



# American Health Care Association

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September 21, 2007

The Honorable Tom Harkin  
 731 Senate Hart Office Building  
 Washington, DC 20005

Dear Senator Harkin:

I am writing to you on behalf of the American Health Care Association (AHCA) and National Center for Assisted Living (NCAL), which represent nearly 11,000 non-profit and proprietary nursing facilities, assisted living residences, subacute centers and homes for individuals with mental retardation and developmental disabilities that provide professional, compassionate long term care for millions of Americans.

AHCA/NCAL appreciates your efforts to ensure that individuals, especially people with disabilities, have access to the care and services they need, in the most appropriate setting. Indeed, the intent of the *Community Choice Act of 2007* mirrors the first of several guiding principles that AHCA/NCAL developed in 2006 on Medicaid reform, which reads: *Publicly and privately financed long term supports and services must meet consumers' and families' needs and be responsive to their preferences.* A complete copy of our Medicaid reform principals is attached for your information. In this letter, we detail changes that we need in order to support this legislation.

AHCA/NCAL supports consumer choice, including the right to choose where an individual will receive necessary care and services – whether that care setting is within one's home, community, an assisted living facility, a nursing home, or other type of long term care facility. Our position that individuals should receive the most appropriate care in the most appropriate setting for his or her needs echoes the landmark Supreme Court Olmstead decision that states, "...nothing in the *Americans with Disabilities Act (ADA)* condones termination of institutional settings for persons unable to handle or benefit from community settings." The U.S. Department of Health and Human Services, which offered subsequent guidance to states regarding the Olmstead decision, emphasizes that, "individuals with disabilities and their families (be afforded) the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings."

AHCA/NCAL is concerned about three aspects of *The Community Choice Act of 2007*. First, we are concerned that the new, mandatory Medicaid entitlement for community-based personal attendant care, which this legislation would create, could

divert critical funding away from optional Medicaid programs such as Medicaid 1915(c) Home and Community Based Services Waivers (HCBS), state plans for personal care services, intermediate care facilities for individuals with mental retardation or developmental disabilities (ICFs/MRDD), and away from mandatory programs such as nursing facility care. In 1997, the Congressional Budget Office (CBO) scored this kind of mandatory service at **\$10 - \$20 billion per year**, which we believe would cause budget constraints that would result in states shifting funds from other long term care programs to pay for the mandatory Medicaid benefit.

This prospect is especially troubling given evidence that HCBS programs generally increase state long term care (LTC) spending. To illustrate, Avalere Health recently conducted a study that demonstrates that most HCBS programs increase total LTC spending and are not cost effective for state LTC budgets. The study shows that cost-effectiveness is achieved only when states target HCBS to people who would have gone into a nursing home. However, evidence of such targeting was found in only a few states and programs. According to the Avalere study, HCBS expansion has not significantly reduced demand for Medicaid-financed services in any state; in fact, evidence indicates that the presence of HCBS increased demand.

In Minnesota, for example, HCBS recipients increased nearly 80 percent from 2000 to 2006, compared to a decrease of 21 percent among nursing facility recipients. Specifically during this period, the number of HCBS recipients increased from 26,798 to 48,108, while nursing home recipients decreased from 26,419 to 20,775. In terms of spending, this translates into a 149 percent increase in HCBS expenditures from 2000 to 2006, while nursing facility expenditures were flat with an increase of less than 1 percent during the period. The *Deficit Reduction Act of 2005 (DRA)* is now attempting to introduce controls on such growth by establishing an HCBS state plan option that allows states to limit enrollment and expenditures. Despite these controls, however, the CBO counted the option as a cost—indicating that it would increase Medicaid spending by \$766 million between 2006 and 2010 and \$2.6 billion between 2006 and 2015.

