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Center for Independence of the Disabled, NY

Testimony in Favor of Resolution 1783-A, calling upon the U.S. Congress to pass and the President to sign H.R. 1670/S.683, legislation known as "The Community Choice Act"

Committee on Aging and Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse & Disability Services

Testimony by:
Noor Alam, Community Organizer
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Center for Independence of the Disabled, NY

Testimony in Favor of Resolution 1783-A

The Center for Independence of the Disabled in New York (CIDNY) is a leading organization serving the disability community, reaching 12,000 people across all disabilities in New York City. We thank you for holding this hearing on Resolution 1783-A, which would put New York City on record as being in support of the federal Community Choice Act.

People with disabilities have been fighting for many years to get this bill passed because it is at the heart of our civil rights movement. We have the right to live in our own homes, rather than being forced to move to nursing homes to get the same care we could get at home.

Over a quarter of a million New Yorkers are living in their own homes instead of in nursing homes, because our State has chosen to cover home and community-based services with Medicaid funds. Many other states have not been so sensible. Some have no home care at all, condemning elderly and disabled people to lifelong institutionalization in what can feel like prison.

The Community Choice Act would require all states to offer community-based services for people needing the level of care formerly provided only in nursing homes. It would also reward states like New York with additional Medicaid funds for being among the first to voluntarily offer home care.

New York City has some of the best home and community-based services in the country. Our State offers an array of Medicaid-funded programs: home health care, personal care, and home delivery of additional services, needed by people with developmental disabilities, traumatic brain injuries, as well as other disabilities.

Some New Yorkers retire to warmer states with lower taxes and enjoy many years of good health. Eventually, they may develop disabilities and discover that their new states do not have the same Medicaid benefits as New York. They will then learn that the only way they can avoid spending the rest of their life in a nursing home is to return to New York, where home care will allow them to live in their own home, or in the home of a family member.

The Community Choice Act would eliminate the incentive for people to move from states with no home care to states that have home care. That would benefit New York State and City.

In 2007, two out of three New Yorkers receiving Medicaid long-term-care were living in the community, not in institutions. The average cost of their care was less than 70% of what it would have cost to keep that same number of people in nursing homes. As a result, the total spending for community-based care was less than half of the total Medicaid long-term-care bill.

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CIDNY has first-hand experience of the value of community-based care because we operate two Medicaid waiver programs that help people move out or stay out of nursing homes. Such programs help thousands of people statewide each year to live independently, in their own homes, with the particular combination of services that each of them needs.

Even with the Waiver programs too many New Yorkers are still in nursing homes. In 2007 it cost Medicaid an average of $82,000 a year for each nursing home resident. As we have all heard through news reports and the through actions taken by the attorney general, people are not living wonderful lives inside of nursing homes. Here are just two examples of proven abuse and neglect inside New York State nursing homes[1]:

> [Employee] took resident, who had become agitated and defiant when another staff member tried to give resident medications, to his room. [Employee] attacked and repeatedly pushed resident to the floor, yelled racial epithets, and pinned the resident to the bed with his knee in the patient's back.
>
> Defendant failed to follow resident's care plan requiring a two-person assist. When the defendant alone transferred 99-year-old resident from wheelchair to toilet, resident fell and broke her leg. Defendant did not report the incident and did not obtain treatment for the resident.

Even the best nursing homes are institutions where residents are told when to get up in the morning and when to eat their meals.,They are expected to report every trip outside of the facility or even ask permission to go. They cannot have overnight visitors or drink a glass of wine in their rooms. This is no way to live on a permanent basis, although many people do, sometimes for decades.

In 2005 New York State, despite its established system of community-based services, had the highest number of nursing home residents in the country, and with one of the lowest rates of disability among elderly residents. Our number of nursing home beds rose between 2000 and 2005, when we had the third highest occupancy rate in the country. The powerful nursing home lobby is preventing our state from reducing the number of nursing home beds, which severely limits our ability to use the savings to pay for more community-based care.

