End the Institutional Bias: No More Stolen Lives!

MiCASSA, Money Follows the Individual and More!

Testimony of the ADAPT Community Before the Senate Finance Committee, Washington DC. April 6, 2004

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Good Morning. My name is Bruce Darling, and today I am testifying on behalf of the ADAPT Community and the many thousands of people with disabilities who want to have a REAL CHOICE so that they may live fulfilling and productive lives in the community.

I am the Executive Director of the Center for Disability Rights (CDR), an Independent Living Center based in Rochester, New York, which provides community-based services that support people with disabilities in the community and advocates on disability issues. About four years ago, CDR began to formally transition people out of nursing homes.

Since that time, our Center has helped over 100 people return to community living.

Over the last few years, I have also trained literally hundreds of people from 37 different states and the Territory of Guam on how to assist people with disabilities to return to community living from institutional settings. As I have traveled throughout the country, I have heard the same stories from people who had years of their lives stolen by a system that supports institutions over individual rights.

- People who were separated from their families,
- People who lost their homes,
- People who lost their freedom and thought their lives had ended.

People with disabilities and our allies are fighting the institutional bias, but conviction, training, and hard work are simply not enough. We need YOU to take action and establish a national Community First policy! You have the power to end the institutional bias and assure that there are no more stolen lives.

PROBLEM STATEMENT AND ITS IMPACT ON REAL PEOPLE

Our long-term care system has remained essentially unchanged since its creation nearly 40 years ago. No one would have guessed that today this system would warehouse over 1.4 million Americans in nursing facilities and 110,572 in ICFs, or Intermediate Care Facilities for the Mentally Retarded.

The system was built on a medical model. At the time of its creation, individuals with disabilities were considered patients who needed to be cared for. Over the years, the medical model has added costs, requiring medical staff to do tasks which could be done by an unlicensed attendant either through delegation or assignment of a health professional. In this system, health-related tasks are often done by a nurse, who charges Medicaid over $100, rather than an attendant who is billed at only $15.

Bruce Darling holds a section of the FREE OUR PEOPLE banner

The medical model fostered a system where services were made available based on diagnosis, creating fragmentation and service gaps. I worked with a woman named Lisa Cyphers. She wanted to be at home rather than a nursing home. To go home she needed support services that were provided under the state's Traumatic Brain Injury waiver, but because she had Multiple Sclerosis she was not eligible for them. Even though she had the same exact functional needs, she wasn't eligible for the services to get her home.

Over the years long term care services have become even more fragmented. Attempts at modernizing the system, including the development of new programs and a multitude of Medicaid Waiver programs, have created a disjointed mish-mash of services, which vary from state to state, and even county to county. States may have a dozen different waivers and a complicated array of services that even the most skilled social worker couldn't navigate.

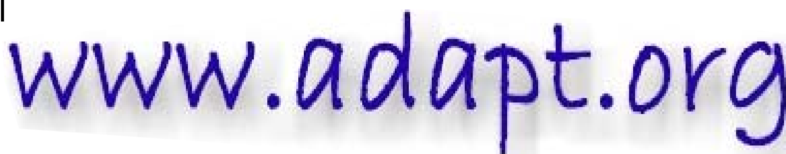
Our spending in long term care clearly illustrates the institutional bias. According to 2002 *Medstat* data, 70% of the $82.13 billion that is spent on long term care services goes to institutional services, while only 30% funds community services and supports.

The institutional bias is demonstrated on a personal level as well.

Medicaid rules allow individuals who are in nursing facilities (or deemed eligible for a nursing facility and receive services through a Medicaid Waiver) to retain income up to 300% of the Supplemental Security Income (SSI) federal benefit rate, nearly $1,700 per month for a single person. By comparison in most states, individuals who need personal care or home health care are only allowed to retain one third of that amount.

If an individual's spouse is institutionalized in a nursing home, federal rules allow them to keep at least some of their income and resources without totally impoverishing themselves. The same is not true for community-based services. As an example, we worked with Phyllis Patnode. As a 50-year-old woman, Phyllis was forced to leave her husband and home and go into a nursing home because her husband worked and she didn't want to financially devastate him and her daughters.

