Why We Need MiCASSA NOW!

- The demographics of our nation are changing - population is aging, more people with disabilities are living and needing assistance with daily living tasks.
- Although people with disabilities overwhelmingly prefer home and community services and supports over institutional services, the current long-term care system favors costly institutional programs and profit seeking corporations.
- Currently, in America, non-institutional long-term care services are fragmented between many different funding sources and administering agencies and eligibility tends to be based on age or medical diagnosis rather than functional need.
- The over 30-year-old system we have now does not work.
- MiCASSA gives people a real choice of how to live their lives.

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Medicaid Community-Based Attendant Services and Supports Act of 2003, MICASSA.

S 971 and HR 2032 MiCASSA

A Vision for Attendant Services and Supports for the New Millennium

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 Federal Medicaid policy, the deck is stacked in favor of living in an institution. The purpose of our bill is to level the playing field and give eligible individuals equal access to community-based services and supports.

Those left behind are often needlessly institutionalize because they cannot access community alternatives. A person with a disability's civil right to be integrated into his or her community should not depend on his or her address. In *Olmstead v. LC*, the Supreme Court recognized that needless institutionalization is a form of discrimination under the Americans With Disabilities Act.

This creative proposal addresses a glaring gap in Federal health coverage.

- Senator Arlen Specter
May 1, 2003

This MICASSA legislation is designed to do just that and 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. For example, in 2000, 49.5 billion dollars were spent on institutional care, compared to 18.2 billion on community based care.

An individual should not be asked to move to another state in order to avoid needless segregation. They also should not be moved away from family and friends because their only choice is an institution.

Senator Tom Harkin
May 1, 2003
Introducing MiCASSA

www..adapt.org

Specifically what does this bill do? MiCASSA.. . .

1. Provides community attendant services and supports which range from assisting with activities like: eating, toileting, grooming, dressing, bathing, transferring, meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community, and health-related functions like taking pills, bowel and bladder care, ventilator care, tube feeding, etc.

2. Includes hands-on assistance, supervision, help to learn, and also 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 Attendant Services and Supports that are based on an assessment of functional need; 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 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 of which are required to be consumer controlled.

6. For consumers who are not able to direct their own care independently, MiCASSA 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 or ICF/MR 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 the potential for employment.

10. Provides for quality assurance programs that promote consumer control and satisfaction.

11. Allows states to limit the aggregate amount spent on long-term care in a year to that amount the state would have spent on institutional services for such eligible individuals in the year.

12. Provides maintenance of effort requirement so that states cannot diminish more enriched programs already being provided.

MiCASSA also provides grants for Real Choice Systems Change Initiatives to help the states transition from current institutionally dominated service systems to ones more focused on community services and supports.

Talking Points

1. Our long term service system must change. Created over thirty years ago it is funded mainly by Medicare and Medicaid dollars. These medical dollars were not to have met the long-term care needs of people. We must think out of the box to new system that empowers people and allows REAL choices.

- 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 be neutral and let the users choose where services should be delivered. The current system is not neutral.
- Over 70% of our Medicaid dollars spent on long term care is spent on institutional services, leaving only 30% for all community services.
- Current system is expensive and ways to meet the needs of people in the most cost-effective way must be explored.
- Community services on average have been shown to be less expensive then institutional services and better liked by individuals.

2. Demographics of our country are changing

   a. Aging process
   b. Children being born with disabilities
   c. Young adults - Medical technology is keeping people alive longer.

3. Families must have REAL choice. People with disabilities both old and young, even those with severe mental or physical disabilities want services in the most integrated setting possible.
4. People with disabilities and their families want REAL choice which means:

   a. Equitable funding opportunities.
   b. No programmatic or rule disincentives to community services.
   c. Options for services delivery to include agency, vouchers and fiscal intermediaries. Empower people with disabilities and families.

5. Family values, keep families together.

   a. communities taking care of their own.
   b. children belong in families.
   c. Mom and Dad together with their grandkids.

6. Money following the individual can eliminate overburdening rules and regulations by government regulators.

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

8. 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.