Nationwide, much of the opposition to Home and Community-Based Services comes from the nursing home industry, which has a lot to lose from having to close down beds as the need for them decreases. Neither the state nor the federal government can afford to give in to this pressure, because Medicaid nursing home costs are a major factor in the rise of Medicaid costs.

CIDNY urges the full Council to vote in favor of Resolution 1783-A, and to help us educate the Governor and State Legislature about the need to reduce nursing home use and increase funding and availability of home and community-based services in New York City and New York State.

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[1] The State Attorney General took enforcement actions against these individuals. Reported in "The Monitor," by the Long Term Care Community Coalition, Spring 2009.

Mental Health Committee of the Council of the City of New York
Hearing on hunger and city's aging population
June 17, 2009

Testimony submitted by: Rachel Sherrow
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My name is Rachel Sherrow and I am the Director of Programs and Community Affairs at Citymeals-on-Wheels. I would like to begin by thanking the City Council for your continued support of aging services including Citymeals which will serve over 2 million meals citywide this year. We hope you, our partners in city government, will continue to support this partnership with our citizens.

As most of you know, Citymeals-on-Wheels is a not-for-profit agency working in partnership with the New York City Department for the Aging. The Department funds community-based agencies for meals that homebound elderly receive Mondays through Fridays. Citymeals-on-Wheels funds these same agencies for weekend and holiday meals, as well as sending packages of shelf stable foods for times of emergency. These 115 days a year are those Citymeals covers when our aged neighbors would otherwise be without food or human company.

Over forty years ago, the federal government concluded from a study that there were two factors that would keep people over 60 in their communities longer: nutrition and socialization. By feeding this population literally and figuratively, the government felt would stem the tide of unfortunate consequences of this growing demographic. Seven

hundred Offices of Areas on Aging were created, the NYC Department for the Aging being the largest. Within the continuum of care concept, if the centers are not serving their elders effectively, this population will end up in nursing homes and our Medicaid costs will continue to sky rocket.

Bringing a meal to the homebound elderly's door is one way to prevent them from slipping into more expensive kinds of care. This is a savings in Medicaid costs that the city would bear if these neighbors of ours were living in nursing homes instead.

New York City's younger aged minority population is poorer and less healthy. They have a higher incidence rate of diabetes and other health issues. A 1993 study by the Urban Institute estimated that nearly 5 million elderly Americans (age 60 and over) experience "food insecurity", meaning they do not get enough to eat.[2] The Nutrition Screening Initiative estimates that one in four senior citizens living in our communities is malnourished.[3] It has been estimated that up to 55%of seniors admitted to hospitals are suffering from malnutrition.[4] 14% of our meal recipients (over 2,400 people) rely solely on the one meal a day they receive. Citymeals-on-Wheels funded a supper meal program for 1,400 nutritionally at risk clients which was to help supplement their daily meal and give them more food. Unfortunately because of budgetary constraints and tough economic times, we ended this program in July of last year. These homebound elderly are in more desperate need of additional food which Citymeals is trying to supply through our emergency box program.

Citymeals packages three shelf stable meals which are delivered to the homebound prior to a holiday, to ensure they don't go without food when their centers are closed. In addition, we also send a 12 meal box via UPS to all meal recipients before Thanksgiving

which are meant to help during the winter months when the cold harsh weather prevents them from getting out or sometimes, deliveries getting to them. Citymeals has been able to use these emergency boxes during difficult times in the city's history to make sure people continued to get fed; after 9/11 when no deliveries were being made in Lower Manhattan, the blackouts of 2003 and 2006, and the most recent horrific killing of a meal deliverer in the fall of 2008. It is critical Citymeals is able to fund these meals which help our homebound remain in their communities where they feel comfortable and wish to be for the remainder of their lives, without burdening Medicaid. We therefore depend greatly on the $1million from the City Council which funds the first Sunday meal of every month, Thanksgiving and Christmas, and in times of emergency.

