited and capped HCBS options will not likely be adequate to accomplish rebalancing. Rebalancing can happen only if narrowly targeted population-based HCBS infrastructure is retooled for a large and diverse group of users. Unless reforms are in place, with limited HCBS waivers and networks on one side of the equation and broad diverse users on the facility side, the demonstration will be work-intensive with little result or with results similar to the under-resourced community mental health system of the past.

This is a call to renew a vision for HCBS reform at the local, state, and federal level in order to make ready a system that already has customers with critical needs waiting at the door. The growing numbers and diversity of users creates an imperative to focus on the consumer, their preferences, their family and persons who help them, to coordinate assessments so that the focus is on the person being assessed rather than their Medicaid eligibility group, and to retool and reform access to much preferred community-based alternatives. While the DRA has created the opportunity and the incentive, states must shuffle HCBS reform into the budget deck along with fires, floods and other public health priorities. Renewed political energy and vision is critical at this time so that the frailest citizens can expect high-quality HCBS options in their home communities.

- ❖ Take on the challenges of choice by attending to consumer-specific quality of life, self-management, and risk.
- ❖ Refocus on consumer decisions with technically sound procedures and tools.
- ❖ Systematically identify personal preferences during service planning processes.
- ❖ Embrace and value informal caregivers as a meaningful part of each service plan.
- ❖ Retool and coordinate assessments of need.



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