A fundamental problem is that Medicaid funding for long term care services is securely tied to the institutions. States must provide institutional services, like nursing home care, while community-based services are completely optional. To provide alternatives to nursing homes or ICF-MR facilities, states must apply for a Medicaid Waiver, which means that the federal government is agreeing, on a case-by-case basis, to waive certain Medicaid requirements in order for that state to provide home and community based services. There are often no waiting lists for nursing homes. However, when states apply for a Medicaid Waiver, the federal government authorizes a certain number of "slots", which results in waiting lists for Home and Community Based Medicaid Waiver Services. Because institutional services are mandatory, states cannot cut their funding. We are in tough fiscal times. States have no choice but to cut community based services. Even states



that want to provide less expensive community-based alternatives are prevented from doing so by a federal policy that mandates institutional care.

In addition to all of this, there is one very important reason we must change this system. **It isn ' t what people want**.

According to the data from the Centers for Medicare and Medicaid Services, nearly 19% of individuals in nursing homes have expressed an interest in returning to the community. This information was collected by the nursing homes themselves. From our experience, the number of people who want to live in the community is actually much higher. We have the data that shows this. According to Barriers to Independence, a study conducted by Access Living and the Center for Urban Research and Learning at Loyola University in Chicago, 64.5% of the nursing home residents that were surveyed expressed that they would prefer to live somewhere else if the opportunity were available.

PERSONAL IMPACT: REAL VOICES

Last year, as part of our Stolen Lives Campaign, ADAPT began documenting the names and stories of people from nursing homes and institutions.

These stories document the voices of people institutionalized as children:

> **Like Leonard Roscoe**, from Georgia. Leonard was put in the institution in 1972 after living in hospital the first 3 years of his life. Leonard has Osteogenesis Imperfecta (brittle bones). He was institutionalized for 35 years before he got out.
>
> **Like Patrick King** from Austin, Texas. When Patrick was eight he got hit on the head in a schoolyard accident resulting in multiple disabilities. He ended up in a Texas State Mental Health Hospital and stayed there for over a decade because he had what was described as 'bizarre behaviors.' Nobody believed Patrick could live in the community and he lost over a decade of his life because of this neglect.

These stories document the voices of people who lost their freedom during the prime of their lives ' .

> **Like June Adams** from Denver, Colorado. June had two little boys when she had her stroke. She was put in a nursing home, where she was held captive for 17 years while her children grew up without her.

These stories document the voices of older persons who were forced to leave their homes.

> **Like Betty Cranston** from Lake Katrine, New York. When Betty's COPD worsened and she needed a ventilator, she was forced into a specialized nursing facility hundreds of miles away from her son, home, and small town. Even though she did much of her own personal care at the facility and her son wanted his mother to return home to live with him, she was forced to stay there because she couldn't get approved for community services or a portable ventilator.

I have included the individual stories we received at the end of this testimony. Their words are compelling. Their voices rise up and ask for just one thing: freedom.

SOLUTIONS: REAL CHOICES

It is clear that we need a new model. No longer should community based services be the exception to the institutional rule.

Community based services must become as easy to access as institutional services.

To accomplish this, the tie between the institution and funding must be cut. Individuals must have real, meaningful and effective choices in what services they receive, where they receive services, and who provides those services.

Our nation must pass legislation which reforms the long term care system and incorporates the following principles:

- Attendant services must be available in the community, 24 hours per day, and seven days per week;
- Eligibility must be based on functional need, not on diagnosis, age, or funding stream;
- Incentives are offered to encourage states to allow assignment or delegation of care tasks previously restricted to only doctors and nurses;
- Consumer control must be maximized at every step of the process, including flexible payment and management systems; and
- Attendants must earn a livable wage and benefits.

Immediate Actions

This shift will take time, but there are immediate steps you can take to end the institutional bias.

First, you must pass Money Follows the Individual legislation.