In New York City, as in the rest of the country, the oldest category of elderly is increasing at the fastest rate. From 1990 to 2000, the number of people 85 and older increased by 18.7%, making this group the fastest growing segment of New York City's elderly population.[1] The number of Citymeals-on-Wheels' oldest meal recipients is increasing at a fast pace. The percentage of meal recipients who are 90 or older increased 6% since last year, and those aged 100 and older increased 10%.

We also know that there has been a steady rise of nearly 2% each year in the number of elderly New Yorkers who need food delivered to their door if they are to remain in their own homes for as long as possible, which is what they want. The city needs to make sure there is adequate funding to serve all those in need, including any increase we may start to see because of the greater need for food due to a lack of resources.

Together, the Department of Aging and Citymeals-on-Wheels, are keeping over 17,000 elderly New Yorkers in their own homes and out of nursing homes for as long as possible. It is in their interest and ours to keep them with us, right here in the communities where they have lived for so long. This is a savings in Medicaid costs that the city would bear if these neighbors of ours were living in nursing homes instead.

Citymeals-on-Wheels is underwriting more than one in three meals delivered to our city's 17,000 frail elderly homebound. This past year our funds brought over 2 million meals to elderly New Yorkers. These meals will also bring federal funding to our city. For every meal served through private donations, the City of New York receives 61 cents from the federal government. For every dollar we receive from the City of New York, we bring in more than a dollar in federal funding. We are, therefore a financially less burdensome service that helps the city turn an expense into revenue, while keeping our elderly well nourished and at home.

[1]2000 Census, as reported in NYC Department for the Aging's "Census 2000: Changes in Size and Age, 1990 - 2000." [2]Ibid. [3]Ibid. [4]2000 Census, as reported in DFTA's "Quick Facts," July 2003.

FRIA *The Voice and Resource for Quality Long Term Care*

A New York non-profit consumer advocacy organization working since 1976

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June 17, 2009

Statement by FRIA in Support of Resolution No. 1783-A Calling for Passage of the Community Choice Act

Before The Council of the City of New York
Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services jointly with the Committee on Aging

Good morning. I am Betti Weimersheimer, the Executive Director of FRIA, a not for profit organization that offers advocacy and information on long term care issues. Thank you for allowing FRIA to present this testimony. We strongly support Resolution No. 1783-A calling upon the U.S. Congress and the President to sign the Community Choice Act (S.683/H.R. 1670) which would allow seniors and persons with disabilities increased access to community-based services, thus avoiding nursing home placement.

As seasoned advocates on long term care issues affecting older Americans, we hear a consistent theme from caregivers and senior citizens: older Americans would prefer to age in place rather than enter a nursing home, but remaining in the community is often not affordable or sustainable without adequate assistance. The Community Choice Act would greatly facilitate keeping older adults in their communities.

Medicaid funding for long term care services currently reflects an institutional bias, with 63% of Medicaid dollars being spent on nursing homes and other institutional services and only 37% going toward community services such as home health care, personal care, or waiver programs. The CCA would allow individuals eligible for Skilled Nursing Facilities to choose the alternative of Community-Based Attendant Services which would provide Medicaid dollars for health related services and assistance with activities of daily living to a person in their own home or a supportive housing environment.

Since FRIA's inception we have advocated for the right of the frail elderly to access care in the least restrictive environment possible. Older Americans utilizing long term care services need equitable funding opportunities, with no programmatic or rule disincentives to community services, to be supported in the most appropriate environment for care. FRIA respectfully urges you to support this resolution calling for the passage of the Community Choice Act, which would improve the quality of life of all older Americans and persons with disabilities by giving them the resources they need to remain in their communities.

**Testimony to the City Council's Aging &
Mental Health, Mental Retardation, Alcoholism, Drug Abuse and
Disability Services Committees**

**Oversight - Examining the Alternatives to Nursing Home Care for
Seniors and the Disabled Proposed Res 1783-A**

My name is Vasiliki (Melina) Cowan, I am an artist and I have spinal muscular atrophy.