Second, although the legislation as written would apply to all Medicaid beneficiaries, it would seem more appropriately directed toward a smaller population, including higher-functioning people with disabilities. Much like the Supreme Court's Olmstead decision cautions against reading the *Americans with Disabilities Act* to mean that states should eliminate institutional-based care; the *Community Choice Act of 2007* should not imply that all people with disabilities are best served in home- and community-based settings. Many individuals with profound and severe mental retardation, for example, may prefer to receive care and services in ICFs/MR, which are homelike settings where 24-hour care as well as basic life skills training or "active treatment" is available. A brochure that explains both ICFs/MR and waiver group homes for persons with mental retardation is included for your information. Naturally, the needs and preferences of individuals with profound and severe mental retardation and their families must remain an important consideration in developing legislation that impacts this special population. Again, AHCA/NCAL is concerned that by broadly mandating community-based Medicaid services, funding essential to ICFs/MR and their clients could be effectively reduced.

Finally, the Supreme Court Olmstead decision stated that a state's responsibility, "once it provides community-based treatment to qualified persons with disabilities, is not boundless." Under the Court's decision, States are required to provide community-based services when the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving State-supported disability services. Yet, the legislation, as written, includes the provision, "That the State will provide community-based attendant services and supports to an individual described in section 1902(a)(10)(D)(ii) without regard to the individual's age, type or nature of disability, severity of disability, or the form of community-based attendant services and supports that the individual requires in order to lead an independent life." This provision is in direct contradiction to the protection the Supreme Court afforded to states of limiting their responsibilities by reasonableness. In order to meet this proposed legislative provision, States may need to fundamentally alter the states' services and programs, contrary to the Olmstead decision.

Like you, Senator, we support beneficiary choice, and applaud that you recognize the importance of choice and that you have articulated in *The Community Choice Act*. **We respectfully request that you take into consideration the changes mentioned in this letter as we both have the same goal in mind.** We look forward to working with you and your staff, and in partnership with key stakeholders, to affect change that preserves consumer choice when selecting the most appropriate care setting to meet an individual's needs to include facility-based care when desired and/or needed. Thank you for your consideration of these comments and we look forward to helping people with disabilities receive care the most appropriate care, in the most appropriate settings.

Sincerely,



Bruce Yarwood  
President & CEO  
American Health Care Association

cc: Steve Ackerson

Enclosures

Been too long  
We should get  
together & chat  
about this &  
other things  
AJ



American Health Care Association



National Center For Assisted Living

## Principles for Long Term Care Reform Executive Summary

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### Preamble

Continued Medicaid cost growth and increasing numbers of long term care users are driving states and the federal government to fundamentally reform the Medicaid program. Because long term care costs drive much of Medicaid growth, long term care reform – primarily within Medicaid reform efforts – has become a top policy priority for the federal government and most states.

In order for AHCA/NCAL to best represent member interests, a cross-cutting member work group developed a set of broad long term care reform policy principles – or essential programmatic elements – to guide or serve as a framework for AHCA/NCAL long term care policy development and reaction to federal and state proposals. The long term care reform principles build upon current AHCA long term care and Medicaid policies and will guide future AHCA/NCAL activity. Additionally, the principles also support one or more of AHCA's long term care and/or Medicaid policy goals previously developed by AHCA's Finance Subcommittee.

The member work group determined that managed care warrants its own set of principles.

### The Principles

Three key principles frame a long term care program(s) that will: (a) support consumer preferences and needs; (b) foster policy efforts aimed at creating a more sustainable array of long term care financing options; and (c) provide a viable operating environment for long term care providers. Each principle includes several key elements.

**Principle I. Publicly and privately financed long term care and related supports and services must meet consumers' and families' needs and be responsive to their preferences.**

- *Recognize that consumers are key stakeholders in long term care policy decision making and government must include them in development, oversight and monitoring.*
- *Provide that every eligible individual who needs long term care services receives them in a timely manner in an appropriate setting, taking into account individual preferences and clinical needs.*

- *Acknowledge the key role that family care givers play and provide family care giver supports.*

**Principle II. Long term care policies should promote and integrate a comprehensive array of public and private long term care financing options.**

- *Encourage individuals to plan for long term care and provide viable private long term care financing options.*
- *Ensure that individuals have the tools they need to manage their long term care services as beneficiaries assume more personal responsibility for services – publicly and privately financed.*
- *Recognize the impact of reimbursement changes on long term care providers.*
- *Ensure that efficient coordination of benefits reduce administrative burdens on beneficiaries and providers.*
- *Encourage individuals, providers and government payers to engage in a policy debate on balancing public and private financing of long term care.*
- *Encourage the design of tax policies that coordinate with long term care financing strategy alternatives.*

