

# Community Choice Act

## A Vision for Attendant Services and Supports for the New Millennium

### Community Choice Act:

This legislation is needed to truly bring people with disabilities into the mainstream of society and provide equal opportunity for employment and community activities.

In order to work or live in their own homes, Americans with disabilities and older Americans need access to community-based services and supports. Unfortunately, under current Medicaid policy, the deck is stacked in favor of living in an institutional setting. Federal law requires that States cover nursing home care in their Medicaid programs, but there is no similar require-

ment for attendant services. The purpose of our bill is to level the playing field, and to give eligible individuals equal access to the community-based services and supports that they need.

Although some States have already recognized the benefits of home and community-based services, they are unevenly distributed and only reach a small percentage of eligible individuals. Some States are now providing the personal care optional benefit through their Medicaid program, but others do not.

Those left behind are often needlessly institutionalized because they cannot access community alternatives. The civil right of a person with a disability to be integrated into their own community should not depend on their address. In *Olmstead v. L.C.*, the Su-

preme Court recognized that needless institutionalization is a form of discrimination under the Americans with Disabilities Act. We in Congress have a responsibility to help States meet their obligations under *Olmstead*.

The Community Choice Act is designed to do

just that, and to make the promise of the ADA a reality. It will help rebalance the current Medicaid long term care system, which spends a disproportionate amount on institutional services.

Today, almost two-thirds of Medicaid long term care dollars are spent on institutional services, with only one-third going to community-based care.

Senator Tom Harkin  
*Democrat, Iowa*

*This creative proposal addresses a glaring gap in Federal health coverage. ... The time has come for concerted action in this arena.*

- Senator Arlen Specter  
*Republican, Pennsylvania*



# How the Community Choice Act Works



1) Provides **community-based attendant services and supports** ranging from assistance with:

- activities of daily living (eating, toileting, grooming, dressing, bathing, transferring),
- instrumental activities of daily living (meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community),
- and health-related functions.

2) Includes **hands-on** assistance, **supervision and cueing**, as well as **help to learn**, keep and enhance skills to accomplish such activities.

3) Requires services be provided in **THE MOST INTEGRATED SETTING** appropriate to the needs of the individual.

4) Provides Community-based Attendant Services and Supports that are:

- **based on functional need**, rather than diagnosis or age;
- provided in **home or community settings** like -- school, work, recreation or religious facility;
- selected, managed and **controlled by the consumer** of the services;
- supplemented with **backup and emergency** attendant services;
- furnished according to a service plan **agreed to by the consumer**; and that include **voluntary training** on selecting, managing and dismissing attendants.

5) Allows consumers to choose among **various service delivery models** including vouchers, direct cash payments, fiscal agents and agency providers. All models are required to be consumer controlled and comply with federal and state labor laws.

6) For consumers who are not able to direct their own care independently, the Community Choice Act allows for "**individual's representative**" to be authorized by the consumer to assist. A representative might be a friend, family member, guardian, or advocate.

7) Allows **health-related functions or tasks to be assigned to, delegated to**, or performed by unlicensed personal attendants, according to state laws.

8) Covers **individuals' transition costs from a nursing facility, ICF-MR or IMD to a home setting**, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.

9) Serves individuals with **incomes above the current institutional income limitation -- if a state chooses** to waive this limitation to enhance employment potential.

10) Provides for **quality assurance programs** which promote consumer control and satisfaction.

11) Provides **maintenance of effort requirement** so that states can not diminish more enriched programs already being provided.

12) Allows **enhanced match** (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs.

13) Between 2009 and 2014, after which the services become permanent, **provides enhanced matches** (10% more federal funds each) for states which:

- begin planning activities for changing their long term care systems, and
- include Community-based Attendant Services and Supports in their State Plan.

Medicaid Long-Term Care Spending per Person Served, (2005)



come permanent, **provides enhanced matches** (10% more federal funds each) for states which:

- begin planning activities for changing their long term care systems, and
- include Community-based Attendant Services and Supports in their State Plan.

## SYSTEMS CHANGE

14) Provides **grants for Systems Change Initiatives** to help the states transition from current institutionally dominated service systems to ones more focused on community based services and supports, guided by a Consumer Task Force.

