

CITY COUNCIL  
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

of the

COMMITTEES ON AGING AND MENTAL HEALTH

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June 17, 2009  
Start: 10:09am  
Recess: 11:59am

HELD AT: Council Chambers  
City Hall

B E F O R E:

G. OLIVER KOPPELL  
Chairperson

MARIA DEL CARMEN ARROYO  
Chairperson

COUNCIL MEMBERS:

- Council Member Brewer
- Council Member Foster
- Council Member Stewart
- Council Member Mark-Viverito
- Council Member Eugene
- Council Member Ferreras
- Council Member Felder
- Council Member Gennaro
- Council Member Palma

## A P P E A R A N C E S

Lilliam Barrios-Paoli  
Commissioner  
Department for the Aging

Matt Sapolin  
Commissioner  
Mayor's Office on Disabilities

Edith Prentiss  
Vice President of Legislation Affairs  
Disabled in Action of Metropolitan New York

Lawrence Carter-Long  
Executive Director  
Disabilities Network of New York City

Phillip Bennett  
Home Care Worker

Rachel Sherrow  
Director of Programs and Community Affairs  
Citymeals-On-Wheels

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

Alejandra Espina  
Member  
Disability Actors Community

Thomas Small  
Attorney  
New York State Independent Living Council

## A P P E A R A N C E S (CONTINUED)

Nadina LaSpina

Member

ADAPT

Marvin Wasserman

Executive Director

Brooklyn Center for Independence of the Disabled

Julie Maury

Family Member

Betti Weimersheimer

Executive Director

FRIA

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2 CHAIRPERSON KOPPELL: Good morning.

3 [PAUSE]

4 CHAIRPERSON KOPPELL: Good morning,  
5 everyone. I'm Council Member Oliver Koppell,  
6 chairman of the committee on mental health, mental  
7 retardation, alcoholism, drug abuse and disability  
8 services. This is a joint hearing of our  
9 committee and the committee on aging, chaired by  
10 Maria del Carmen Arroyo. Council Member Maria del  
11 Carmen Arroyo called me a little while ago,  
12 indicated she was somewhat delayed in traffic and  
13 delayed in the start of her journey, but she's on  
14 her way. She should be here shortly, but because  
15 it's past the 10:00 starting time, I think we're  
16 going to begin. Let me read an opening statement.  
17 Today's hearing, entitled Oversight: Examining the  
18 Alternatives to Nursing Home Care for Seniors and  
19 the Disabled, will consider proposed resolution  
20 1783A, availing on the United States Congress to  
21 pass and the president to sign HR1670 S683, known  
22 as the Community Choice Act, which would reduce  
23 reliance by senior citizens and persons with  
24 disabilities on nursing home care by increasing  
25 access to community based services. This

1  
2 important legislation would expand the choice of  
3 people with disabilities and seniors to allow them  
4 to remain in our communities, at their homes and  
5 out of nursing homes. Unfortunately, council  
6 member Michael Nelson, who is cosponsor of this  
7 resolution and in fact the lead sponsor, is unable  
8 to join us today due to an injury, but he's asked  
9 me to read a statement on his behalf, which I will  
10 in a moment. I'd like to acknowledge the  
11 committee staff that worked on this and sent out  
12 notices. First of all, Tracy Udell, who is here  
13 to my left. Michael Benjamin, who is over in the  
14 corner there, the policy analyst. Rocco D'Angelo--  
15 -I don't know if he's here, but he's working on  
16 the budget right now. I also want to thank --,  
17 my personal counsel who works on committee matters  
18 and we have an intern who's helped us with the  
19 hearing as well, and her name is Cambridge Peters.  
20 She's a law student from New York Law School.  
21 She's here as well. Where is she? She's over way  
22 on the other side. You want to stand up? That's  
23 Cambridge. She's very helpful and has integrated  
24 into the staff very quickly. So far, I guess the  
25 only member who's joined is Simcha Felder, who's

1  
2 always with us, and we appreciate your being here.  
3 I'm also pleased that we have Commissioner Lilliam  
4 Barrios-Paoli from the Department of the Aging and  
5 also Matt Sapolin, who is in charge of the Mayor's  
6 Office on Disabilities. We're going to ask them  
7 to testify in a few minutes. I do want to read  
8 Council Member Nelson's testimony in part. It's  
9 lengthy, but it speaks to this in very personal  
10 terms, and he asked me to read it, and I think  
11 it's appropriate. He points out that he's unable  
12 to be here because of an injury. I've long been  
13 interested in the needs of the disabled and the  
14 ways in which government could respond to those  
15 needs. Of particular concern to me is the need to  
16 promote independence of the disabled, especially  
17 with regard to living arrangements and the  
18 meaningful option of home care, which should be  
19 available as an alterative to nursing home care.  
20 My innate concern for the need for viable home  
21 care option for the disabled has been reinforced  
22 by personal experience. Deborah Miller Weiss, a  
23 valued member of my office staff and for over 30  
24 years a friend of my late wife Sheila and myself,  
25 also a colleague in volunteer work with teens at

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2 risk where the underlying issue involved learning  
3 disabilities--she was raised in a home where both  
4 her parents were physically disabled. Her father  
5 was a post polio quadriplegic. Her mother became  
6 physically disabled as a Holocaust victim in Nazi  
7 Germany. I was aware of the continual difficult  
8 challenges over the years that Dr. and Mrs.  
9 Clarence Miller, parents of Ms. Miller-Weiss,  
10 faced so as to ensure that they'd be able to lead  
11 productive and self-determining lives living in  
12 their own home. Dr. and Mrs. Miller were  
13 successful in this regard, but it should be  
14 remembered that even though they were both highly  
15 educated, they still faced many barriers to  
16 overcome in order to secure home care. How many  
17 others would not be able to navigate a system  
18 where the deck is stacked in favor of nursing home  
19 care and their loved one would have no alternative  
20 to a nursing home? On an even more personal note,  
21 my recent experience in arranging care for my late  
22 wife Sheila has provided a vivid example of the  
23 marked deficiencies that exist in assuring those  
24 with disabilities they can maintain their  
25 independent living--productive lives with dignity

1  
2 at home. Prior to her passing last December,  
3 Sheila battled for several years, cancer as well  
4 as the complications from diabetes, which affected  
5 her vision and balance. While for most of that  
6 period she was able to continue her activities as  
7 a vibrant member of the community and a  
8 participant in civic and political organizations,  
9 at the end of her illness when she required  
10 special care, I became painfully aware of the  
11 great difficulty in obtaining quality care at home  
12 and the bias in favor of nursing home care. It  
13 came to my attention there's a bill before the  
14 United States Senate and House of Representatives  
15 that has the potential to drastically change the  
16 current broken institution of nursing home  
17 services. I felt it was most important New York  
18 City lend its support to this measure. The term  
19 community based attendance services and supports  
20 means help with accomplishing activities of daily  
21 living, eating, toileting, grooming, dressing,  
22 bathing and transferring, instrumental activities  
23 of daily living, meal preparation, managing  
24 finances, household chores and participating in  
25 the community and health related functions, which



1  
2 can be delegated or assigned as allowed by state  
3 law. The Community Choice Act specifically  
4 mandates that service should be delivered in the  
5 most integrated setting appropriate to the needs  
6 of the individual in a home or community setting  
7 which may include a school, workplace or  
8 recreational facility. More and more people with  
9 disabilities are living and could be thriving.  
10 People are living longer lives. Our long term  
11 service system funded mainly by Medicare and  
12 Medicaid dollars was created over 40 years ago.  
13 It is medical dollars not originally meant to meet  
14 long term care needs. The money should follow the  
15 individual, not the facility or provider. A long  
16 term service policy should not favor any one  
17 setting over another. Our current system is not  
18 neutral and does not reflect people's choices.  
19 Thank you for your consideration and support of  
20 resolution 1783. That is Council Member Nelson's  
21 testimony. I think it's quite on point and  
22 obviously points to support for the resolution.  
23 I'm delighted to have been joined by my Bronx  
24 colleague, Maria del Carmen Arroyo, who's chair of  
25 the Committee on Aging, and I'm glad you could get

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2 here, and if you want to say a brief statement,  
3 we'd welcome it.