9. Overwhelmingly people prefer community services to stay in their own home. Federal government needs to work in partnership with the states to create flexible delivery systems that gives people with disabilities REAL choice.

10. Change can cause fear of the unknown. There are some long time providers of services and families who believe REAL choice would threaten what they have. We cannot continue the system as it is today. It is expensive, fragmented, over medicalized and not liked by almost everyone.

Our Homes NOT Nursing Homes!

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.

9. What are the transitional services?

Currently Medicaid does not cover some essential costs for people coming out of nursing homes and ICF-MR facilities. 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 MiCASSA.

10. How is Quality Assurance addressed in MiCASSA?

States are required to develop quality assurance programs that set down guidelines for operating Community 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 public results of the quality assurance program public as well as 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.

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

MiCASSA 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.

FreeOurPeople.org

What does passing such a bill involve?

MiCASSA has over 600 organizations signed up as supporting the bill. If you or your group has not signed on yet, now is the time. Powerful lobby groups like the nursing home PAC the American Health Care Association, and pro-institution groups like Voice of the Retarded are actively working to kill MiCASSA. It will take all our combined efforts to create the changes that are so badly needed.

Benefits to various consumer groups:

Studies show that people currently living in America's institutions and nursing homes - from children up to seniors - do not have more severe disabilities than those who live at home and use attendant services and supports.

Young people with disabilities are not in institutions or nursing homes because of the amount of care they need. They are in because of the lack of attendant services and supports. Families DON'T want to place their children in institutions; they want children with disabilities to live at home where they can maintain family ties, go to school and grow as other children do. Parents 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 are that many parents can't hold down a job that supports their family AND provide full-time care to a child with disability. Also, as the child grows up, many 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. In addition, parents fear that when their child is old enough to move out of the house, no independent living, community options will be available.

MiCASSA at a glance:

- MiCASSA 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.
- MiCASSA will be available to young adults when they move out of their parents' homes into the community.

Similarly, Older Americans generally prefer to be in their own homes. They do NOT want to live in nursing homes. Most people who need long term services and supports prefer to remain in their homes and to "age in place."

In fact 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 MiCASSA will provide.

Some Questions About the Medicaid Community Attendant Services And Supports Act, MiCASSA

1. How are community attendant services and supports defined in MiCASSA?

In MiCASSA, the term community 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 can be done through hands-on assistance, supervision and 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.

MiCASSA 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 MiCASSA services?

Yes! People who have difficulty managing their services themselves, due to a cognitive disability for example, 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 MiCASSA?

No. If you are eligible to go into a nursing home or an ICF-MR facility you are eligible for MiCASSA. Financial eligibility for nursing homes is up to 300% of the SSI level (roughly $1,500 for a single person). In addition, states can choose to have a sliding fee scale for people of higher incomes; MiCASSA specifically references this as an incentive for employment. This sliding fee scale can go beyond the current Medicaid eligibility guidelines.

4. Is MiCASSA biased towards an agency delivery model?

No. MiCASSA 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.

5. Will MiCASSA replace existing community-based programs?

MiCASSA does not effect 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 MiCASSA, people who are eligible for nursing homes and ICF-MR facilities 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 MiCASSA a new unfunded mandate?

No. MiCASSA is a way to make the existing mandate for nursing homes, and the virtual mandate for institutions for people being served by the various state Mental Retardation/ Developmental Disability systems, responsive to the needs and desires of the consumers of these services. MiCASSA says the people who are already eligible for these services will simply have a choice of where they receive services. MiCASSA would adjust the current system to focus on the recipients of service, instead of mandating funding for certain industries and facilities.

7. Why is MiCASSA needed?

Our current long-term services system has a strong institutional bias. Seventy percent of Medicaid long term care dollars go to institutional services, leaving 30% 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. MiCASSA says, let's level the playing field; give the person, instead of government or industry, the real choice.

8. Will MiCASSA bust the bank? What about the "woodwork" effect?

MiCASSA 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 about the people who are eligible for institutional services, would never go into the institution, but would jump at the chance to use MiCASSA. (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.