REAL PEOPLE – REAL VOICES
No More Stolen Lives

A Proposal to Reform the Institutionally Biased
Long Term Services and Supports System

- **Disability is a "normal" part of life (children, young adults, older folks);**
- **Demographics expanding at all age levels;**
- **Cure versus care debate;**
- **Current paradigm – Disabled people are broke - Society will fix us;**
- **Need to convert from "medical" to a "social" model of support services;**
- **Long term care system almost 40 years old – Social Security Act – Title XVIII and Title XIX (Medicare/Medicaid) passed in 1965;**
- **Fragmented – Based on disease categories instead of function;**
- **Services following the funding stream instead of needs of individuals;**
- **Inequitable – System creates winners and losers;**
- **Medically focused due to Medicare/Medicaid funding;**

- **Barriers to change:**

1. **Support services versus program services mentality; Receive whole package of services to get the piece we need to be as independent as possible;**
2. **Political inertia – incremental vs. comprehensive reform strategies;**
3. **Industries have developed around the "caring for" disabled and older people with so many "special interests" that reform seems to be politically impossible; Disabled people have become a crop to be harvested for economic gain by professionals and providers;**
4. **Consumers/advocates fear of losing what we have; Win the rhetoric war but lose the $$$$$$;**
5. **Identity politics: Developmental Disabilities versus Aging versus Mental Health versus Physical Disability versus Sensory Disabilities; Circle the wagons mentality;**
6. **Health care liability – Little "risk management"- Dignity of risk - Choice**

Reform Strategies

1. **MiCASSA – S.401, HR 910;**
2. **Implementation of National Money Follow the Person policy;**
3. **Implementation of Olmsted decision – President's Executive Order;**
4. **Comprehensive Medicaid Reform – Social Model;**
   a. **National Long term services and supports program that includes heath maintenance services RATHER THAN Health care program including long term services and supports.**

Short Term Ideas

1. **Level nursing home entitlement; Allow choice for community services;**
2. **Consumer direction in all community programs including all managed care efforts to integrate acute and long term services and supports;**
3. **Transition away from categorical funding to functional system based on need**
4. **Define health and safety that recognizes the dignity of risk and allows negotiated risk;**
5. **Promotion of nurse delegation/assignment for health maintenance activities;**
6. **Quality measurement based on consumer satisfaction and community integration evaluators;**
7. **Coordination of support services and accessible, affordable, integrated housing; (Access Across America) Funding of "Housing Coordinators".**

Long Term Ideas

Long term services and supports need to be considered as an entity in of itself rather than as a component of health care funding. Medicaid/Medicare funding has focused on acute/insurance services with long term services and supports considered as a stepchild. Specific and dedicated funding needs to be allocated to create a National Long Term Services and Supports Program (NLTSSP) possibly combining LTSS funds currently in Medicaid, Medicare with a new individual contribution program.

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INTERIM PROGRAMMATIC/COST EFFICIENT MEDICAID CHANGES TO END THE INSTITUTIONAL BIAS

SUBMITTED TO THE
MEDICAID COMMISSION
BY
THE ADAPT COMMUNITY
May 17, 2006

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The ADAPT Community welcomes the opportunity to submit written testimony on how to change the Medicaid program to better serve people with disabilities of all ages and older Americans. These changes need to fulfill the promise in the Americans with Disabilities Act of services provided in the most integrated setting.

Though changes in the Medicaid program are needed, reducing Medicaid funding growth by $10 billion at a time when the population needing Medicaid funded services is growing, is terrible public policy which will have unintended negative consequences.

These comments will focus on how Medicaid's long term service and support system can MORE EFFECTIVELY serve more people with disabilities and older Americans in the community. The most important piece is to reform the institutional funding bias that has existed since 1965; we adamantly believe this can be done without block granting or arbitrarily capping Medicaid funding.

Flexibility should not be a codeword for reducing services to people needing support to participate in the community.

ADAPT is the largest national grassroots activist disability rights organization in the country. Composed primarily of people with disabilities of all ages, many of our members have been in nursing homes and other institutions. Established in 1983 in Denver Colorado, ADAPT has contact offices there and in Austin, Texas as well as a network of groups throughout the United States.

Outline

A. Most Integrated Setting
B. Consumer Direction
C. Nurse/Physician Delegation/Assignment
D. Worker/Personnel Issues

I. SUMMARY OF RECOMMENDATIONS

A. Allow people eligible for nursing home services or ICF-MR services to choose a home and community service instead of these institutional services.
Currently there is an entitlement only to nursing homes services. Amended language in statue to make this entitlement more flexible in terms of the service options. Community services are, on average, 2/3 the cost of their institutional equivalent service.

B. Permit more consumer direction in service delivery options by means of vouchers, fiscal intermediaries, agency with choice as well as traditional agency options. These service delivery options should be included in all Medicaid community programs: Home Health, Personal Care, Frail Elderly, Home and Community Waivers. Family members, including a spouse, should be able to provide attendant services in State Plan and 1915 c waiver programs to reduce costs.