4 CHAIRPERSON ARROYO: As soon as I  
5 can catch my breath. Good morning. I apologize  
6 for my tardiness. Thank you, Council Member  
7 Koppell, for holding this joint hearing with the  
8 Committee on Aging today to examine the status of  
9 long term care options available for seniors and  
10 the disabled. Specifically, we will take a look  
11 at the alternatives available to nursing homes and  
12 institutionalization of those who need higher  
13 levels of care. There is a common misconception  
14 that long term care equates with living in a  
15 nursing home, and today, given the information  
16 that we know, our preference is for individuals to  
17 lead a quality life at home as long as possible.  
18 I want to thank Council Member Nelson for his  
19 dedication to ensuring that we have this  
20 conversation, and I look forward to the testimony  
21 and the input from the agency and the advocates.  
22 Thank you.

23 CHAIRPERSON KOPPELL: Thank you  
24 very much, Council Member. We'll hear as our  
25 first witness Commissioner Paoli of the Department

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2 for the Aging.

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LILLIAM BARRIOS-PAOLI: Good

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morning, Chairs Arroyo and Koppell and Council

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Member Felder. My name is Lilliam Barrios-Paoli.

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I'm the Commissioner for the Department of the

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Aging. I am pleased to be here today with my

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colleague, Commissioner Sapolin, to discuss the

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topic of alternatives to nursing home care for

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seniors and individuals with disabilities. This

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is an important topic that is central to the

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mission of the department for the aging.

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Countless studies indicate that older adults want

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to continue to live in their homes and in their

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communities for as long as possible. Providing

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supportive services that allow seniors to age in

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place and maintain their independence for as long

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as possible both honors the preference of our

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clients and can be less costly than institutional

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care. On a more personal note, I strongly believe

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that when older adults are supported in the

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familiar environments of their homes and

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communities, they remain happier, healthier and

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less prone to deterioration. DFTA is committed to

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working towards a system in which nursing homes

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2 are reserved only for those older adults with very  
3 serious healthcare needs. DFTA funds and  
4 administers several services that support our  
5 philosophy of helping the frail elderly maintain  
6 their independence for as long as possible. I  
7 will now describe some of those initiatives. Home  
8 delivered meals--each weekday, more than 17,000  
9 frail, older adults receive nutritious meals  
10 delivered to their homes through a partnership  
11 between DFTA and its home delivered meal  
12 providers. Over 50% of home delivered meal  
13 recipients are at least 80 years old, and more  
14 than 10% are aged 90 or older. This service goes  
15 a long way in helping home bound adults avoid  
16 institutionalization. The city's elderly  
17 population is projected to grow 25% by 2030, and  
18 demand for meals will also increase. In order to  
19 ready the city for the expected growth and demand  
20 for home delivered meals, DFTA redesigned its  
21 program to create more clearly defined service  
22 areas, a better connection to case management  
23 services and the potential for additional capacity  
24 in the future. DFTA recently completed all  
25 borough transitions in the home delivered meals

1  
2 program and is currently focused on enhancing meal  
3 quality and diversity to better meet the cultural  
4 and taste preferences of our home bound clients.

5 Case management. Case management is the  
6 gatekeeper for in home services such as home  
7 delivered meals and home care. The critical  
8 service that helps older adults age in place and  
9 to remain in their communities. Approximately  
10 20,000 clients currently benefit from case  
11 management services supported by DFTA. Last year,  
12 DFTA redesigned the case management system to  
13 create more clearly defined service areas for case  
14 management providers. The redesigned system also  
15 fostered more holistic assessment of clients'  
16 overall needs. Through these assessments, clients  
17 are evaluated as to whether they would benefit  
18 from a variety of programs and services including  
19 home delivered meals, home care, medical and  
20 respite care, legal services, counseling,  
21 transportation and benefit and entitlement  
22 programs. Telephone reassurance and friendly  
23 visiting. Another smaller but important part of  
24 the service continuum to home bound elderly is the  
25 provision of wrap around services such as friendly

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2 visiting and telephone reassurance programs.  
3 These services reflect the fact that home bound  
4 older adults have needs beyond nutrition and  
5 medical care and can also derive great benefit  
6 from something as simple as a phone call or a  
7 visit. Several case management agencies, home  
8 delivered meal providers and senior centers have  
9 telephone reassurance and friendly visiting  
10 programs in place. However, in the case of some  
11 providers, this is not their primary function. It  
12 can be difficult to maintain these types of  
13 programs in a time of scarce resources. To this  
14 end, I am very pleased to report that DFTA's  
15 launching an initiative to support wrap around  
16 services for home bound seniors. Time Bank NYC is  
17 a reciprocal service exchange program that relies  
18 on volunteers to provide services to the home  
19 bound and older adults and also values the  
20 potential reciprocal contributions of the older  
21 adults receiving services. For example, Time Bank  
22 members or volunteers could provide services to  
23 the elderly that would help them remaining in  
24 their homes and communities such as friendly  
25 visiting, telephone reassurance, errand running or

1 shopping, escort services, home repairs or basic  
2 household tasks. Elderly members could in turn  
3 contribute service to the other Time Bank members  
4 such as tutoring and mentoring, peer to peer  
5 telephone reassurance, peer to peer escort  
6 services, cooked meals or language and craft  
7 lessons. DFTA is currently working to pilot Time  
8 Bank NYC in 25 communities across New York City.  
9 Based on the results of the pilot, we will work to  
10 expand the initiative city wide. Home care.  
11 DFTA's expanded in home care services for the  
12 elderly program, or EISEP, serves frail older  
13 adults who are not Medicaid eligible but who  
14 cannot afford the cost of private care. The EISEP  
15 program is designed to help eligible elderly  
16 individuals remain safely at home rather than in a  
17 nursing home by providing home attendants who help  
18 with the daily living tasks such as dressing,  
19 toileting, bathing, cooking, shopping and errands.  
20 DFTA funded home care currently serves  
21 approximately 1,440 clients and is available to  
22 eligible adults for an average of 12 to 20 hours a  
23 week. As you may know, the primary city sponsored  
24 home care program, the Personal Care Program, is  
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1  
2 administered by the Human Resources Administration  
3 and serves seniors and individuals with  
4 disabilities who are Medicaid eligible. Home care  
5 is a critical service in supporting the city's  
6 goal of meeting the changing needs of older adults  
7 who prefer to remain in their homes and  
8 communities in lieu of institutional care. NORCs.  
9 DFTA also administers \$6.5 million in city funding  
10 and \$1 million of which is generously allocated by  
11 the city council to coordinate housing based  
12 support services programs for low and moderate  
13 income elderly residents in naturally occurring  
14 retirement communities. These interdisciplinary  
15 programs are located in the buildings or housing  
16 developments where seniors live and are designed  
17 and administered as a partnership between senior  
18 residents, housing owners and managers as well as  
19 social services and healthcare providers. NORCs  
20 have many of the benefits of supporting senior  
21 housing yet allow individuals to remain within a  
22 familiar, multigenerational atmosphere of their  
23 homes and immediate communities. I feel strongly  
24 that NORCs provide a model for the future of aging  
25 in place in New York City. The population of



1  
2 older adults is continuing to grow, and housing  
3 does not meet this ever increasing demand. It  
4 only makes sense to support the low cost NORC  
5 model which can afford supportive services such as  
6 transportation, escort and shopping, social  
7 activities and connection to the community and  
8 government resources to older adults within the  
9 residential buildings or neighborhoods. NORCs  
10 were born in New York City, and I look forward to  
11 supporting their continued growth as the  
12 population of our city ages in place. Support for  
13 caregivers. As we look for ways to delay or avoid  
14 institutional care for the elderly, it is  
15 imperative to consider the needs of caregivers.  
16 The majority of older adults do not live alone but  
17 rather reside with family members. Families play  
18 a vital role in our city as a primary caregiver of  
19 older adults. Without supportive and respite  
20 services, caregivers are much more likely to  
21 choose institutional care for their loved ones.  
22 DFTA's Alzheimer and Caregiver Resource Center  
23 provides support for caregivers of seniors through  
24 counseling, education and training, resource and  
25 referral and respite care services. The