I lived in Alabama with my husband for 15 years. Medicaid provided me 25 hours per week of personal attendant care; 25 hours per week was the maximum hours permitted in Alabama. If someone needed more hours, they were sent to a nursing home.

My husband was able to work full time as a forensic scientist, and also to be my main personal attendant for 15 years. However, the last couple of years his health deteriorated rapidly, so he could not help me with my personal needs such as bathing, dressing, etc.

The only options I had was either to end up in a nursing home or to move to a State that provides the hours of personal attendant I need. About 2 years ago we moved to NYC in order for me to be able to live at home.

Melina Cowan melijeff@aol.com 212-942-3765

The quality of the help at home cannot be compared to the help offering in a nursing home, and for this reason, despite of my serious disability, my health is very good. I take no medicine or need medical care. Yet in a nursing home, not only my health, but also my life would be in danger.

I do not understand why people are segregated in nursing homes while they can have the help they need at home.

Thank you for listening to my testimony

Melina Cowan melijeff@aol.com 212-942-3765

Department for the Aging

TESTIMONY

presented by

Lilliam Barrios-Paoli

Commissioner

at a hearing on

Alternatives to Nursing Home Care for Seniors and Individuals with Disabilities

before the

New York City Council Aging and Mental Health Committees

on

Wednesday, June 17, 2009

10:00 A.M.

at

City Council Committee Room

City Hall

New York, NY

Good morning, Chairs Arroyo, Koppell and Subcommittee Chair Mark-Viverito and members of the Committees on Aging and Mental Health. I am Lilliam Barrios-Paoli, Commissioner of the Department for the Aging (DFTA). I am pleased to be here today with my colleague, Commissioner Sapolin, to discuss the topic of alternatives to nursing home care for seniors and individuals with disabilities. This is an important topic that is central to the mission of the Department for the Aging. Countless studies indicate that older adults want to continue to live in their homes and in their communities for as long as possible. Providing supportive services that allow seniors to age in place and maintain their independence for as long as possible both honors the preferences of our clients, and can be less costly than institutional care. On a more personal note, I strongly believe that when older adults are supported in the familiar environments of their homes and communities, they remain happier, healthier and less prone to deterioration. DFTA is committed to working toward a system in which nursing homes are reserved for only those older adults with very serious health-care needs. DFTA funds and administers several services that support our philosophy of helping the frail elderly maintain their independence for as long as possible. I will now describe some of these initiatives.

Home Delivered Meals

Each weekday, more than 17,000 frail older adults receive nutritious meals delivered to their homes through a partnership between DFTA and its home delivered meal providers. Over 50 percent of home delivered meal recipients are at least 80 years old and more than 10 percent are aged 90 and older. This service goes a long way in helping homebound adults avoid institutionalization. The City's elderly population is projected to grow 25% by 2030 and demand for meals will also increase. In order to ready the City for the expected growth in demand for home-delivered meals, DFTA redesigned its program to create more clearly defined service areas, a better connection to case management services and the potential for additional capacity in the future. DFTA recently completed all borough transitions in the home delivered meals program and is currently focused on enhancing meal quality and diversity to better meet the cultural and taste preferences of our homebound clients.

Case Management

Case management is the gatekeeper for in-home services such as home delivered meals and home care. This critical service helps older adults age in place and to remain in their communities. Approximately, 20,000 clients currently benefit from case management services supported by DFTA. Last year, DFTA redesigned the case management system to create more clearly defined service areas for case management providers. The redesigned system also fostered more holistic assessments of clients' overall needs. Through these assessments, clients are evaluated as to whether they would benefit from a variety of programs and services, including: home delivered meals, homecare, medial and respite care, legal services, counseling, transportation and benefit and entitlement programs.