**Principle III. Through sufficient federal and state governmental infrastructure, policies should ensure that long term care service delivery systems provide an adequate array of services and administered by knowledgeable and quality driven providers across the long term care spectrum.**

- *Include a strategic plan for building needed infrastructure and ensure a sufficient supply of long term care providers that engage in a variety of services to meet the needs of the population.*
- *Ensure that beneficiaries may move seamlessly among services across the long term care spectrum.*
- *Foster and support quality and efficiency in Medicaid services, as well as provide operational flexibility.*
- *Managed care plans should recognize that long term care providers deliver services that are distinct from acute care providers.*

- *Funding is adequate and timely in order to provide stability and predictability to meet the needs of long term care recipients at the appropriate time, in the appropriate place, and at the appropriate cost.*
- *Encourage development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.*

## Complete AHCA/NCAL Principles for Long Term Care Reform

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### Introduction

Patients and their families are increasingly interested in sources of care and sites of services that are non-facility based, including home- and community-based settings (HCBS). Local communities, states, and the federal government are responsive, particularly since they believe that HCBS will be less costly and therefore save money. Because of consumer preferences and related federal and state policy changes, the proportion of long term care services delivered in facility-based settings is smaller than in the past. Medicaid reform has become the major vehicle for these and other long term care reform efforts at both the state and federal levels.

To date, many long term care reform proposals focus on delaying or preventing facility-based placement while encouraging use of personal long term care planning and expanding HCBS availability. The culminating outcome likely will be decreasing use of nursing homes and intermediate care facilities for persons with mental retardation (ICFs/MR).

This is not to suggest that the need for facility-based services will disappear. Rather, facility-based services are likely to play a relatively smaller role at least in the next ten to fifteen years. In the longer term, it is less clear how long term care will be delivered. Short term pressures and out-year ambiguity suggest that AHCA – the largest formal long-term care provider group in the country – adopt a forward-looking, leadership-based approach to shape long term care policies and ensure that there is a sustainable array of long term care services – and related privately and publicly financing options – for all Americans.

In late January, AHCA and NCAL members began the process of developing a set of guiding Medicaid reform principles. Principles were developed and assessed against the following dimensions:

- *Will the principles foster policy efforts aimed at creating a more sustainable long term care financing model?*
- *Do the principles support consumer preferences and needs?*
- *Will the principles foster a viable operating environment for long term care service providers?*

The principles were drafted to encapsulate existing AHCA/NCAL policy and provide a more succinct tool for sharing AHCA/NCAL positions as well as to frame proactive policy initiatives. The principles build on past policies by condensing concepts that are highly interrelated, promoting policies that are viable in the current political and budgetary environment, and providing a proactive positive framework for representing AHCA/NCAL interests. The principles also directly relate to AHCA long term care and Medicaid policy goals developed by the AHCA Finance Subcommittee.

### **The Principles**

Three key principles frame a long term care program(s) that will: (a) support consumer preferences and needs; (b) foster policy efforts aimed at creating a more sustainable array of long term care financing options; and (c) provide a viable operating environment for long term care providers. Each principle includes several key elements and also supports one or more of AHCA's long term care and/or Medicaid Policy goals previously developed by AHCA's Finance Subcommittee.

**Principle I. Publicly and privately financed long term care supports and services must meet consumers' and families' needs and be responsive to their preferences.** Unlike acute and primary health care services, long term care services are not discrete events (i.e., a sore throat, broken leg, etc.) that require specific medical interventions. Instead, receipt of long term care services becomes a lifestyle for both the person receiving services and his or her family. Long term care services are integrated into virtually every aspect of an individual's life and make the experience of long term care highly personal. To that end, long term care policies must:

- *Recognize that consumers are key stakeholders in long term care policy decision making and government must include them in development, oversight and monitoring.* State Medicaid agencies are required to provide public notice and time for comment when changes to the Medicaid program are proposed. They also are required to respond to stakeholder concerns. The federal government should require documentation that these requirements have been met.
- *Provide that every eligible individual who needs long term care services receives them in a timely manner in an appropriate setting, taking into account individual preferences and clinical needs.* Policies must recognize the individual – to the extent possible – as the key decision-maker regarding their supports and care. For privately financed options, policies also must ensure that these options – particularly insurance products – recognize the importance of consumer preference.
- *Acknowledge the key role that family care givers play and provide family care giver supports.* Family care givers are a critical – but often unrecognized – segment of the long term care spectrum. State and federal programs must provide incentives and assistance for family care giving such as income tax deductions, availability of respite and day programming, and family counseling services.

**Principle II. Long term care policies must promote and integrate a comprehensive array of public and private long term care financing options.** As the proportion of our population age 65 or older increases and the number of younger persons with disabilities increases, the federal government and states must take steps to increase use of private long term care options. Increasing the use of private options will improve the sustainability of a publicly financed long term care program, currently Medicaid. And, reimbursement policies must recognize the potentially interrelated impacts of payment policy changes to ensure a stable long term care provider marketplace. A stable array of long term care providers will be better positioned to meet consumers' needs and preferences. To increase use of the array of long term care financing options, policies must:

- *Encourage individuals to plan for long term care and provide viable private long term care financing options.* The federal government should promote the development of innovative programs, such as incentives for families to purchase long term care insurance, save money for long term care or otherwise plan for private long term care needs. State and federal government also should fund programs to raise awareness of long term care planning needs and help individuals and families make the best long term care financing decisions.
- *Ensure that individuals have the tools they need to manage their long term care service as beneficiaries assume more personal responsibility for services – publicly and privately financed.* Long term care reform proposals include a wide range of elements that give beneficiaries more control over services and service dollars. Examples include HCBS Individualized Budgeting models, Money Follows the Individual and Cash and Counseling programs. In addition to increased control and responsibility, government also should provide adequate supports to beneficiaries on how to direct their own services and wisely allocate service dollars. Government should have safeguards and oversights in place to ensure that these services are appropriate and effective in achieving the care planning goals of the beneficiary.
- *Recognize the impact of reimbursement changes on long term care providers.* Long term care providers receive payments from private sources, Medicaid, and Medicare for post acute care stays. Policy changes that decrease or otherwise affect revenue streams should be evaluated in the broader context of the array of financing sources, e.g., the impact of changes to Medicare payments when providers experience shortfalls under Medicaid.
- *Ensure that efficient coordination of benefits reduce administrative burdens on beneficiaries and providers.* Beneficiaries should be able to move seamlessly among services across the long term care spectrum without limitation due to burdensome administrative requirements that are commonly placed on providers and beneficiaries. Attention to streamlining coordination of benefits will result in better care as needs change.
- *Encourage individuals, providers and government payers to engage in a policy debate on balancing public and private financing of long term care.* The increasing long term care

population and accompanying growing costs results in a need for all stakeholders to be engaged in discussions on how best to finance this expanding population's care. This discussion should examine and weigh both public and private financing options.

- *Encourage the design of tax policies that coordinate with long term care financing strategy alternatives.* Identification of financing strategy alternatives is valuable only to the extent that such alternatives are implemented. Incentives, such as tax policies, will aid implementation efforts.

**Principle III. Through sufficient federal and state governmental infrastructure, policies must ensure that long term care service delivery systems provide an adequate array of services and service providers across the long term care spectrum.** Long term care reforms are being proposed and implemented at a rapid pace. Changes in service delivery systems, such as significant increases in HCBS use, must be accompanied by adequate increases in state administrative infrastructure including quality assurance and improvement, payment systems, data collection, and consumer and family information and referral services. To ensure market driven long term care system change at an appropriate pace, policies must:

- *Include a strategic plan for building needed infrastructure and ensuring an adequate array of long term care providers.* For publicly financed programs, government should require a reasonable plan for phasing-in changes that require substantial build ups in provider capacity and state infrastructure development. Government also should require that milestones or markers be met before additional changes or expansion. Government should encourage the notion that beneficiaries who need long term care services receive them at the needed intensity level (including facility-based services) as well as an adequate array of care management supports that do not place undue hardship on the individual or family caregivers.
- *Ensure that beneficiaries may move seamlessly among services across the long term care spectrum.* Long term care systems and providers are highly insular. For many beneficiaries, the result is typically a fragmented service system that is confusing and produces questionable outcomes. Government must ensure that long term care providers have the capacity to develop service arrays, partnerships, and business arrangements that foster a seamless service experience.
- *Foster and support quality and efficiency in long term care services, as well as provide operational flexibility.* Long term care providers face significant operational costs including purchasing or upgrading health information technology systems, capital improvements to existing facilities, and financing innovative services that could support specialty populations. Government regulation should not impede long term care service innovations among long term care providers that follow consumer preferences in a cost effective manner.
- *Managed care plans should recognize that long term care providers deliver services that are distinct from acute care providers.* A key long term care reform component is

managed care – particularly for Medicaid-financed long term care. Experiences in states like Arizona show both positive outcomes and concerns for long term care providers. As managed care for Medicaid beneficiaries who are elderly, blind and have disabilities is expanded, federal and state officials should avail themselves of the long term care professionals' policy, operational, and clinical expertise as these arrangements unfold.

- *Funding is adequate and timely in order to provide stability and predictability to meet the needs of long term care recipients at the appropriate time, in the appropriate place, and at the appropriate cost.* Government should recognize that demand for long term care services and financial pressure on providers – as well as increased risk bearing at the plan, provider and consumer levels – make additional investment in provider capacity, service quality and efficiency a necessity. Government payment rates at all levels of the long term care spectrum should be sufficient to provide quality services and cover the cost of operating, as well as needed capital improvements.
- *Encourage development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.* As opportunities to receive services are expanded, the need for uniformity in assessment becomes increasingly important.

### **Framework for Moving Forward**

Since the inception of the Medicaid program, responsibility for long term care financing and delivery gradually has migrated away from the beneficiary and the family to the public sector. Increasing reliance on Medicaid for long term care services raises serious questions about programmatic sustainability. Additionally, demography, care delivery challenges (such as worker shortages), marketplace demands, financing, legal and regulatory, and industry trends, create an unprecedented need for the long term care professionals to help shape its future.

In partnership with consumer groups, long term care providers, including HCBS providers and facility-based, will lead the effort toward development of an integrated, flexible long term care array that responsibly informs and educates Americans about their long term care responsibilities and options, but also delivers Medicaid-financed services in a cost-effective, customized manner. In order to achieve these goals, AHCA/NCAL will partner with other long term care organizations based on its long term care policy principles to address the challenges and opportunities associated with building a sustainable long term care system.

### **AHCA/NCAL Managed Care Principles**

At the AHCA/NCAL long term care reform work group meeting held on January 26, 2006, participants decided that managed care warrants its own set of principles. Staff were assigned the responsibility of drafting such principles for discussion at the March meeting.

Work group participants asked that additional attention be paid to managed care because of growth in:

1. ***Managed care for Medicaid-only Beneficiaries Who Are Aged, Blind or have Disabilities.*** The effects on long term care systems will be: a) increasing pressure to use less costly services including earlier hospital discharges into sub-acute facilities or temporary placement in nursing homes; b) limited use of nursing home services until all less costly options have been explored; c) increased competition among nursing homes based on managed care organizations' (MCO) focus on best price; d) additional bureaucratic layer, which results in the redirection of a significant portion of available dollars from the bedside into administration; e) increased potential for duplication (among and between MCO's) in both quality assurance and regulatory intervention, which is both costly and cumbersome; and f) increased flexibility and opportunity for innovation.
2. ***Managed Medicare and Medicaid Integration Programs.*** The Medicare Modernization Act of 2003 Special Needs Plan (SNP) authority could lead to increased state interest in managed care arrangements that integrate or better coordinate the Medicare and Medicaid programs. Commercial interest has been considerably greater than expected; to date, 296 SNP products are available.<sup>1</sup> Additionally, the 2007 Medicare Advantage plan application includes an expanded SNP section for Medicare and Medicaid integration options. And, Dr. McClellan has made integration one of his top policy priorities. A significant number of states are exploring managed care arrangements that would capitate both Medicare and Medicaid payments to managed care plans. In turn, providers would be reimbursed with rates based on the Medicare and Medicaid capitation payments to plans. While integrated care may be helpful from a continuity of care perspective, Medicare and Medicaid Integration programs will negatively impact provider reimbursement as it will be considerably lower than traditional Medicare
3. ***Managed Care Delivery of Preventive Care (i.e., disease management (DM), care coordination, and wellness initiatives).*** DM, care coordination and disability management programs hold the promise of reducing disability acuity and the impact of chronic illnesses. In turn, such outcomes also result in lower costs and reduce financial strain on the health care system. Many Section 1115 Medicaid waivers include wellness incentive programs for beneficiaries. States also are heavily leveraging Medicaid managed care plans and/or integrated Medicare/Medicaid managed care plans to deliver such services.