1 Alzheimer's and Caregiver Resource Center also  
2 conducts training sessions on a wide array of  
3 topics around care giving for caregivers, seniors,  
4 professionals and general public. The Alzheimer's  
5 and Caregiver Resource Center also oversees 14  
6 contracted Title III-E national family caregiver  
7 support programs, through which community based  
8 organizations provide support and respite for  
9 caregivers of frail, older adults. These  
10 community partners serve a specialized population,  
11 including Chinese, Russian speaking and Spanish  
12 speaking immigrants, gay and lesbian caregivers,  
13 grandparents with sole responsibility for their  
14 grandchildren and Chinese and Korean speaking  
15 caregivers. Social adult day services are  
16 structured programs for physically frail,  
17 cognitively or memory impaired older adults that  
18 focus on personal care, nutrition, socialization,  
19 supervision or managing in a protective setting  
20 during part of the day. These programs not only  
21 serve as a therapeutic experience for participants  
22 but can also provide much needed relief and  
23 respite for overwhelmed caregivers. I need to add  
24 here that it's thanks to the city council and the  
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1  
2 leadership of Chairperson Arroyo that caregiver  
3 programs are back on the budget, so I'm very  
4 grateful, among other things that I'm grateful  
5 for. Investing in home and community based care  
6 respects the wishes of older adult New Yorkers to  
7 age in place and help to preserve their valuable  
8 contributions to our city. The Department for the  
9 Aging's continuum of care reflects how people want  
10 to age at home and in the community. I appreciate  
11 the support of the city council in all these  
12 programs, and I look forward to discussing ways to  
13 continue the enrichment of home based services for  
14 the rapidly increasing population of older adults  
15 in New York City. I will now take questions or  
16 defer to my colleague, Mr. Sapolin.

17 CHAIRPERSON KOPPELL: Thank you  
18 very much, Commissioner. Now, we'd like to hear  
19 from Commissioner Sapolin. Before you speak,  
20 Commissioner, let me say that I just heard this  
21 morning that you lost your friend and guide dog,  
22 who I always enjoyed seeing here at the hearings.  
23 He seemed to be a wonderful animal, and I'm sure  
24 you miss him.

25 MATT SAPOLIN: I do. Thank you so

1  
2 much for those kind words, council member. Yeah,  
3 usually I would defer to him for any of the  
4 difficult questions that you all would pose a  
5 little later. Thank you. It's been a tremendous  
6 loss for me and my family, and the wonderful  
7 community of our folks here and you all that  
8 embraced him since we all met about seven or eight  
9 years ago. Thank you so much for those kind  
10 words.

11 CHAIRPERSON KOPPELL: They're  
12 wonderful. Those animals are just wonderful.

13 MATT SAPOLIN: They really are, and  
14 I think in the fall--I'm not ready to work that  
15 hard through the summer, but I think in the fall,  
16 I'll go get another dog. I actually spoke with  
17 the group last night, and they've got another big  
18 male golden retriever to shed all over all of us  
19 picked out for me. The Mayor can reinstall his  
20 joke about being shed on and stuff that he always  
21 talks about when I'm present. I'm no longer  
22 shedding, but thank you. To the business. Thank  
23 you for having me, Chairs Arroyo and Koppell and  
24 Council Member Felder. Let me start by saying a  
25 little bit of background on our office so that we

1  
2 can understand a little bit of the differences  
3 between the vast services you just heard described  
4 and the role our offices plays. Since 1973, our  
5 office, the Mayor's Office for People with  
6 Disabilities, formed under an executive order, was  
7 established to ensure that the voice of people  
8 with disabilities was represented in the  
9 development of our city's programs and services.  
10 To that extent, my role has been more to be out  
11 there in the community with our friends here who  
12 will testify later and really try to get the pulse  
13 of the community and bring that back to the mayor  
14 and the mayoral team and hopefully provide advice  
15 that would shape policies and programs to include  
16 and improve the inclusiveness for people with  
17 disabilities across all of the opportunities that  
18 New York has to offer. I was appointed in 2002,  
19 and since that time have tried to forge  
20 partnerships with the other city agencies who are  
21 critical to us, such as Department for the Aging,  
22 Human Resource Administration, Department of  
23 Buildings, Parks Department and others who engage  
24 the community every day. I've made a strong  
25 effort to get back out into the community and meet

1 the constituents and the agencies in which they  
2 work and receive services from to forge  
3 partnerships to be able to carry out our role.  
4 Another part of our role is to serve as the in  
5 house advocate for constituents and communities  
6 representing people with disabilities in an effort  
7 to try and advance policies and programs and help  
8 navigate complicated systems of services. That's  
9 a little bit of background on the office. Some of  
10 the things we do as it relates directly to  
11 diversion, the question at hand here, really  
12 typically related more to the day to day advocacy  
13 that we're able to do through the influence of the  
14 mayor's office and our partnerships to hopefully  
15 impact the lives of people either through  
16 preventing institutionalization or helping  
17 facilitate and create liasonship to community  
18 based services for constituents. One of the  
19 things that we conduct out of our office and was  
20 modeled on a statewide effort as well is something  
21 called a barrier removal program called Project  
22 Open House. This is a program where we use  
23 community development, block rents to prevent  
24 institutionalization by creating modifications in  
25

1 people's homes. This is typically privately owned  
2 homes rather than landlord run buildings. Our  
3 commission on civil rights does a good job of  
4 creating settlements and other injunctions where  
5 landlords are concerned. For private home owners  
6 and usually one to three or four family homes,  
7 we're able to come in, widen doorways, modify  
8 bathrooms, modify kitchens with some of this  
9 community development block rent dollars that we  
10 have. Similar to that, we've been able to benefit  
11 from a DFTA program that Commissioner was unable  
12 to comment on in her testimony, which was so  
13 robust, but the project Metro Pair, which will do  
14 some smaller rehabs and modifications to bathrooms  
15 and kitchens such as grab bars and other smaller  
16 changes. Those programs we hope have had impact,  
17 and we're sure to have had impact on some numbers  
18 of folks out there to prevent  
19 institutionalization. That was modeled at the end  
20 of the Pataki regime, I believe, with a program  
21 called Access to Home, whereby I think it was \$10  
22 million were allocated. Several of those millions  
23 came downstate here, and we partnered with United  
24 Cerebral Palsy over the past several years on a  
25

1 project called Doorways to Independence, which  
2 again just mirrors what Project Open House does.  
3 Project Open House, Doorways to Independence or  
4 Access to Home do not reach the numbers of people-  
5 -the supply cannot reach the demand, and so we  
6 hope that in the future, the state and others can  
7 find ways to expand those programs. Our waiting  
8 list is rather long, and we are now, due to some  
9 better situations of contracting with the  
10 community getting these jobs done more quickly and  
11 preventing institutionalization. We've also used  
12 that in a couple of occasions to transition people  
13 out of nursing homes whereby they would be in  
14 their home if the home was modified adequately.  
15 We find its typical application is the prevention  
16 mode. You know, obviously we depend on some of  
17 our sister city agencies who are here with us  
18 today for things like one shot deals, rental  
19 assistance and things like that, again, to prevent  
20 institutionalization where people may have gaps  
21 between their household income and their ability  
22 to pay. The one shot deal and rental subsidies  
23 and other things like that clearly come out of our  
24 human resource administration. We also partner  
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1  
2 with HPD, and again, all these programs do not fit  
3 all, but we believe reach a good number of folks.  
4 To market their set aside programs whereby 5% of  
5 HPD developments are set aside for people with  
6 physical disability and 2% for people with sensory  
7 disability. Often, we can try and link people in  
8 institutions up with these application processes  
9 which are competitive application processes which  
10 really function under I believe HUD regulation in  
11 terms of criteria and eligibility and how these  
12 things are drawn. We have gotten HPD to work with  
13 developers to do things like accept Section 8  
14 vouchers and other types of housing subsidies as  
15 guaranteed rental income so that things like  
16 income floors and income ceilings, which often  
17 become a problem to people to qualify for these  
18 programs, do have an opportunity to qualify.  
19 We've had some success in placing people there as  
20 well. Also, HPD, I must add, does help us with  
21 some of our construction efforts with Project Open  
22 House and those other barrier removal programs I  
23 talked about. We also are somewhat successful  
24 from time to time at helping to prevent evictions.  
25 Believe it or not, when somebody with a disability