15) Calls for national 5 -10 year **demonstration project**, in 5 states, to enhance coordination of services for individuals **dually eligible for Medicaid AND Medicare**.

# THE COMMUNITY CHOICE ACT HELPS FAMILIES OF CHILDREN WITH DISABILITIES

The Community Choice Act redirects the focus of the Medicaid long term services program from institutions to home and community services and supports, enabling families to make real choices. Given "REAL CHOICE" people overwhelmingly choose "HOME SWEET HOME."

Studies show that children currently living in America's institutions and nursing homes do not have more severe disabilities than those who live with their families at home and use attendant services and supports.

- Families DON'T want to place children with disabilities in institutions. Families want children to live at home where they can maintain family ties, go to school and grow as other children do.
- Families also want their children to have a secure future and real options for home and community services and supports when their families are no longer providing full-time care.

Some of the real reasons why children and young adults with disabilities go into institutions or nursing homes:

- Parents can't hold down a job that supports their family AND provide full-time care to a child with a disability.
- Parents may be able to provide much of the care that a young child needs, but may not be physically able to manage lifting and positioning as the child grows up.
- Waiting lists for community services are so long families get worn down while waiting, sometimes 10 years and longer!
- Parents fear that when their child is old enough to move out of the house, no independent living, community options will be available.
- People don't know that there are community alternatives to nursing homes and other institutions.
- Public policy supports institutions, NOT people with disabilities and their families.
- Young people with disabilities are not in institutions or foster care because of the amount of care they need. They are in because of the lack of attendant services and supports. Many, many children with significant disabilities DO live at home with their families.

## Community Choice at a Glance:

- CCA provides Medicaid funding for attendant services and supports for people of all ages.
- Services can be provided at home, in school, at work and at play.
- Assistance is available for a broad range for needs, such as bathing, dressing, meal preparation, money management and certain health-related tasks.
- CCA will be available to young adults when they move out of their parents' homes into the community.





# Frequently Asked Questions

## ***1. What are the community-based attendant services and supports in the Community Choice Act?***

In the Community Choice Act, the term community-based attendant services and supports means help with accomplishing activities of daily living (eating, toileting, grooming, dressing, bathing, and transferring) instrumental activities of daily living (meal preparation, managing finances, shopping, household chores, phoning, and participating in the community), and health-related functions (which can be delegated or assigned as allowed by state law). These services and supports can be done through hands-on assistance, supervision and/or cueing. They also include help with learning, keeping and enhancing skills to accomplish such activities.

These services and supports, which include back up, are designed and delivered under a plan that is based on a functional needs assessment and agreed to by the individual. In addition they are furnished by attendants who are selected, managed, and dismissed by the individual, and include voluntary training for the individual on supervising attendants.

The Community Choice Act specifically states that services should be delivered, "in the most integrated setting appropriate to the needs of the individual" in a home or community setting, which may include a school, workplace, or recreation or religious facility.

## ***2. If someone can't manage their attendant services completely independently are they still eligible for the Community Choice Act services?***

Yes! People who, due to a cognitive disability for example, have difficulty managing their services themselves can have assistance from a representative, like a parent, a family member, a guardian, an advocate, or other authorized person.

## ***3. Do you have to be impoverished to be eligible for the Community Choice Act?***

No. If you are eligible to go into a nursing home, an ICF-MR facility or an Institution for Mental Disease, IMD, (these are the technical names, not ones we would pick) you would be eligible for the Community Choice Act. Financial eligibility for nursing homes is up to 300% of the SSI level (roughly \$1,800 per month for a single person). In addition, with the Ticket to Work and Work Incentives Improvement Act of 1999, TWWIIA, states can choose to have a sliding fee scale for people of higher incomes beyond the current Medicaid eligibility guidelines.

## ***4. Is the Community Choice Act biased towards an agency delivery model?***

No, the Community Choice Act assumes that one size does not fit all. It allows the maximum amount of control preferred by the individual with the disability. Options include: vouchers, direct cash payments or a fiscal agent, in addition to agency delivered services. In all these delivery models the individual has the ability to select, manage and control his/her attendant services and supports, as well as help develop his/her service plan. Choice and control are key concepts, regardless of who serves as the employer of record. All delivery models must comply with Federal and state labor laws.