## **Managed Care Principles**

**Managed care policies should recognize that long term and post acute care providers deliver services that are distinct from acute care providers.** A key long term care reform component is managed care. Experiences in states like Arizona show both positive outcomes and concerns for long term care providers. As managed care for Medicaid-only beneficiaries who are elderly, blind and have disabilities or for dually eligible individuals is expanded, federal and state officials should avail themselves of the long term and post acute care professionals' policy,

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<sup>1</sup> Presentation by Jennifer Podulka, MEDPAC staff person using CMS data, at the MEDPAC meeting. January 11, 2006

operational, and clinical expertise as these arrangements unfold. Five key managed care elements should be considered with the managed care principle:

- *Enhanced Flexibility in a More Competitive Operating Environment.* Long term care providers should have the freedom to take on a wide array of roles in the coordination and provision of individuals' long term and post acute care. Policies should allow providers to take on various roles, alone or in partnership, in the delivery of long term and post acute care services including risk contracting, administrative organizations roles, information and referral, care coordination of an individual's clinical needs, as well as care management and disease management.
- *Inclusion in Managed Care Program Development and Operational Decision Making.* Long term care providers should be meaningfully included and engaged in managed care program design. Specific points of engagement should include: (1) ongoing participation in capitation payment methodology and rate development and refinement; (2) agreement on, development and testing of a uniform assessment tool that identifies service needs and will ensure a reasonable and adequate payment by site of service; (3) plan contracting requirements – specifically, plan profit requirements (ensuring that plan profits and overhead costs are not excessive), development of provider rates and processes for reconciliation; (4) ensuring a level playing field, including decisions on “any willing provider” requirements; (5) prompt payment; and (6) coverage, prior authorization and utilization management processes.
- *Special Consideration As Capitation Rates, Risk Adjusters, and Subsequent Provider Rates Are Developed.* Long term and post acute care providers must have the resources to deliver services, meet capital costs associated with facility or unit maintenance, and meet both state and federal licensure and operating requirements. First, MCO contracts and state oversight must ensure that plan capitation payments – including any frailty adjuster – associated with individuals using long term care be fully available for that purpose. Second, in Medicare and Medicaid integration arrangements, states must ensure that rates including or based on Medicare capitation payments to plans and providers also be actuarially sound (currently a Medicaid requirement for managed care capitation payment rates). Third, the long term care provider marketplace faces significant capital costs to maintain aging facilities, upgrade existing facilities, and/or develop new service settings – such as small congregate settings or single occupancy capacity. Payment rates must include a margin that will support critical capital maintenance and development and ensure provider financial viability and sustainability.
- *All long term and post acute care settings should have quality measures tailored to the type of service setting and long term or post acute care populations.* Acute care quality measures and measurement tools are inappropriate for long term care settings and, in some instances, long term care populations. States and plans must work with long term and post care providers to: identify a quality measurement system that is (a) targeted to long term care or post acute care service outcomes; and (b) based on current clinical or social supports best practices. Finally, all willing providers with the capacity to

implement and collect data on the quality measures in a managed care coverage region should have the opportunity to participate in the provider network.