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2 becomes evicted from a living situation that's  
3 appropriate, it can lead to institutionalization,  
4 and that may not be a common thought intuitively,  
5 but believe me, we read and see and hear it all  
6 the time. We've worked closely with our sheriff,  
7 Sheriff Lindsay, and with our marshals to be  
8 tolerant, if you will, when it comes to slapping  
9 that marshal's lock on a door. Now, again,  
10 housing court is housing court and they have their  
11 rules, but we have had cooperation from the  
12 sheriff and the marshals in being a little bit  
13 cooperative in helping prevent those evictions if  
14 there were ways and good faith efforts on the  
15 behalf of the constituents to comply with whatever  
16 settlements were agreed to or what have you  
17 related to avoiding that eviction. Community  
18 reintegration, as I said--sometimes, our barrier  
19 removal programs are successful at that, but we  
20 find, and I was even having a conversation before  
21 taking this seat with a young woman here, that we  
22 can help by getting out there into the  
23 institutions and meeting with constituents in a  
24 capacity to listen and assure that all venues have  
25 been explored and to see if there's anything that

1  
2 our influence or our relationships internally can  
3 do to expedite things like applications for  
4 housing or services with other city agencies,  
5 state or federal agencies, and again, the thing  
6 that bothers me about these things that we do for  
7 individuals is not everybody knows my phone  
8 number. For those who do, we're able to support  
9 in this way, but for the silent masses that we  
10 don't reach, obviously, our stomach hurts. We  
11 always ask for you all and others here to refer  
12 these kinds of things to us so we can do more of  
13 this and hopefully systemize some of these things  
14 that we're doing on a constituent by constituent  
15 basis with terrific partnerships by all these  
16 agencies I speak of. That includes us outreaching  
17 to the institutions, letting people know we're  
18 here so we can get to those silent masses. We're  
19 out there in the community a lot, and I appreciate  
20 our community partners for letting us come to  
21 their institutions and try to help, whether it's  
22 diversion or anything else we can do. Obviously,  
23 information and referral--when folks call our  
24 office, since we're not a service organization, we  
25 provide--we get more than 300 to 400 calls a week

1  
2 in our office, a lot of which have to do with  
3 either housing or reintegration or prevention, and  
4 so a good deal of our frontline staff's work does  
5 go into information and referral, technical  
6 assistance and sort of navigation, if you will.  
7 Again, you can always couple that with advocacy.  
8 Where appropriate, we will use our office's  
9 influence to conduct appropriate advocacy. We  
10 hope to advance the opportunities for folks to  
11 stay or reenter the community. Those linkages are  
12 critical to us, whether it be personal care or  
13 other services through HRA. Many people diver  
14 nursing homes because of the more than 35,000  
15 constituents or more that get home care services.  
16 A lot of these folks are not just in home  
17 services, but they're folks who are working, and  
18 their work is keeping them from being  
19 institutionalized as well. We depend on our other  
20 city agencies for these services and the  
21 relationships that we have. Where we can, we are  
22 able to use those partnerships to really leverage  
23 some good outcomes. Again, food and nutrition  
24 programs--believe it or not, while Meals on Wheels  
25 and a lot of other programs are designated for

1  
2 seniors, there is some overlap here. We are  
3 grateful to that. Obviously, there's been  
4 advocacy over the years to expand those programs  
5 completely to people with disabilities as well,  
6 but we understand attrition and budgets, and  
7 that's hard, but we do find cooperation from local  
8 food organizations in the community and nutrition  
9 organizations in the community where it comes to  
10 providing food support and others for folks who  
11 otherwise, if their nutrition slips could find  
12 themselves institutionalized. Waivers--again, we  
13 know about the state diversion waivers and all  
14 those other things, and we'll work with anybody  
15 out here in the community who are using these  
16 waivers to help them in any way we can navigate,  
17 if you will, the systems where city agencies,  
18 state and federal agencies are engaged. Again,  
19 transportation is critical to keeping people  
20 independent and free and operating out here in our  
21 community with dignity. We feel we need to  
22 continue to advocate for more increased access in  
23 all of our transportation systems, and we will.  
24 We've seen some progress there, and some of that  
25 progress has included opportunities for people to

1  
2 remain in the community. The Built Environment is  
3 an interesting place, and again, people often  
4 think why would the Mayor's Office for People with  
5 Disabilities have anything to do with the Built  
6 Environment and what's the impact on  
7 institutionalization? Well, in our office, by  
8 law, we're charged with being involved in the  
9 building code where waivers of the access  
10 requirements are concerned. For any building that  
11 goes up in the city, if folks are following the  
12 building code, they will have to run a waiver  
13 request by this gentleman if they wish not to  
14 comply with the accessibility provisions. That  
15 goes further where we were asked to chair the  
16 technical subcommittee on access for the adoption  
17 of the new building code, which will formally kick  
18 in in just a few days here in July, and we're  
19 proud to say that while it was a difficult  
20 process, we believe that the new chapter on  
21 accessibility, Chapter 11 of the building code,  
22 provides greater access than our former code in  
23 many areas, including scoping and some of the  
24 other areas that give us access to more stock.  
25 This is important to us. The more stock that is

1  
2 available will help us divert and reintegrate  
3 folks. The other thing I'll add to the new  
4 building code is we obviously promote and have  
5 done several publications on inclusive design, and  
6 in concert with the mayor's memorandum of 2005, we  
7 encourage our city design professionals and  
8 developers to integrate universal design to exceed  
9 the minimums of the building code when developing  
10 housing and city projects and other private  
11 developments that go on in our city. We'll soon  
12 be coming out with our third publication, which  
13 will get very specific and give architects and  
14 design professionals direction as it relates to  
15 creating environments that are usable by all. I  
16 want to wrap this up. I think the Build  
17 Environment, as I said, gives us an opportunity to  
18 create an environment for people to live in. We  
19 need to expand that stock of housing. I believe  
20 this new building code will achieve that and with  
21 that, I thank you for your attention. I want to  
22 make it clear again that please understand, our  
23 role is here more of an advocate and a linkage to  
24 the services where agencies like DFTA, HRA and  
25 other great city agencies actually provide the

1  
2 important services that we're creating these  
3 linkages to. I thank you, Chairs. I thank you,  
4 Council Members. I thank the audience for their  
5 attention and before I do sign off, Councilman  
6 Koppell, I want to thank you for your advocacy in  
7 reminding us to work on the signage program here  
8 in the public's most civic of places, our own city  
9 hall. As you know because of your advocacy and  
10 others' advocacy, our bathrooms here are now ADA  
11 complaint. We do now have some access to the  
12 rotunda outside, but we could always look to  
13 improve these, and your comments about the signage  
14 were very helpful. I hope you see those  
15 improvements.

16 CHAIRPERSON KOPPELL: I saw the  
17 change. Thank you. Thank you very much,  
18 Commissioner. I want to welcome Annabel Palma,  
19 who's a member of our Committee on Mental Health  
20 for joining us. It sort of sounds from both of  
21 your testimonies that we don't need HR1621. I'm  
22 being a little facetious, but perhaps one of you  
23 might want to comment on how you or your staffs  
24 have reviewed it and how it would enhance what you  
25 already do.



1  
2 MATT SAPOLIN: I'll start just by  
3 saying as I stated through my testimony, there are  
4 not enough of any of the resources that we tap  
5 into to meet the demand. That will always be, and  
6 I think it's important for all tiers of government  
7 to look for ways to improve what we have.

8 Homestead said it years ago--least restrictive  
9 environment. I don't think anybody would argue  
10 with that philosophically. If that particular  
11 bill that you cite is the root to getting there, I  
12 know that's what advocates have called for.

13 CHAIRPERSON KOPPELL: Commissioner?

14 LILLIAM BARRIOS-PAOLI: What I  
15 would add to that is that I think that we have not  
16 yet as a society understood that aging in place is  
17 a value and an important thing for most human  
18 beings, particularly seniors and disabled, but  
19 importantly, it's also much more cost efficient,  
20 and I think we still are not conscious of that as  
21 a society, so I think any law that enhances that  
22 and pushes us toward that goal is an important  
23 law.

24 MATT SAPOLIN: I'll just add one  
25 other thing. One of the--we all know that the

1  
2 cost of a nursing home is upwards of \$120,000 to  
3 keep people in it. As Commissioner just stated,  
4 we know that there are in many cases more cost  
5 effective ways of doing that with creating  
6 employment opportunities for people and all these  
7 other things that we know it does. I think the  
8 difficulty is figuring out the answer to diverting  
9 those resources back to it, and I guess I'm not an  
10 accountant, but from an accounting principle, I  
11 guess it's hard to recognize and realize that  
12 \$120,000 from the nursing home expense back to the  
13 community. It's easy to understand the value  
14 offset, but from accounting principles, it's hard  
15 to really recognize it.