## ***5. Will the Community Choice Act replace existing community-based programs?***

The Community Choice Act does not affect existing optional programs or waivers and includes a maintenance of effort clause to ensure these programs are not diminished. Waivers include a more enriched package of services for those individuals who need more services. With the Community Choice Act, people who are eligible for nursing homes, ICF-MR facilities or IMDs can choose community attendant services and supports as a unique service that is a cost-effective option. The money follows the individuals not the facility.



### *6. Is the Community Choice Act a new un-funded mandate?*

No. The Community Choice Act is a way to make an existing mandate for nursing homes and virtual mandate for institutions for mentally retarded persons responsive to the needs and desires of the consumers of these services. The Community Choice Act says the people who are already eligible for these services will simply have a choice of where they receive services. The Community Choice Act would adjust the current system to focus on the recipients of service, instead of mandating funding for certain industries and facilities.

### *7. Why is the Community Choice Act needed?*

Our current long term services system has a strong institutional bias. Sixty seven percent of Medicaid long term care dollars go to institutional services, leaving 33% to cover all the community based services. Every state that takes Medicaid funds must provide nursing home services while community based services are completely optional for the states. The Community Choice Act says, let's level the playing field, give the person, instead of government or industry, the real choice.

### *8. How does the Community Choice Act help states?*

The Community Choice Act provides a five year transformation period for the states by providing both an enhanced match and grants for the transition to Real Choice before the benefit becomes permanent. The Community Choice Act offers states financial assistance to reform their long term service and support system to provide services in the most integrated setting, and thereby helps with compliance with the Supreme Court's Olmstead decision as well.

### *9. Will the Community Choice Act bust the bank? What about the "woodwork" effect?*

The Community Choice Act assures that a state need spend no more money in total for a fiscal year than would have been spent for people with disabilities who are eligible for institutional services and supports.

There is a lot of discussion that the people who are eligible for institutional services would never go into the institution but would jump at the chance to use the Community Choice Act. (This is called the woodwork effect.) The states of Oregon and Kansas have data to show that fear of the woodwork effect is blown way out of proportion. There may be some increase in the number of people who use the services and supports at first, but savings will be made on the less costly community based services and supports, as well as the decrease in the number of people going into institutions. Belief in the woodwork effect assumes caregivers are now delivering a lot of "free care". There is a real question whether this care is truly "free". Research on the loss to the economy of the "free" caregivers is beginning.

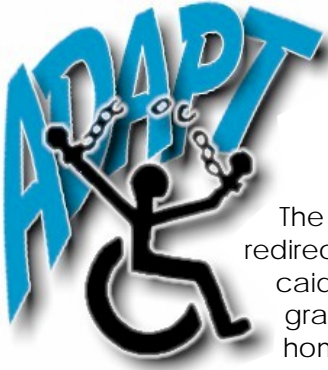
### *10. What are the transitional services?*

Currently Medicaid does not cover some essential costs for people coming out of nursing homes or other institutions. These include deposits for rent and utilities, bedding, kitchen supplies and other things necessary to make the transition into the community. Covering these costs would be one of the services and supports covered by the Community Choice Act.

### *11. What about people who need more supports?*

For people whose costs are higher than 150% of the average nursing home cost, the Community Choice Act will provide additional federal support to the states, so that people are not stuck in institutions because they need more services and supports.

[www.adapt.org](http://www.adapt.org)



# OLDER AMERICANS AND THE COMMUNITY CHOICE ACT

The Community Choice Act redirects the focus of the Medicaid long term services program from institutions to home and community services and supports. It enables older people to make real choices. Given "REAL CHOICE" people overwhelmingly choose "HOME SWEET HOME."

Studies show that seniors currently living in America's institutions and nursing homes do not have more severe disabilities than those who are living in their own homes with attendant services and supports.

## The Community Choice Act means REAL CHOICE!

- ✓ Older Americans generally prefer to be in their own homes. They do NOT want to live in nursing homes.