Telephone Reassurance and Friendly Visiting

Another smaller but important part of the service continuum to homebound elderly is the provision of wrap-around services such as friendly visiting and telephone reassurance programs. These services reflect the fact that homebound older adults have needs beyond nutrition and medical care and can also derive great benefit from something as simple as a phone call or a visit. Several case management agencies, home delivered meal providers and senior centers have telephone reassurance and friendly-visiting programs in place. However, in the case of some providers, this is not their primary function and it can be difficult to maintain these types of programs in a time of scarce resources.

To this end, I am very pleased to report that DFTA is launching an initiative to support wrap-around services for homebound seniors. Timebank NYC is a reciprocal service exchange program that relies on volunteers to provide services to the homebound and other older adults, and also values the potential reciprocal contributions of the older adults receiving services. For example, time bank members (or volunteers) could provide services to the elderly that would help them remain in their homes and communities, such as friendly visiting, telephone reassurance, errand-running or shopping, escort services, home repairs or basic household tasks. Elderly members could in-turn contribute services to other time banks members such as tutoring and mentoring, peer-to-peer telephone reassurance, peer-to-peer escort services, cooked meals or language and craft lessons. DFTA is currently working to pilot Timebank NYC in 25

communities across New York City, and based on the results of the pilot, will work to expand the initiative citywide.

Homecare

DFTA's Expanded In-Home Care Services for the Elderly Program or EISEP serves frail older adults who are not Medicaid-eligible but who cannot afford the costs of private care. The EISEP program is designed to help eligible elderly individuals remain safely at home, rather than in a nursing home, by providing home attendants who help with daily living tasks such as dressing, toileting, bathing, cooking, shopping and errands. DFTA-funded homecare currently serves approximately 1,440 clients and is available to eligible adults for an average of 12-20 hours a week. As you may know, the primary city-sponsored homecare program, the personal care program, is administered by the Human Resources Administration and serves seniors and individuals with disabilities who are Medicaid eligible. Homecare is a critical service in supporting the City's goal of meeting the changing needs of older adults who prefer to remain in their homes and communities in lieu of institutional care.

NORCs

DFTA also administers $6.5 million in City funding, $1 million of which is generously allocated by the City Council to coordinate housing-based supportive service programs for low and moderate-income elderly residing in Naturally Occurring Retirement Communities. These inter-disciplinary programs are located in the buildings or housing developments where seniors live, and are designed and administered as a partnership between senior residents, housing owners and managers, as well as social service and healthcare providers. NORCS have many of the benefits of supportive senior housing, yet allow individuals to remain within the familiar multi-generational atmosphere of their homes and immediate communities. I feel strongly that NORCs provide a model for the future of aging in place in New York City. The population of older adults is continuing to grow and housing does not meet this ever-increasing demand. It only makes sense to support the low-cost NORC model, which can offer supportive services such as transportation, escort and shopping, social activities and connection to community and government resources to older adults within their residential buildings or neighborhoods.

NORCs were born in New York City and I look forward to supporting their continued growth as the population of our City ages in place.

Support for Caregivers

As we look for ways to delay or avoid institutional care for the elderly, it is imperative to consider the needs of caregivers. The majority of older adults do not live alone but rather, reside with family members. Families play a vital role in our city as the primary caregivers of older adults. Without supportive and respite services, caregivers are much more likely to choose institutional care for their loved ones. DFTA's Alzheimer's & Caregiver Resource Center provides support for caregivers of seniors through counseling, education and training, resource and referral and respite-care services. The Alzheimer's & Caregiver Resource Center also conducts training sessions on a wide array of topics around caregiving for caregivers, seniors, professionals and the general public.

The Alzheimer's & Caregiver Resource Center also oversees 14 contracted Title III-E National Family Caregiver Support Programs, through which community-based organizations provide support and respite for caregivers of frail older adults. These community partners serve specialized populations including: Chinese, Russian-speaking, and Spanish-speaking immigrants, gay and lesbian caregivers, grandparents with sole responsibility of their grandchildren, and Chinese and Korean-speaking caregivers.