16 CHAIRPERSON KOPPELL: Thank you.

17 Go ahead, Council Member Arroyo.

18 CHAIRPERSON ARROYO: Thank you, Mr.  
19 Co-Chair. I'd like to acknowledge we've been  
20 joined by members of the Committee on Aging.  
21 First, our chair of the subcommittee on senior  
22 centers, Council Member Melissa Mark-Viverito and  
23 Council Member Mathieu Eugene from Brooklyn. And  
24 Council Member Viverito represents Manhattan,  
25 Upper East Side and East Harlem and a little bit

1  
2 of the Bronx, which is the best part of the  
3 district. I have a couple of questions. First  
4 and foremost, thank you for your testimony,  
5 Commissioner Paoli. Thank you for your  
6 partnership and your work with the council on the  
7 budget process. I think that we have emerged from  
8 the process very successful in restoring some very  
9 critical services that speak to the issue that  
10 we're discussing today. Seniors staying at home  
11 longer, living independently with the right  
12 supports, and it's very frustrating that we had  
13 the struggle that we had to keep those services  
14 funded. I certainly hope that as we move forward  
15 that we remember this conversation today and  
16 remember how critical the services that we had to  
17 fight to restore are to keeping people living at  
18 home longer. First, I want to know what is your  
19 opinion of the resolution we're here discussing.  
20 Are you in support? Any of you speak against it?  
21 Give me your thoughts.

22 LILLIAM BARRIOS-PAOLI: Again, I  
23 think although we haven't fully reviewed it, I  
24 think we would in principle be supportive of it  
25 because anything that keeps people in the

1  
2 community, actively and healthy, is important. I  
3 think we have to look at the cost and shifts in  
4 cost that we have to make in order to make the  
5 resolution alive and vital and effective. I think  
6 that you have our commitment, my commitment that  
7 aging in place is the most important function the  
8 agency can have, and the support of seniors doing  
9 that.

10 CHAIRPERSON ARROYO: I guess after  
11 this hearing, follow up conversations about how we  
12 can certainly continue the conversation at the  
13 state and federal level to make sure that the  
14 shifts happen because they make a great deal of  
15 sense but that they happen in a way that makes  
16 sense for everyone effected. Commissioner, the  
17 home care program that you described in your  
18 testimony, expanding home care services. Cost and  
19 what is the eligibility? How does someone become  
20 a participant of the program?

21 LILLIAM BARRIOS-PAOLI: It is  
22 essentially designed for people who do not qualify  
23 for Medicaid. They have income above the Medicaid  
24 numbers but still need at home care, and it's  
25 usually somewhere between a very few hours and up

1  
2 to 20 hours a week. It's not for the most  
3 disabled of seniors. I think it's a finite  
4 program, and that's part of the issue is that we  
5 have a limited budget for it so that we do have  
6 waiting lists. It is something that I have not  
7 had the time, honestly, in the four months that  
8 I've been there to really look at. I will be  
9 doing that. I think it's a very vital compliment  
10 to the Medicaid provided service that HRA does,  
11 and I think there may be ways of looking at the  
12 intensity of the care that some people receive and  
13 ways of building bridges towards--from the DFTA  
14 service to HRA and the other way around. I am  
15 very happy to sit down and discuss this with you  
16 and see how we can improve the service.

17 CHAIRPERSON ARROYO: I think  
18 moving forward, discussing how we can expand the  
19 programs that provide the support for individuals  
20 to stay at home, whether it's the home care  
21 program, NORCs, that are so incredible in the  
22 community. We have a pilot program in the Bronx  
23 that the committee was able to fund in a community  
24 that I share with my colleague, Council Member  
25 Palma. I met with a group of seniors during

1  
2 Senior Advocacy Day here in city hall, and there  
3 was a handful of individuals from the neighborhood  
4 shop NORC in the Morrison-Lafayette/Boynton-  
5 Lafayette developments who are extremely pleased  
6 and looking forward to that program expanding. We  
7 need to work on making sure that we provide for  
8 NORC opportunities in communities across the city  
9 because it is one of the benefits our city is not  
10 very comprehensive in in that not every community  
11 can benefit from a NORC funded by either DFTA or  
12 state funding. We really need to work on making  
13 sure that we make those programs available across  
14 the city. I want to talk a little bit about an  
15 issue that I have had a lot of discussions with a  
16 lot of people here, and I'm happy to see the  
17 Commissioner from the Mayor's Office on  
18 Disabilities here. The set aside in housing  
19 development excludes seniors, and that's a  
20 problem. So that as we have a set aside, a 5% for  
21 disabled and 2% for those who have visual  
22 impairments, we need to have the inclusion of  
23 seniors in that set aside population, and more  
24 importantly, include oversight to ensure that all  
25 housing developed actually houses individuals who

1  
2 these set asides are dedicated for. I'm not sure  
3 we do that. I think we have to have conversations  
4 about how to do that in a way that's productive  
5 but in a way that ensures that if we're going to  
6 set aside 5% that 5% are indeed individuals who  
7 meet that definition. We need to include seniors  
8 in that set aside compliment. The need for senior  
9 housing in our city is incredible. It is growing  
10 every year. Most people who are on a 202 housing  
11 waiting list die waiting for an apartment, and  
12 that is unacceptable. We can relieve those  
13 demands by making sure that we include seniors in  
14 the set asides and that we have appropriate  
15 oversight programs and monitoring to ensure that  
16 those percentages are met, that there is no way  
17 for any developer or any management company to get  
18 around those requirements. I'm going to conclude  
19 there unless any of my colleagues have any  
20 questions.

21 CHAIRPERSON KOPPELL: Council  
22 Member Palma had a question.

23 COUNCIL MEMBER PALMA: Thank you,  
24 Madame Chair. Commissioner, I wasn't here when  
25 you read your testimony, but I was going through

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2 it and I was interested in the DFTA Time Bank New  
3 York City initiative, and I just wanted more  
4 clarity on it in terms of I know it's going to be  
5 a volunteer run program, but what's going to be  
6 the cost to DFTA to run this program and will  
7 these volunteers--where would they come from? How  
8 are they going to be identified? Are they going  
9 to get background checks before they're paired up  
10 with a senior and have the 25 communities already  
11 been identified?

12

LILLIAM BARRIOS-PAOLI: We're in  
13 the process of thinking through exactly where the  
14 communities are going to be. They're going to be  
15 city wide, and they're going to be probably in  
16 communities that have a high level of poverty.  
17 The idea of time banking is something that has  
18 been around for quite a while but has not been  
19 done in great numbers. Visiting nurse services  
20 has a very successful model that I believe they  
21 implemented in Washington Heights. The idea is  
22 that it's based on reciprocity. You identify your  
23 talents and you bank them, and then you withdraw  
24 from that banking--you can withdraw on other  
25 people's talents. For example, I give you three



1  
2 or four hours to do telephone reassurance for  
3 seniors. On the other hand, if I need--if I want  
4 to learn a language and a senior can tutor me, you  
5 can then withdraw from there. We're looking into  
6 issues of making sure that people are--that  
7 there's a vetting process to make sure that people  
8 are not going to take advantage of anyone or do  
9 anything untoward to the seniors, and I think at  
10 the beginning, we are going to begin doing it  
11 either by telephone reassurance or things that  
12 don't mandate one to one going into people's  
13 apartments or having interactions one on one. If  
14 we do any kind of interaction, it would be more of  
15 a group nature or at least two or three people.  
16 We are starting the program probably based on  
17 either senior centers or our case management  
18 agencies, and we're using Title V seniors to sort  
19 of do the actual time banking function of entering  
20 the data and interviewing people, and these are  
21 seniors that we've been able to hire through  
22 stimulus funding. It's a double purpose. These  
23 are seniors that we're very happy to be able to  
24 provide them stipends and employment. The idea is  
25 to train them so that they can eventually go back

1  
2 into the labor force, and those are stimulus  
3 funds, so it's not any money that we're using that  
4 was for other purposes. The volunteers will be  
5 identified through the mayor's efforts through  
6 this big volunteer effort the mayor was doing and  
7 through our agencies that have any large number of  
8 volunteers.