- ✓ Surveys show that most people who need long term services and supports prefer to remain in their homes and to "age in place." What do YOU want for yourself, for other family members? Tell your legislator!
- ✓ Home-based services DO work for older Americans.
- ✓ Although people in nursing homes do tend to be elderly (average age: 84 years) many older Americans are living in their own homes and communities with the help of community services and supports, but these programs are very limited.
- ✓ Some Americans diagnosed with Alzheimer's are cared for at home, but both the individual and the family members need appropriate supports, which the Community Choice Act could provide.
- ✓ Family members can't do it all, need help. The Community Choice Act is the answer!

Questions and Answers about The Community Choice Act continued . . .

### 12. What about people who are dually eligible for both Medicaid and Medicare?

The Community Choice Act includes a national 5 to 10 year demonstration project in 5 states to enhance coordination of services for individuals dually eligible for Medicaid AND Medicare. These individuals often fall through the cracks now.

### 13. How is Quality Assurance addressed in the Community Choice Act?

States are required to develop quality assurance programs that set down guidelines for operating Community-based Attendant Services and Supports, and provide grievance and appeals procedures for consumers, as well as procedures for reporting abuse and neglect. These programs must maximize consumer independence and direction of services, measure consumer satisfaction through surveys and consumer monitoring. States must make results of the quality assurance program public as well as providing an on-going process of review. Last but not least sanctions must be developed and the Secretary of Health and Human Services must conduct quality reviews.

### 14. What is the purpose of the Real Choice Systems Change Initiatives section of the bill?

The Community Choice Act brings together on a consumer task force, the major stakeholders in the fight for community-based attendant services and supports. Representatives from DD Councils, IL Councils and Councils on Aging along with consumers and service providers would develop a plan to transition the current institutionally biased system into one that focuses on community-based attendant services. The people that have an investment in the final outcome, the consumers, must think through closing institutions, or at least closing bed spaces. The plan envisions ending the fragmentation that currently exists in our long term service system.

In addition, the bill sets up a framework and funding to help the states transition from their current institutionally dominated service model to more community-based services and supports. States will be able to apply for systems change grants for things like: assessing needs and gathering data, identifying ways to modify the institutional bias and over-medicalization of services and supports, coordinating between agencies, training and technical assistance, increasing public awareness of options, downsizing of large institutions, paying for transitional costs, covering consumer task force costs, demonstrating new approaches, and other activities which address related long term care issues.

# Talking Points



1) The demographics of our country are changing. More and more people with disabilities are living, and could be thriving! Reasons for these changes include:

- a) the aging process, the graying of America,
- b) children born with disabilities are living,
- c) young adults, who previously would have died from accidents or illnesses, are living -- thanks to medical technology and other advances.

2) Our long-term service system must change. Created over forty years ago, it is funded mainly by Medicare and Medicaid dollars, medical dollars not originally meant to meet people's long-term care needs. We must think out of the box to empower people and allow REAL choices.

3) The money should follow the individual, not the facility or provider. A national long-term service policy should not favor any one setting over the other. It should let the users choose where services should be delivered. Our current system is not neutral, and it doesn't reflect people's choices.

4) The current system is needlessly expensive. We must explore cost-effective ways to meet people's needs.

5) People with disabilities -- both old and young -- even those with severe mental and/or physical disabilities want services in the most integrated setting possible. Overwhelmingly people prefer community services so they can stay in their own home.

6) People with disabilities and their families want REAL choice, which means:

- a) equitable funding opportunities,
- b) no programmatic or rule disincentives to community services, and
- c) options for services delivery which include agency based services, vouchers, and fiscal intermediaries.

*"Creating a mandatory PAS benefit for those with an institutional level of need is a fiscally achievable policy strategy to redress the imbalance between institutional and community-based services under Medicaid."*

LaPlante, MP, Kaye, HS, & Harrington, C. (2007). Estimating the expense of a mandatory home- and community- based personal assistance services benefit under Medicaid. Journal of Aging & Social Policy, 19(3), 47-64. DOI: 10.1300/J031v19n03\_04

The Community Choice Act empowers people with disabilities and families.

7) Family values keep families together

- a) children belong in families
- b) Mom and dad together with the grandchildren
- c) communities take care of their own.