- *Managed care plan coverage determination processes (i.e., medical necessity definitions and related procedural guidance) must reflect the difference between acute care service outcomes and long term care service outcomes.* Because of the unique needs of the long term care population and the nature of long term and/or post acute care settings, coverage determinations on access to care should emphasize maintenance of functioning and specialized healthcare needs. Additionally, coverage determinations should reflect that long term care consumers' physical and psychosocial support needs are ongoing and must be tailored to individual preferences to the degree possible.
- *Development and use of a standardized post-acute assessment and benefit package to facilitate determination of patient need and placement.* As opportunities to receive services are expanded, the need for uniformity in assessment becomes increasingly important.

### **Conclusion**

The long term care system is under considerable pressure driven by payer and consumer preferences to shift from facility-based care to consumer-directed home- and community-based or more home-like services, along with tighter reimbursement, and difficult to manage Medicare and Medicaid operating requirements. Considerable attention must be given to the potential impact of managed care on the stability of the long term care provider marketplace to ensure erosion of capacity is not accelerated. The principles and key elements above should be used by policymakers, providers and others to help craft policies, including a long term care provider bill of rights to address issues arising from the expansion of managed care for long term care populations.



American Health Care Association

Working to Ensure that Choice is Provided

Services and Supports Options

For Individuals with Developmental Disabilities

The Keys: Client Needs, Abilities and Preferences

Intermediate care facilities for individuals with mental retardation and developmental disabilities (ICFs/MR/DD), Medicaid home- and community-based (HCB) program group homes and home care provide settings to accommodate the needs, functional abilities and preferences of individuals with developmental disabilities (DD). The real advantage of today's residential alternatives is that, collectively, they offer real choice to clients and families.

Fast Fact

The federal government defines any facility with four or more beds an "institution"

Each of today's residential choices offers advantages based on the best interest, capabilities and needs of the client. That choice may be an institution, albeit a small one as the federal government considers a facility to be an "institution" if it has four or more beds. According to the U. S. Supreme Court's *Olmstead v. L.C.* decision "nothing in the Americans With Disabilities Act (ADA) or its implementing regulations condones termination of institutional settings for individuals unable to handle or benefit from community settings... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Thus, today's imperative is to provide access to services and supports in a full array of settings to accommodate a broad range of disabilities, and this includes individuals with developmental disabilities.

Consider these facts about ICFs/MRDD facilities:

- The median number of clients in an ICF/MRDD is six (CMS).
- A group home can be part of an ICF/MRDD that operates several small residences under one license.
- ICFs/MRDD sometimes have fewer beds than HCB group homes.
- ICFs/MRDD can be private or public; profit or not-for-profit.
- ICFs/MRDD provide 24-hour staffing.

While the needs, functional abilities and preferences should be the main criteria in selecting a living arrangement for MR/DD clients, there are major differences between the settings in terms of the supervision, services and supports provided.

### **ICFs/MRDD—Serving the Most Vulnerable**

ICFs/MRDD generally serve individuals with profound and multiple disabilities, thus they are staffed accordingly and offer an array of supports and services to clients with DD and their families. Larger facilities often serve clients with the most severe and multiple handicaps as they offer a wider array of in-house or contract services. Supports and services offered by ICFs/MRDD add to the quality of life of clients and motivate and guide them in learning practical life skills. The goal for a client with DD is to enable travel, recreation, and potential employment and to graduate to a more independent housing option. ICFs/MRDD provide:

#### **Health Care Services**

Includes a comprehensive medical care plan; physician services; annual physical exams; dental and pharmacy services; and drug administration.

#### **Active Treatment**

Incorporates a team approach to teach skills and socially responsible behavior to attain maximum independence and minimize regression.

#### **Respect**

Ensures and protects client rights even outside the facility.

#### **Positive Social Behavior**

Uses positive techniques to teach socially responsible behavior.

### **ICFs/MRDD Staff and Client Outcomes**

Staff training is continuous on topics such as: infection control; detection of abuse and neglect; client rights; disaster preparedness, etc. Staffing level, which must conform to government standards, is based on client age and level of ability.