C. Eliminate unnecessary medical/nursing requirements in all community programs: Home Health, Personal Care, Frail Elderly, Home and Community Waivers. Instead institute incentives for the States to amend their Nurse Practices Acts to allow for delegation and assignment of personal care tasks. Monitor to assure that States are no longer using "the homebound requirement" for Medicaid Home Health. There needs to be a comprehensive review of how consumer direction can be included as a requirement in managed care as it expands into the long term services and supports arena.

D. Require Money Follows the Person concepts so that all Medicaid funded individuals currently in nursing homes and other institutions who choose to leave the facility can be served in the community by an existing State home and community program. This can be facilitated by requiring that when a person answers yes on the MDS Q1a and gives his/her permission, her/she will be referred to a federally designated community based organization such as a AAA or an ILC.

E. Require more substantive consumer input in all State Plan and waiver activities to promote innovative cost efficient program development. Require statewide public hearings for all 1115 waiver applications.

F. Change waiver requirements that currently encourage "silo-like" programs to non-capitated waivers, based on functional need with uniform cost neutrality criteria.

G. CMS and HHS/OCR should aggressively monitor and enforce state implementation of the Supreme Court's Olmstead decision.

H. Earmark $100 million for Real Choice System Change grants to states.

I. Endorse legislative reforms embraced in proposed MiCASSA (S401 HR 910) and concepts embraced in the passed Money Follows the Person legislation

II. STATEMENT OF ISSUES

The number of people with mental and/or physical disabilities and older Americans needing ongoing support services is growing at a rapid rate. The aging of the American population is well documented. Baby boomers are moving into old age. With age comes the higher chance of acquiring some type of physical and/or mental disability. What is less obvious and less well documented is the growing number of children and young adults who also need similar ongoing support services. These increases are due to advancements in medical technology, rehabilitation techniques and new life saving drugs. The overwhelming numbers of people with disabilities, old and young, want long-term service and support services in their own homes and communities. The crux of the problem is that these support services currently are provided:
-Mostly in institutionalized setting,
-In an overly medical way that is frequently unnecessary and frequently unnecessarily costly, and
-Only when people "spend down" to poverty and get on Medicaid.

The current long term service and support system was originally developed in 1965 when the Medicare and Medicaid programs were created. These funding streams were originally designed with an institutional bias that favors nursing homes and other institutions over home and community services. This bias continues today.

Medicare funds mostly acute care services, but not ongoing support services after the acute episode. Medicare Home Health, though community based, was conceived as short-term assistance after a hospital stay but was never designed to provide ongoing long term services and supports for chronic conditions.

Medicaid, the state run federally matched program for low-income people, created an entitlement to nursing home services that states must provide to all eligible low-income people if the state was to receive any Medicaid funds. Home and community services were then, and remain now, optional services - provided at states' choice. As a result, Medicaid has become the largest funder of institutional long-term service and support programs.

Data
62% of our long-term care funding comes from public funding. Over $89 billion (32% of all Medicaid funding) is spent on long-term care programs. 64.5% of this ($57.6 billion) is spent on institutional services, leaving only 35.5% ($31.7 billion) for ALL home and community services. (See attachment)

CMS requires each State to survey every nursing home resident on their health status. Question Q1a asks them if the want to move back to the community. Almost 20% of those in nursing homes today want out. This statistic, in all likelihood, is actually low because the question is asked - and data collected -- by a nursing home staff person. But even with these conservative numbers, over 250,000 residents of nursing homes currently want to return home with community services rather than

stay in the nursing home. This is a strong argument against the institutional bias and for a money follows the individual program, and for a Real Choice/Community First national policy!

III. LEGISLATIVE SOLUTONS

Short Term Solutions

The Administration has publicly gone on record, as part of their "New Freedom Initiative"(NFI), supporting a Money Follows the Person demonstration. In this concept, any individual who chooses to leave the nursing home or other institution could have the funds being spent on their institutional services moved to cover the cost of their services in the community. This now law and the funding begins January 1, 2007.

The ADAPT Community strongly supports HHS/CMS implementing Money Following the Person legislation and providing ongoing technical assistance that would encourage states to apply and follow such a policy. Another short term action Congress can take, as an incentive for states to choose home and community services, would be to increase the FMAP by 5%-10% when a state chooses home and community services. This would give states an economic incentive to choose home and community services. ADAPT could be a short term transition to rebalancing the system but the entitlement only to nursing home services must end.

Long Term Solutions

MiCASSA, the Medicaid Community Attendant Services and Supports Act, S 401 HR 910, would allow real choice, money following the person and enhance consumer direction. Simply, if you are eligible for a nursing home or ICF-MR facility you can choose instead to have a community service titled "Community Attendant Services and Supports". You could select to have this service delivered through the traditional agency model, fiscal intermediary, or voucher system. MiCASSA would assure that no one goes into a nursing home or other institution because of lack of options, and it would assure greater consumer control of services. It assures REAL CHOICE.