Social Adult Day Services are structured programs for physically frail, cognitively or memory impaired older adults that focus on personal care, nutrition, socialization, supervision and monitoring in a protective setting during part of a day. These programs not only serve as a theraputic experience for participants but can also provide much-needed relief and respite for overwhelmed caregivers.

Conclusion

Investing in home and community-based care respects the wishes of older New Yorkers to age in place and helps to preserve their valuable contributions to our City. The Department for the Aging's continuum of care reflects how people want to age—at home and in the community. I

appreciate the support of this Council in all of these programs and I look forward to discussing ways to continue the enrichment of home-based services for the rapidly increasing population of older adults in New York City. I will now take your questions.

Disabled In Action of Metropolitan New York, Inc.
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Testimony to the City Council's Aging & Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services Committees

Oversight - Examining the Alternatives to Nursing Home Care for Seniors and the Disabled Proposed Res 1783-A

June 17th, 2009

Edith M Prentiss
Vice President – Legislative Affairs

Edith M Prentiss 917-733-3794 edith@disabledinaction.org

My name is Edith Prentiss. I am the President of the 504 Democratic Club, Vice President for Legislative Affairs of Disabled In Action of Metropolitan New York (DIA), and a member of the Disability Network of New York City (DNNYC).

The CCA seeks to eliminate the current institutional bias which mandates institutional service while considering community based services optional. At present, 67% of the Medicaid long term care funds go to institutions (nursing home, adult homes, group home and residential facilities) and 33% go to community services. Some community based services have waiting list of up to ten years.

In one form or another, the Community Choice Act (CCA) has been around since the 107th Congress that is more than ten years. It was introduced in at least in either the Senate or the House in every Congress since the 107th and died each session.

2009 ushered in the 111th Congress and the CCA bills were reintroduced. HR 1670, introduced by Representative Danny Davis, already has 93 co-sponsors including 18 from New York State. S 683, introduced by Senator Tom Hawkins, has 23 co-sponsors included both of New York's Senators.

In the 110th Congress; S 799 only reached 21 cosponsors (22%) which included both of New York's senators; and HR 1621 died with 125 co-sponsors (28%) including 21 of New York's 29 Members. New York and Pennsylvania provided more than 25% of the co-sponsors while 8 states had none. Hopefully some of those state's Representatives will be co-

sponsors in the present Congress. And hopefully we will see more co-sponsors from New York, as well.

Two recent studies support the belief that community based services are cheaper than institutional services. They are: "Do Non-Institutional Long-Term Care Services Reduce Medicaid Spending?" H.S. Kaye, M. LaPlante, & C. Harrington Health Affairs, Vol 28, #1 (01-02/09) http://content.healthaffairs.org/index.dtl and "Taking the Long View: Investing in Medicaid Home and Community-Based Services Is Cost-Effective" by R. Mollica, E. Kasser, L. Walker, & A. Houser INSIGHT on the Issues, Vol 126 (03/09), AARP Public Policy Institute. www.aarp.org/ppi

At present, under Medicaid, states do not offer the same level of community based services. While some offer 24 hours/day services others offer as little as 4-8 hours of service/week! If you need more hours, you're on the fast track to a nursing home. What would you do if you lived in one of those states? Although I only spent about a month doing rehab in a nursing home I know my answer; I'd be moving a state that offers more hours of community based services!

Formerly known as MiCASSA, the CCA will:

- Give people real choice in long term care options by reforming Title XIX of the Social Security Act (Medicaid) by ending the institutional bias.
- Increase access to community-based services & other supports.
- Build on the Money Follows the Person initiative to pave a way to a real choice in long term care.

- Allow people who are eligible for nursing homes or other Medicaid-funded institutions to have the choice of living in the community with services & supports.
- Provide enhanced federal matching funds to help states develop their long term care infrastructure & grant funds to help states increase their ability to provide home & community-based services.
- Will create a demonstration project to evaluate service coordination & cost sharing approaches for those eligible for both Medicaid & Medicare services

Attached, you will find Kansas ADAPT's CCA Q&A. I hope it will help you understand CCA better and understand why all Americans' deserve the same community based service options. People should not be forced to uproot themselves, leaving their home, family and community to move to a state and locality where they can receive community based services rather than being forced into a nursing home or a residential facility. We believe access to community based services is a civil right!