Under this legislation, the Federal government will fund community-based services for the first year for individuals who transition out of institutions! This legislation would provide a critical incentive to the states in providing Real Choices in long term care. This will encourage states to build their capacity to more effectively transition people back into the community.

Senator Harkin introduced the Money Follows the Person Act of 2003 (S.1394) on July 11th. Shortly after that, on July 25th, the White House distributed its own draft legislation: the New Freedom Initiative Medicaid Demonstration Act of 2003. We understand that you, Senator Grassley, are considering introducing legislation based on the administration's proposal. This more comprehensive legislation would authorize a Money Follows the Individual Demonstration program and support other initiatives to promote community-based services.

Thousands of people with disabilities in nursing homes and other institutions will benefit if you fund these initiatives and give states the incentive to move people into the community. This first step, though not the complete answer to ending the institutional bias, will lay the foundation for the more comprehensive changes to the Medicaid system that must occur if nursing homes and other institutions are to become the alternative rather than the entitlement.

Whether you pass S. 1394 or the administration's proposal, it is imperative that you take action now. This legislation must be passed during this session. The CMS data I spoke about earlier shows that at least 267,000 people with disabilities want to return to the community NOW!

267,000 people are telling the nursing homes that they want to go home; 267,000 people are asking you to help them go home; and On behalf of those 267,000 people, I am pleading with you not to make them wait one more day!

There are other steps you could take to address the institutional bias. You could create

an Enhanced Federal Medicaid Matching Rate for home and community based services. By paying a larger percentage of the cost of home and community based services, you will create a strong and on-going incentive for states to promote community living.

Such a step would help the states address their budget difficulties during these difficult times and promote community living options. It would also send a clear message that our nation values the freedom of all of its citizens, including those with disabilities.

A Lasting Solution

While demonstration programs and enhanced Medicaid matches would promote community living, they still leave much work to be done. The ultimate solution to ending the institutional bias, which has stolen the lives of so many thousands of seniors and people with disabilities, is clear.

Pass MiCASSA!

The Medicaid Community Attendant Services and Supports Act (S. 971) gives people Real Choice in long-term care. MiCASSA provides individuals eligible for Nursing Facility Services or ICFs with the opportunity to choose Community-Based Attendant Services and Supports.

Rather than be forced into institutional placement, people would get assistance in their own homes. Such assistance would include the basic activities of daily life that most people take for granted like meal preparation, eating, toileting, bathing, grooming, shopping, managing finances, and participating in the community. MiCASSA addresses the need for assistance with health-related functions.

MiCASSA implements other necessary reforms. It would:

- **provide assistance** in the home and community, such as at school, work, or religious activities;
- **include systems** for securing back-up attendants;
- **offer options** for consumer control of services;
- **address the inequity** in financial eligibility between nursing facilities and community based services; and
- **support essential**, but minor expenses needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

Free Our People!

Because the money is following the individual, MiCASSA is not a new, unfunded mandate. We pay for this assistance already. MiCASSA makes the existing mandate more responsive to consumers. People who are already eligible for services will have a Real Choice.

Every major national disability organization supports MiCASSA. In fact, 92 national organizations are MiCASSA supporters. An additional 255 state or regional organizations also support the bill, as well as 306 local groups. I have included the full list at the end of my testimony. As you look through the list, you will notice that ADAPT is working with children's advocates and senior advocates. Supporting organizations represent people with all types of disabilities: people with cognitive disabilities, people with sensory disabilities, people with mental health labels and people with physical disabilities.

We are asking that you take action now!

We would not be here today had it not been for the heroic efforts of hundreds and hundreds of ADAPT members who have put their bodies on the line year after year.

On behalf of these people, I would like to thank you for this hearing.

But on their behalf, I must point out that we need more than hearings.

We need action.

Take the steps I have outlined today and pass these important pieces of legislation to FREE OUR PEOPLE!

For an institution free America,

Bruce E. Darling

129 ADAPT Activists are arrested in the Senate Finance Committee Hearing Room.