9 COUNCIL MEMBER PALMA: Thank you,  
10 Commissioner.

11 MATT SAPOLIN: Chair, may I make a  
12 response to see if it's helpful to Chair Arroyo  
13 regarding the set asides? Fortunately, for folks  
14 with disability, those set asides I believe are  
15 mandated by the Fair Housing Act, so I will bring  
16 that conversation up on behalf of seniors with  
17 Commissioner Sisteros when I meet with him next,  
18 and on the issue of using those percentages more--  
19 getting that utility up, the gentleman to my right  
20 has some very aggressive ideas about that. What  
21 we're doing currently is the current rules require  
22 a three cycle canvas. Developers are not supposed  
23 to be filling those apartments with people who  
24 aren't meeting the eligibility criteria without  
25 first canvassing those at least three times.

1  
2 Again, we still believe that utility can go up,  
3 and that's why we're trying to do increased  
4 marketing. The other problem we really see, and  
5 this is why it was important to have cooperation  
6 from both Commissioners Donovan and now Sisteros  
7 about getting the developers to accept the housing  
8 subsidies as guaranteed income. What we find is  
9 the most vulnerable folks who call us often fall  
10 below that income floor, and so if that income  
11 floor is \$21,000 household dollars a year and  
12 these folks are at \$17,000, it's just so sad to  
13 see them not qualify. They've piloted some things  
14 with us, but you make a great point on the 5%.  
15 Right now, what we're doing is the three canvases,  
16 and I will try to get some more information for  
17 you on the actual utilization. It's very hard for  
18 us to track those exact numbers. We hear your  
19 point. We feel your point, and I just wanted to  
20 give you that information.

21 CHAIRPERSON KOPPELL: Thank you  
22 very much. Let me just say I don't mean to be  
23 contentious here. Council Member Arroyo and I  
24 have to have a conversation. I'm a little bit  
25 concerned about seniors as a whole being included

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2 in the set aside because we have such need for the  
3 disabled housing, and I don't want to get into a  
4 fight.

5 CHAIRPERSON ARROYO: We can take it  
6 to the parking lot.

7 CHAIRPERSON KOPPELL: Since I'm a  
8 senior myself, I think that I'm--but at least not  
9 seriously disabled. I think that in a sense, I'm  
10 speaking against my interest here, but I do feel  
11 that we must make sure that those who are most in  
12 need get housing, and we're in great--we don't  
13 have enough units as it is. As chair of the  
14 Committee on Mental Health and Disability Rights,  
15 one of the things that I have stressed over the  
16 years is getting more housing. There's nothing  
17 more important than support of housing across the  
18 board. But I don't want us to see the disabled  
19 more disabled. I think we have to have a  
20 conversation about those priorities. I had to say  
21 it because it's a problem. When you have a  
22 limited pie, how you slice the pie is always a big  
23 problem.

24 MATT SAPOLIN: That's why I said  
25 specifically that I believe it fell under the Fair

1  
2 Housing Act. It's not a choice I made. It's the  
3 Fair Housing Act. I will bring both of your  
4 comments to Commissioner Sisteros at our next  
5 meeting.

6 CHAIRPERSON ARROYO: I'd just like  
7 to add that we could take it to the parking lot or  
8 we can have a conversation behind closed doors.  
9 For me, it is a concern and something that I think  
10 we can without compromising the pie, and the  
11 access to those with disabilities to increase the  
12 senior population, to increase the set asides so  
13 that we don't have a competition between seniors  
14 and disabled. Many seniors are disabled and could  
15 potentially fall into that category.

16 MATT SAPOLIN: That will make them  
17 eligible, Council Member. I'm sorry to interrupt,  
18 but that's a very important point. If you're a  
19 senior and you have a qualifying disability, fill  
20 out the application. You have a disability.

21 CHAIRPERSON KOPPELL: No doubt. I  
22 certainly don't want to disqualify disabled  
23 seniors, but I'd be concerned a little bit about  
24 able seniors taking the place of a disabled  
25 person. I met a woman this morning at the bus

1  
2 stop who's 88 years old and still running her own  
3 business. That's an example of a senior who's  
4 very able.

5 LILLIAM BARRIOS-PAOLI: Let me just  
6 say that I don't think in the past few years DFTA  
7 has been as aggressive an advocate on housing as  
8 it could have and should have been, and I think we  
9 have to find creative avenues for creating more  
10 senior housing without having to compete with any  
11 other very worthy community. I think we need to  
12 add it to our agenda as a very important senior  
13 need, whether or not we building housing. We  
14 still can be a powerful advocate. I think we need  
15 to talk more about how to do it and how we should  
16 push for it, but I think housing has to become a  
17 very important part of the agenda, and I totally  
18 agree with you.

19 CHAIRPERSON KOPPELL: We don't  
20 disagree at all. In my opinion, if you want to  
21 look at the problems we face, right at the top is  
22 providing enough appropriate housing both income  
23 wise and facility wise for our population. If you  
24 want to talk about the problem of homelessness or  
25 the problem of disability, and it not only

1  
2 includes physical but also mental disability--the  
3 problem of supportive and appropriate housing is  
4 way at the top of the agenda. Thank you both for  
5 coming, and let me introduce another Bronx  
6 colleague. Look how the Bronx is represented here  
7 this morning. It shows you who are the most  
8 concerned people here except for Simcha Felder,  
9 who's not here anymore, and Mathieu Eugene, but  
10 all the rest of us are from the Bronx. Okay,  
11 Jimmy Vacca, I didn't mention his name. Council  
12 Member Jimmy Vacca.

13 COUNCIL MEMBER VACCA: Can I  
14 request that my name be added to the resolution  
15 1783?

16 CHAIRPERSON KOPPELL: Yes, indeed.  
17 Thank you commissioners. Thank you. By the way,  
18 I want to mention we had a representative of HRA  
19 here this morning who didn't ask to testify but  
20 was available for questions, and we want to  
21 recognize you. Thank you. Now we have the first  
22 panel. We're going to have panels of three, and  
23 we have Lawrence Carter-Long, Executive Director,  
24 Disabilities Network of New York City. We have  
25 Phillip Bennett, healthcare worker, and we have

1  
2 Edith Prentiss, who's a wonderfully diligent  
3 advocate of the disabled. It's a little  
4 inconvenient with the--yes?

5 [PAUSE]

6 CHAIRPERSON KOPPELL: Where's the  
7 Sergeant in Arms? We need him. The Sergeant is  
8 here, so he'll help you try and set up. While  
9 people are getting set up, let me introduce Gale  
10 Brewer, member of the Committee on Mental Health,  
11 etcetera. Nice to see Manhattan now represented.

12 COUNCIL MEMBER BREWER: Thank you.

13 EDITH PRENTISS: Hello. My name is  
14 Edith Prentiss, and I am the President of the 504  
15 Dems, Vice President for Legislative Affairs for  
16 the Disabled in Action and a member of the  
17 Disability Network of New York City.

18 CHAIRPERSON KOPPELL: Before you  
19 begin, because of pressure of time and we're in  
20 the budget, I'm going to ask people to limit their  
21 remarks to three minutes. That doesn't include  
22 any questioning time. Thank you.