8) Money following the individual can eliminate overburdening government rules and regulations.

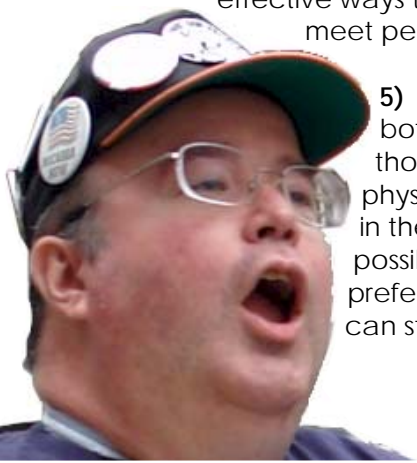
9) A functional system based on need instead of medical diagnosis could end FRAGMENTATION of the service delivery system.

10) Keeping people in the community allows the possibility for individuals with disabilities to train for work so they can become TAXPAYERS instead of TAX USERS.

11) The federal government needs to work in partnership with the states to create flexible delivery systems that give people REAL choice.

12) Change can cause fear of the unknown. Some long time providers of services and families believe REAL choice would threaten what they have. We cannot continue the system as it is today; it is expensive, fragmented, overly-medical and disliked by almost everyone.

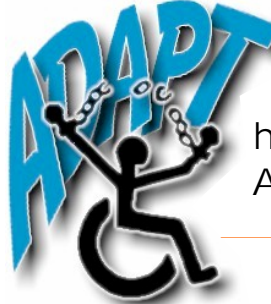
**There's No Place Like Home!**



**The Community Choice Act** is a bill to amend title XIX of the Social Security Act to provide individuals with disabilities and older Americans with equal access to community-based attendant services and supports.

What does passing such a bill involve?

Over 600 organizations support the Community Choice Act. Will your group help us make the change America needs?



"I understand that there is nothing more important to people than the dignity of being able to live and to live self-sufficiently."

Congressman  
Danny Davis  
- Democrat, Illinois

## Medicaid Long-Term Care Spending for Older People and Adults with Physical Disabilities in the US, 2007

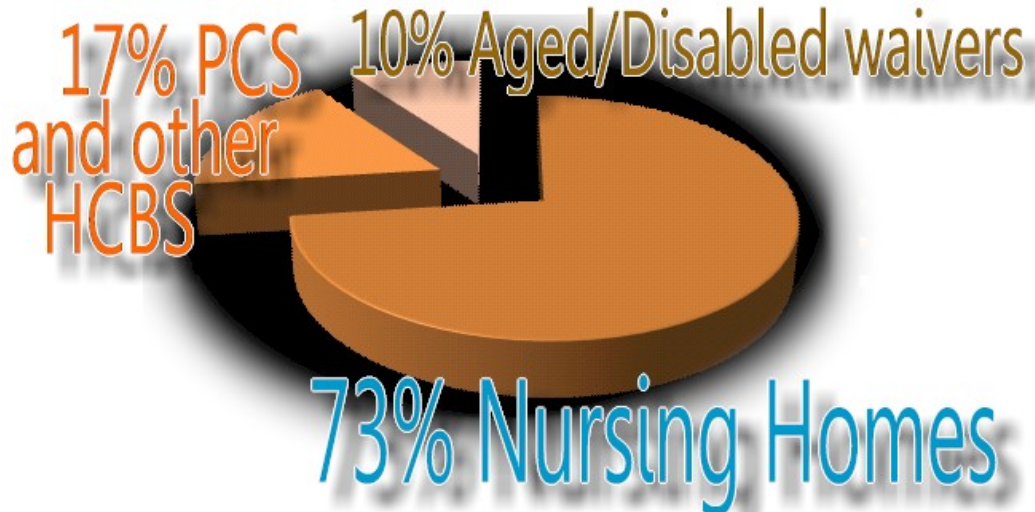


CHART DATA FROM: "Taking the Long View: Investing in Medicaid Home and Community-Based Services Is Cost-Effective" written by R. Mollica, E. Kasser, L. Walker, and A. Houser. It is in the publication entitled INSIGHT on the Issues, vol 126 (March 2009).

## Community Choice Act: S 683 and HR 1670



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