Our Homes, Not Nursing Homes!

Thank you for the opportunity to address the Committees,

Edith M Prentiss 917-733-3794 edith@disabledinaction.org

KANSAS ADAPT

FREE OUR PEOPLE!!!

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Some Questions & Answers about the Community Choice Act

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 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 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 the Community Choice Act?

No. If you are eligible to go into a nursing home or an ICF-MR facility you would be eligible for the Community Choice Act. Financial eligibility for nursing homes is up to 300% of the SSI level (roughly $1,500 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.

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 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 the Community Choice Act a new unfunded 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. 67% 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 about 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 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 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.

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 non-elderly 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.

My name is Julie Maury. In 2006, I had a boyfriend named Michael, of six years who died of a bedsore that caused Sepsis, which then caused organ failure. He was in a Nursing Home. It was preventable – he did not have to die. He was reasonably young and had life left to live. But, it is very hard to prove Nursing Home neglect when one already suffers from Paralysis and other chronic health issues, as Michael did. He was hospitalized for a health issue, and while there, the staff, like bad car salesmen, convinced him to go into a Nursing Home. They "sold" the living in a Nursing Home idea to him like it was going to be Heaven. However, the Nursing Home was a nightmare from Hell. Michael would say in the Nursing Home: "Why is everyone telling me: It's ok to 'let go?' I love life. I love the trees; I love the birds...."

I know that, if passed, the Community Choice Act will help American's choose where they want to live. Choice is an inalienable human right. Most Animals hate cages and crave freedom. Humans don't want to be caged either. Passing the Community Choice Act would be like opening the door of a gigantic cage and giving people the freedom to live their lives. Many people in Nursing Homes want to be out working, shopping, and having families--just living, normal, everyday, happy lives. Letting them free would help the economy. The Paradigm must be shifted. People with Disabilities and the Elderly more than deserve the legal right to choose to live in the Community with whatever Services they would need to do so.

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I represent: ADAPT

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I represent: Brooklyn Center for Independence of the Disabled BROOKLYN

Address: _____

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Name: Philip Bennett

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I represent: Health Care Workers

Address: _____

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Name: Thomas Small

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I represent: NY3 LLC

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(PLEASE PRINT)

Name: MY name is Julie Maury I am reading

Address: for myself + Melina Cavan
220 E 94 St. #2F NY NY 10128

I represent: _____

Address: _____

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I represent: DIA

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Name: Alejandra Ospina

Address: 109 Duane St. New York, NY 10007

I represent: Nicholas F. Dupree

Address: 900 Main St. NY NY 10044

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(PLEASE PRINT)

Name: NOOR ALAM

Address: 811 CORTELYOU RD #6N BROOKLYN NY 11218

I represent: CENTER FOR INDEPENDENCE OF THE DISABLED-NY

Address: 841 BROADWAY #301 NY NY 10003

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Name: Betti Weimershimer

Address:

I represent: FRIA

Address: 18 John St, Suite 905, NY 10038

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Name: William Barrios - Parks Commissioner

Address: 2 Lafayette St.

I represent: DPR

Address: _____

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Name: Rachel Sherrow

Address: _____

I represent: City Meals on Wheels

Address: _____

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(PLEASE PRINT)

Name: Mary Harper

Address: 180 Water Street, NY, NY

I represent: Human Resources Administration

Address: _____

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(PLEASE PRINT)

Name: Matt Salzberg, Commissioner

Address: Mayors Office for People With Disabilities

I represent: _____

Address: _____

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☒ in favor ☐ in opposition

Date: June 17, 2009

(PLEASE PRINT)

Name: Lawrence Carter-Long

Address: 121 Avenue of the Americas, 6th floor

I represent: Executive Director, Disabilities Network of NYC

Address: _____

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