23 EDITH PRENTISS: Okay. Since you  
24 have my written testimony, I am only going to give  
25 you the highlights. First, I would like to say



1  
2 that it's wonderful to hear all the things that  
3 DFTA does. I would like to point out that  
4 disabled New Yorkers do not have a smidge of those  
5 services. EISEP would be a wonderful addition for  
6 our community as well. There are younger disabled  
7 New Yorkers who could certainly use Meals on  
8 Wheels. I am one of the original members of VNF  
9 Time Bank. I am one of the coordinators. It's  
10 very important to notice that individuals with  
11 disabilities who also very desperately need those  
12 levels of supports to stay in the community do not  
13 get them because we are younger. We don't get  
14 EPIC. We have a disparity in the - - programs.  
15 These all impact our abilities to stay in the  
16 community. As my rent increases now to well above  
17 my Social Security benefit, I am at risk. This is  
18 a risk that no senior has to face. I think there  
19 is patently wrong. CCA is the issue that most of  
20 us are concerned with. I would like to say first  
21 and foremost that we are not concerned about  
22 supportive housing. We are concerned with  
23 integrated, affordable, accessible housing,  
24 primarily. That is very important. The three  
25 tenants of housing. Many of us live in housing

1  
2 that we make do with. We manage to stay in our  
3 houses because we know there's no place else for  
4 us. The Community Choice Act would eliminate the  
5 current institutional bias. Presently, 67% of all  
6 Medicaid long term healthcare dollars go to  
7 institutional care, be it nursing homes, adult  
8 homes, group homes or residential facilities.  
9 Only 33% go to community services. Nationwide,  
10 there are reports of community based services  
11 having ten year waiting lists. Talk about 202  
12 housing people dying out of? People are dying  
13 before they get community based services as well.  
14 People are being forced into nursing homes on a  
15 daily basis in different localities. In 2009, we  
16 already have in the 111<sup>th</sup> Congress 28% of the--it's  
17 in there. New York State is very well represented  
18 in both the 110<sup>th</sup>, the previous Congress and the  
19 111<sup>th</sup>, the present Congress. We are well  
20 represented and signed on for CCA. The problem we  
21 face is nationwide. There were eight states that  
22 had not a single cosponsor in the 110<sup>th</sup> Congress.  
23 That's deplorable. The question about the cost of  
24 housing--there are two--I cite two recent studies.

25 CHAIRPERSON KOPPELL: Take a minute

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to finish up.

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EDITH PRENTISS: Two recent studies that showed that the cost is much less. It's very important to know that there is not a universal level of service available under Medicaid, and that's the problem. New York State gives 24 hour service. There are some states that give four to eight hours a week of service. For individuals who need greater service, they're forced into nursing homes. After one month in a nursing home in 2005, I can certainly tell you I would be on the Underground Railroad to New York State where there is better services. In brief, there's an attachment on mine which is the Kansas Adapt CCA Q and A. That will give you better background information, but in brief, people should not be forced to uproot themselves, leaving family, home and community to move to a state or locality where they can receive the community based services rather than being forced into a nursing home or residential facility. We believe access to community based services is a civil right. Our homes, not nursing homes. Thank you very much for the opportunity.

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2 CHAIRPERSON KOPPELL: Thank you  
3 very much, Ms. Prentiss. Mr. Carter-Long?

4 LAWRENCE CARTER-LONG: Thank you.  
5 As the Chair said, my name is Lawrence Carter-  
6 Long. I'm the Executive Director of the  
7 Disabilities Network of New York City. We're a  
8 non profit, non partisan membership organization  
9 promoting the political and economic power of more  
10 than one million children and adults with  
11 disabilities throughout all five boroughs in New  
12 York City. We have over 60 organizations across  
13 the disability spectrum, and we're the largest  
14 cross disability membership organization across  
15 New York City. I'm happy to provide this  
16 testimony this morning on behalf of the  
17 Disabilities Network, our membership organizations  
18 and our individual members, all of whom share our  
19 goal of self determination and full participation  
20 for people with disabilities in all aspects of New  
21 York City's vibrant, civic, social and economic  
22 life. I'm very pleased today to testify in favor  
23 of Resolution 1783A, which supports the important  
24 goal of providing access to community living and  
25 long term services and supports for people with

1 disabilities and seniors. It's time for the  
2 United States Congress to pass this and President  
3 Obama to sign the Community Choice Act. Let's  
4 make no mistake here. Every New Yorker, in fact,  
5 every American, is a stakeholder in today's topic.  
6 There are currently over 10 million Americans in  
7 need of long term services and supports, and that  
8 number is expected to increase to nearly 15  
9 million by 2020. People with disabilities come  
10 from every age group, every ethnicity, every  
11 economic sector and live in every borough and  
12 every neighborhood in every district. We are male  
13 and female, children and adults with a broad range  
14 of disabilities by they physical, sensory,  
15 cognitive or emotional. People with disabilities  
16 are in no way a static population, either. Any  
17 person at any time can acquire a disability. Look  
18 at Christopher Reeve. The concept of disability  
19 rights begins with a simple to understand but  
20 difficult to actualize premise that disability is  
21 a natural part of the human experience which  
22 should in no way limit a person's right to make  
23 choices and partake in both the benefits and  
24 burdens of living and engaging in society. When  
25

1  
2 people ask me what do disabled people want, my  
3 answer is very simple and direct. Adults with  
4 disabilities want to work. Children with  
5 disabilities want to learn and play with their  
6 peers, and the vast majority of individuals in  
7 need of long term services and supports would  
8 rather receive those supports at home with family  
9 and friends than in an institution. Our current  
10 system of long term care dates back to 1965.  
11 That's two years before I was born, when the  
12 Medicare and Medicaid programs were first created.  
13 Sadly, it hasn't evolved much since. Not  
14 surprisingly, given the origins of these programs,  
15 the system continues to exemplify the historically  
16 low expectations society has had for people with  
17 disabilities. With the expectations for us so  
18 low, the mission of the old system was and remains  
19 to this day focused on simply maintaining people  
20 with disabilities locked away in nursing homes,  
21 institutions, back rooms, outside of view and away  
22 from the mainstream. Everybody's talking these  
23 days about the economy. We can talk about the  
24 ethical reasons. We can talk about the ethical  
25 reasons. We can talk about the moral reasons. I

1  
2 just want to give you some economic reasons to be  
3 in support of the Community Choice Act. Research  
4 released in 2006 from the University of California  
5 San Francisco and University of Maryland estimates  
6 that when compared with Medicaid, institutional  
7 care, home and community based waivers created a  
8 national average savings of \$43,947 per  
9 participant. For example, the national average  
10 per participant expenditure for a nursing facility  
11 waiver was \$15,784, 63% lower than the \$42,292  
12 national average per participant expenditure for a  
13 nursing home facility. I could go on all day long  
14 about the reasons. You all know you're in support  
15 of it. I urge you to pass the resolution. I also  
16 urge you to work with your peers and our elected  
17 officials in Albany to put some teeth behind this.  
18 Let's make sure that the waivers that exist in New  
19 York State are actually utilized. I can count on  
20 one hand the number of people that are utilizing  
21 those waivers. I think we need to see more  
22 attention given to that. I thank you for your  
23 time. I thank you for your energy and your  
24 attention to this important issue.

25 CHAIRPERSON ARROYO: Thank you. I

1  
2 want to acknowledge we've been joined by members  
3 of the Aging Committee, Council Member Ferreras  
4 from Queens sitting in front of me and Council  
5 Member Stewart from Brooklyn, who is back here  
6 somewhere.

7 CHAIRPERSON KOPPELL: Thank you.  
8 I'm going to now ask Phillip Bennett to speak.

9 PHILLIP BENNETT: Hi. My name is  
10 Phillip Bennett. I'm a long time home care worker  
11 or I prefer to say personal assistant who, by the  
12 way, rejects the term home bound as a previous  
13 testifier kept saying. Disabled people shouldn't  
14 be bound to nothing. Mr. Carter-Long mentioned  
15 Christopher Reeve. Imagine if he had spent the  
16 last ten years of his life stuck in a nursing  
17 home. You think of the loss to the arts, to  
18 society, to his family, to his children, if he was  
19 stuck in a nursing home and needed permission that  
20 may or may not be granted just to be able to go  
21 outside. And forget about traveling overseas.  
22 Imagine the loss. I'd also like to say that as a  
23 personal assistant, I've worked for people who  
24 only needed four hours a day compared with if he  
25 was in another state, this guy who I was



1  
2 assisting, he would have to receive 24 hours a  
3 day. Think of the savings. You don't have to do  
4 the math. Just think of the savings. Four hours  
5 of paid service per day versus 24 hours. It's a  
6 no brainer. Also, the Community Choice Act allows  
7 for better trained, union workers, which I think  
8 is indispensable because the training we get right  
9 now here in New York is really rather shoddy, and  
10 I could go on and on about that. Finally, I'd  
11 like to say that I've been trying to deal with my  
12 Congress Member, who has been dragging his tukus  
13 about the Community Choice Act, and he is waiting  
14 for a signal from some--maybe from the lobbyist  
15 from the home care industry to tell him whether or  
16 not to support it this year. It's vital that we  
17 give folks like my Congress Member and the  
18 President, who I worked for and who worked for the  
19 Community Choice Act until something got to him.  
20 I don't know what the explanation is. But we must  
21 support this. We need to give the whole country a  
22 kick in the tukus. We need to save these billions  
23 of dollars, as Mr. Carter-Long mentioned. What  
24 was it, 62%? Think about it. The cost of  
25 administering this--the savings far outstrip any

1

costs, and please, keep fighting. Happy day.