A bigger fix would be to reform the entire system and separate out health care funding from long term services and supports. This requires developing a social model of long term services and supports that is coordinated but not linked to the acute/health system. This reform would include in one system those with physical and/or mental disabilities, older Americans and children with disabilities of all incomes who need Activities of Daily Living (ADL) and/or Independent Activities of Daily Living (IADL) assistance, as well as cognitive supports. This reform would require developing a "Long Term Services and Supports, LTSS, Fund" that would include the current dollars in the Medicare/Medicaid used for long term services and supports, as well as a new funding source to meet the growing needs of the US population.

ADAPT opposes any block grant proposals that arbitrarily cap dollars and force reduction in services and/or numbers of people on programs.

IV. ADMINISTRATIVE REMEDIES

The Center for Medicaid and Medicare Services, CMS, could do many things to end the institutional bias AND more efficiently provide community services through changes in rules and policies to enhance community services. These include:
-Put consumer direction in ALL community programs,
-Relax any requirements for the person to be homebound or bound by unnecessary medical requirements Ease restrictions on states' use of Minimum Data Set, MDS, data Add a requirement that federally authorized entities such as Centers for Independent Living and Area Agencies on Aging, be involved when a nursing home resident chooses to live in the community, and
-Require a "most integrated setting" question as part of the process of getting into a nursing home or other institution Create incentives for discharge planners at hospitals and rehabilitation facilities to promote community placements.

The Medicaid Commission should direct CMS to encourage these administrative fixes.

V. ISSUE AREAS

A. Most Integrated Setting/Olmstead

States still have not adequately complied with the Supreme Court's 1996 Olmstead decision which said that unnecessary institutionalization of people with disabilities is discrimination. Congress should put language in the US Dept. of Health and Human Services, HHS, budget bill directing HHS to monitor and ensure states are getting and keeping folks out of nursing homes and other institutions. Dept of Justice and HHS/Office of Civil Rights, OCR, should be directed to assure no civil rights abuses are taking place by folks not getting out or staying out of nursing homes and other institutions.

B. Consumer Direction

A consumer directed philosophy should permeate any and all Congressional legislation. This is not a matter of agency versus consumer-directed services; in other words agency provided services should be consumer directed as well as services that are done on a voucher-type model. As this evolves there needs to be a move towards allowing individuals the “dignity of risk". Health and safety requirements have been used to restrict people with significant disabilities entrance to community services.

The ADAPT Community Definition of Consumer Direction

As it relates to program design for attendant services, consumer direction means the right of the consumer to select, manage, and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

Vouchers
Direct cash
Fiscal intermediaries
Agencies that allow choice (Agencies with Choice)
Concept included in MiCASSA -- S. 401 and HR. 910

C. Nurse/Physician Delegation/Assignment

One of the most costly aspects of community programs is the over-medicalization of services. ADAPT is for quality of services, but we know quality can be accomplished without unnecessary medical involvement.

Delegation/Assignment of tasks is working in states across the country.

This Commission could make recommendations and develop incentives for States to work with advocates to provide "quality services" without unnecessary medical intrusion.

D. Worker/Personnel Issues

The shortage of well paid home care workers is reaching epidemic proportions. Part of the problem is the lack of wages and benefits for these vital workers. Congress needs to develop incentives to bring together consumers, family members, providers, attendants, administrators and union representatives to develop recommendations on how to enhance the pool of workers available to do home care services. Family members, including spouses, should be allowed to provide attendant services in State Plan and 1915 c waivers.
Incentives for pooling for health benefits should be developed.

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MEDICAID LONG TERM CARE DATA - 2004
(September 2003 through September 2004)

Total Medicaid	$282.26 billion
Total Long Term Care	$89.32 billion
LTC	31.64% of Medicaid

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Total Institutional	$57.60 billion
	64.5%
Total Community	$31.72 billion
	35.5%

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HCBS WAIVER BREAKDOWN 2004 BY CATEGORY

Total HCBS Waivers	$21.24 billion
MR/DD	$15.97 billion
	75.19%
Aged/Disabled	$3.78 billion
	17.81%
Physical Disability	$676.57 million
	3.18%
Aged	$412.46 million
	1.94%
Tech Dependent	$106.58 million
	.50%
Brain Injury	$189.77 million
	.90%
HIV/AIDS	$67.00 million
	.30%
Mental Illness/SED	$39.34 million
	.18%

Numbers are taken from a report by MEDSTAT (www.medstat.com)
The MEDSTAT Group Inc. - (617)492-9300
MEDSTAT data taken from CMS 64 reports submitted by the states
Compiled by ADAPT - June 2005 (All numbers are rounded off)