

Mr. Chairman, Ranking member Enzi, distinguished members of the committee,

Good afternoon and thank you for the opportunity to speak today on behalf of the National Council on Independent Living. NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

Founded in 1982, NCIL represents thousands of organizations and individuals including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to affect change. NCIL promotes a national advocacy agenda set by its membership and provides input and testimony on national disability policy.

NCIL currently works on a wide array of disability rights issues, including passage of the Community Choice Act which will provide many people with disabilities the opportunity to choose where and how they receive personal assistance services in their homes and communities.

America is home to:

391 Centers for Independent Living;
330 branch offices; and
56 Statewide Independent Living Councils

From 2004 – 2008, Centers for Independent Living moved 11,451 people out of nursing facilities and other institutions, saving state and federal governments over \$200 million;

Centers provided the core services of advocacy, information and referral, peer support, and independent living skills training to over 3 million individuals with disabilities; and

Centers attracted over \$618 million through private, state, local and other sources annually.

In that same period CILs provided other services to over 659,000 people with disabilities, including assistance with housing and transportation, personal assistants, employment, and technology.

Here are some examples of how NCIL members assist people with disabilities to live independently in the community.

Access Living of Chicago made 61 home modifications, placed 45 people in housing, and transitioned 38 people to the community.

Independent Living Resources of Greater Birmingham provided 65 home modifications, eliminating barriers to independence.

REACH Resource CILs in Texas transitioned 33 nursing home residents, saving the state and federal government \$495,000.

In Rochester, the Center for Disability Rights and the Regional CIL transitioned / diverted 65 individuals, saving NY \$4,041,914.

Three Rivers CIL in Pennsylvania provided housing services to nearly 400 consumers, reducing homelessness and discrimination.

The ENDependence Center of Northern Virginia persuaded Fairfax County to require grantees to ensure ADA compliance.

Arizona Bridge to IL received a Community Hero Award from the City of Phoenix for its Home Modification Program.

In the recent health care reform legislation, NCIL clearly stated its priorities in an effort to integrate the needs of the disability community into the legislation, including language to end the institutional bias in Medicaid. It was our unwavering goal to have the language of the CCA in the final reform bill, and our policy to pursue a compromise only if it became very clear that the CCA would not be a part of the reform legislation. Over the course of developing the legislation it became very clear to disability advocates in Washington and throughout the nation that we would not get CCA into the legislation. Therefore we compromised on including the core principals of CCA into the "Community First Choice Act. This was a major step forward to ending the institutional bias and NCIL thanks each of you for

your support and hard work to keep it in the legislation. Now it is our responsibility to convince the states to adopt the option.

If adopted by a state the Community First Choice (CFC) Option would provide individuals with disabilities who are eligible for nursing homes and other institutional settings with options to receive community-based services. CFC would support the Olmstead decision by giving people the choice to leave facilities and institutions for their own homes and communities with appropriate, cost effective services and supports. It would also help address state waiting lists for services by providing access to a community-based benefit within Medicaid. The option does not allow caps on the number of individuals served, nor allow waiting lists for these services. A significant enhanced Federal Medical Assistance Percentages (FMAP) is provided to encourage states to select this option.

The Community First Choice Option:

- Amends Medicaid to allow state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals.
- Services under this option would include services to assist individuals with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision, or cueing. ADLs include eating, toileting, grooming, dressing, bathing, and transferring. IADLs include meal planning and preparation; managing finances; shopping for

food, clothing, and other essential items; performing essential household chores; communicating by phone and other media; and traveling around and participating in the community.

- Health-related tasks are defined as those tasks that can be delegated or assigned by licensed health-care professionals under state law to be performed by an attendant. Services also include assistance in learning the skills necessary for the individual to accomplish these tasks him/herself; back-up systems; and voluntary training on selection and management of attendants. Certain expenditures would be excluded, including room and board; services provided under IDEA and the Rehabilitation Act; assistive technology devices and services; durable medical equipment; and home modifications.
- Services must be provided in a home or community setting based on a written plan.
- Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.

- Services must be provided regardless of age, disability, or type of services needed.
- States will establish and maintain a comprehensive, continuous quality assurance system, including development of requirements for service delivery models; quality assurance to maximize consumer independence and consumer control; and external monitoring; along with other critical state and federal responsibilities/requirements.
- Service delivery models must include consumer directed, agency-based, and other models, along with requirements to comply with all federal and state labor laws.
- States would be required to establish a Development and Implementation Council to work with the state in developing and implementing the state plan amendment necessary in order to provide the services. The majority of Council members must be individuals with disabilities, elderly individuals, and representatives of such individuals, and must collaborate with, among others, providers and advocates.
- States would cooperate in reporting to Congress.

- CFC services would not affect the states' ability to provide such services under other Medicaid provisions.
- Provision to collect data regarding number of people receiving services, dollars spent, and procedures for consumer control.

NCIL fully supported the CFC as part of the healthcare reform legislation, but we continue to stand firmly behind efforts to see that the Community Choice Act is passed as a stand-alone bill. We realize the limitations of the CFC, being only an option to states. We realize that all 50 state governments are different and our brothers and sisters in institutions will not be freed in every state.

The CFC will lay down a significant foundation, and will move our nation closer to equality, but the CFC will leave the decision to do the right thing up to states, and many states will fail their constituents.

In fact NCIL receives reports from CIL's and Statewide Independent Living Councils from every corner of this country that things are not getting better. It is getting much more difficult for people with disabilities to get out of institutions and live in the community. States are experiencing the worst economic downturn since the great depression and they are being forced to make some very tough decisions regarding their budgets. Unfortunately this has resulted in many of them significantly cutting their Medicaid budgets. Because of the

current institutional bias in the program, most of them are cutting services that support people with disabilities in the community because they believe that they are “optional”.

This is why we will continue to push for the federal government to mandate that states that offer the Medicaid program allow people the choice to get their long-term services and supports in their home or whatever setting they choose.

We know that when states make these types of cuts, they violate the Olmstead decision, however there has been very little enforcement of Olmstead by the federal government. It is very encouraging to NCIL to see this Attorney General vigorously going after states that violate the decision.

The budgets that many states set this past winter will go into effect in just a few days. NCIL is concerned that when these budgets go into effect states will be in violation of the Olmstead decision, and on this anniversary of the decision, NCIL calls on the federal government to point these violations out to states and dedicate the necessary resources to enforcement.

Sadly, NCIL’s vision of equality has not yet been fully realized. Many people with disabilities remain imprisoned in nursing homes and our civil rights laws have been undermined and devalued. As a membership organization, NCIL needs the support of all our nation’s advocates in order to achieve our goals and advance the Disability Rights Movement.

We hope the United States Senate, House and Administration will join us in our quest!