**Fast Fact: Estimated Medicaid spending on ICFs/MRDD in 2006 totaled \$13.1B<sup>1\*</sup>**

A notable distinction between ICFs/MRDD and HCB group homes is the level of involvement from federal and state agencies. Through a process known as “surveying,” conducted annually, or as needed, a team of specialists examines staff performance in achieving client goals.

### **HCB Group Homes, Home Care**

Since 1981 states can make HCB services available to Medicaid recipients who are eligible for nursing facilities, ICFs/MRDD or hospitals. This allows for care at home or at a group home while receiving Medicaid payments.

<u>Fast Fact*</u>			
<u>Trend in Total Spending for HCB Care, 1990-2006</u>			
<u>FY 1990</u>	<u>FY 2001</u>	<u>FY 2006</u>	<u>Percentage Increase</u>
\$3.9B	\$22.7B	\$39.1B	902%

States need to apply to the federal government for a “waiver” of Medicaid rules to offer an HCB program. With a waiver a state may cover, at its discretion, non-medical and social services and supports that allow individuals to stay at home or in the community. An HCB program may provide: case management and services, such as homemaker; home health aide; personal care; adult day care; habilitation; and respite care. States may also offer other, non- medical services, such as transportation, in-home support services, special communication services, minor home modifications and adult day care.

- Fast Facts\*
- **Currently, there are approximately 287 waivers in place serving more than 922,000 individuals;**
  - **Every state has at least one waiver;**
  - **Currently waivers represent 12% of Medicaid long term care expenditures.**

HCB group homes receive only cursory federal and state monitoring of care and services, are not required to provide individualized training for clients and staffing may be minimal and sometimes only part time.

**Olmstead and the New Freedom Initiative**

The “New Freedom Initiative” (NFI) is the government’s effort to help states implement the U S. Supreme Court’s Olmstead decision (*Olmstead v L.C*). In Olmstead the Court held that some individuals with disabilities in institutions might have suffered discrimination under the Americans with Disabilities Act (ADA) by being deprived of an opportunity to live in the community. The Court also held that the ADA does not mandate deinstitutionalization, stating “nothing in the ADA condones termination of institutional settings for individuals unable to handle or benefit from community settings.” NFI provides a framework for giving elders and individuals with disabilities a choice regarding housing arrangements for as long as possible prior to needing a more secure environment. Under the NFI the federal government provides funding for demonstration programs that support HCB services as well as technical assistance to states.

- AHCA is Committed to these Principles**
- Individuals should receive proper supports and services in the most appropriate setting, according to their needs and preferences;
  - Barriers to community placement should be removed;
  - Adequate funding must be provided for the spectrum of facility and HCB services; and

- Quality assurance systems must be built into all services and supports programs and consumer protections enforced through appropriate government regulation.

***Fast Fact***

**ICFs/MRDD and HCB programs are optional benefits of a state's Medicaid program. They are not entitlements.**

**Key Determinants**

The needs, functional abilities and the preferences of the client with DD (and his or her family) should be the criteria in choosing a setting where services and supports are provided, not what the setting is called. Individuals and their families need choices and ICFs/MRDD, group homes and home care each offer advantages to them. Each setting can meet the criteria set down in Olmstead to offer clients the most integrated, least restrictive, and safe setting based on their abilities. These options can provide a person with independence and dignity but their needs, functional abilities, and preferences should be considered when deciding on a residential setting.

*The American Health Care Association (AHCA) is committed to quality and performance excellence in the long term care profession and actively supports Quality First, a covenant for healthy, affordable, and ethical long term care, and adherence to its principles and goals. Nationwide, AHCA represents more than 10,000 non-profit and for-profit facilities that are dedicated to professional and compassionate care for more than one million elderly and disabled individuals daily in nursing facilities, assisted living residences, subacute centers and homes for individuals with developmental disabilities. For more information contact:*

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\*The State Long-Term Health Care Sector 2005: Characteristics, Utilization and Government Funding, American Health Care Association, August 29, 2006. [http://www.ahca.org/research/statestatsrpt\\_20060823\\_final.pdf](http://www.ahca.org/research/statestatsrpt_20060823_final.pdf)