2

3

CHAIRPERSON KOPPELL: Thank you

4

very much for your very good testimony from

5

personal experience. I might say that with

6

respect to Mr. Carter-Long's testimony, in New

7

York State the average cost--at least in New York

8

City, the average cost of nursing home care is

9

over \$100,000 a year, so much higher than the

10

numbers you cited, showing the benefits of people

11

staying at home. Thank you very much. Anybody

12

have a question? No. We have our next panel. We

13

have Rachel Sherrow, Citymeals-on-Wheels. We have

14

Alajandra Espina, and then we have Noor Alam.

15

[PAUSE]

16

CHAIRPERSON KOPPELL: We had

17

Council Member James Gennaro here with us.

18

[PAUSE]

19

CHAIRPERSON KOPPELL: I don't know

20

who is who, but why don't we start with you and

21

you can introduce yourself, please.

22

RACHEL SHERROW: My name is Rachel

23

Sherrow, and I'm the Director of Programs and

24

Community Affairs at Citymeals-on-Wheels, and I

25

want to start by thanking all of you on the city

1  
2 council for your continued support for aging  
3 services, which includes Citymeals, and we'll be  
4 serving two million meals city wide this year.  
5 I'm here today to talk about keeping older people  
6 in their homes where they wish to stay, and I  
7 agree with the previous person's testimony that  
8 homebound is a horrible designated word. However,  
9 that is the word that the Federal Government asks  
10 us to use on our assessment forms, and that's why  
11 it is homebound, although they are not bound to  
12 their homes. As most of you know, Citymeals is a  
13 not for profit working in partnership with the  
14 Department for the Aging. The Department for the  
15 Aging funds community based agencies for meals  
16 that the homebound elderly receive Monday through  
17 Friday. We fund the same agencies for weekend,  
18 holiday and boxes of emergency food. We fill the  
19 115 days a year that the aged population would go  
20 without food if we were not there. Over 40 years  
21 ago, the Federal Government concluded from a study  
22 that there were two factors that would keep people  
23 over 60 in the communities longer--nutrition and  
24 socialization. By feeding this population both  
25 literally and figuratively, the government felt

1 would stem the tide of unfortunate consequences of  
2 this growing demographic. 700 offices of areas on  
3 aging were created in New York City, DFTA being  
4 the largest. Within the continuum of care  
5 concept, if the centers are not serving their  
6 elders effectively, this population would end up  
7 in nursing homes and our Medicaid costs will  
8 continue to skyrocket. Bringing a meal to the  
9 homebound elderly's door is one way to prevent  
10 them from slipping into much more expensive kinds  
11 of care. This is a savings in Medicaid costs that  
12 the city would bear if these neighbors of ours  
13 were living in nursing homes instead. Citymeals  
14 packages three shelf stable meals which are  
15 delivered to the homebound prior to a holiday to  
16 ensure they don't go without food when the centers  
17 are closed. In New York City as in the rest of  
18 the country, the oldest category of elderly is  
19 increasing at a very fast rate. From 1990 to  
20 2000, the number of people 85 and older increased  
21 by 20%, making this group the fastest growing  
22 segment of New York City's elderly population. We  
23 also know that there has been a steady rise of  
24 nearly 2% each year in the number of elderly New  
25

1  
2 Yorkers who need food delivered to their door if  
3 they are to remain in their homes for as long as  
4 possible, which is what we want and what they  
5 want. The city needs to make sure there's  
6 adequate funding to serve all those in need,  
7 including any increase we may start to see because  
8 of the greater need for food due to a lack of  
9 resources. Citymeals is underwriting more than  
10 one in three meals delivered to the city's 17,000  
11 frail elderly homebound. For every dollar we  
12 receive from the city, we bring in more than a  
13 dollar in federal funding. We're therefore a  
14 financially less burdensome service that helps the  
15 city turn an expense into revenue while keeping  
16 our elderly well nourished and at home.

17 CHAIRPERSON ARROYO: Rachel, I just  
18 want to take this opportunity to express my  
19 appreciation on behalf of my colleagues for  
20 Citymeals' work during the disastrous transition  
21 that DFTA went through for the home delivered meal  
22 program. If it had not been for Citymeals, many  
23 of our seniors would have gone without their daily  
24 meal, and you guys stepped up in such a big way.  
25 Thank you.

1  
2 RACHEL SHERROW: I humbly accept  
3 that. I appreciate it.

4 CHAIRPERSON KOPPELL: I also want  
5 to say--most people know this, but the most  
6 outstanding advocate on behalf of senior services  
7 in the recent budget discussions that just ended  
8 is sitting to my left. Our next witness, please?

9 NOOR ALAM: Thank you for having me  
10 here today, and thank you for holding this  
11 hearing. My name is Noor Alam.

12 CHAIRPERSON KOPPELL: Please speak  
13 a little bit more into the mic, please.

14 NOOR ALAM: My name is Noor Alam.  
15 I work as a community organizer of the Center for  
16 Independence of the Disabled in New York. CID-NY  
17 is a leading organization serving the disability  
18 community. We reach about 12,000 people across  
19 all disabilities in New York City. We thank you  
20 for holding this hearing on Resolution 1783A,  
21 which would put New York City on record as being  
22 in support of the federal Community Choice Act.  
23 People with disabilities have been fighting for  
24 many years to get this bill passed. It's at the  
25 heart of the disabilities rights movement. People

1  
2 with disabilities have the right to live in their  
3 own homes rather than being moved into nursing  
4 homes. Over a quarter of a million New Yorkers  
5 are living in their own homes instead of nursing  
6 homes because our state has chosen to cover home  
7 and community based services with Medicaid funds.  
8 Many other states have not been so sensible. Some  
9 have no home care at all, condemning elderly and  
10 disabled people to live long institutionalizations  
11 in what can feel like a prison. The Community  
12 Choice Act would require all states to offer  
13 community based services for people needing the  
14 level of care formerly provided only in nursing  
15 homes. It would also reward states like New York  
16 with additional Medicaid funds for being among the  
17 first to voluntarily offer home care. New York  
18 City has some of the best home and community based  
19 services in the country. Our state offers an  
20 array of Medicaid funded programs, home health  
21 care, personal care, home delivery of additional  
22 services needed by people with development  
23 disabilities, traumatic brain injuries as well as  
24 other disabilities. Some New Yorkers retire to  
25 warmer states with lower taxes and enjoy many

1 years of good health and eventually, they may  
2 develop disabilities and discover that their new  
3 states do not have the same Medicaid benefits that  
4 New York does. They will then learn that the only  
5 way they can avoid spending the rest of their  
6 lives in a nursing home is to return to New York,  
7 where home care will allow them to live in their  
8 own home or in the home of a family member. The  
9 Community Choice Act would eliminate the incentive  
10 for people to move from states with no home care  
11 to states that have home care. That would benefit  
12 New York state and New York City. In 2007, two  
13 out of three New Yorkers receiving Medicaid long  
14 term care services were living in the community,  
15 not in institutions. The average cost of their  
16 care was less than 70% of what it would cost to  
17 keep the same number of people in nursing homes.  
18 As a result, the total spending for community  
19 based care was less than half of the total  
20 Medicaid long term care bill. CID-NY has first  
21 hand experience with the value of community based  
22 care because we operate two Medicaid waiver  
23 programs that help people move out or stay out of  
24 nursing homes. Such programs help thousands of  
25



1  
2 people statewide each year to live independently  
3 in their own homes with the particular combination  
4 of services that each of them needs. Even with  
5 the waiver programs, too many New Yorkers are  
6 still in nursing homes. In 2007, it cost Medicaid  
7 an average of \$82,000 a year for each nursing home  
8 resident, and as we heard, even more in New York  
9 City. As we have all heard through news reports  
10 and through actions taken by the attorney general,  
11 people are not living wonderful lives inside  
12 nursing homes. The state attorney general  
13 documented evidence of abuse which I have quoted  
14 in here. I won't take the time to read it right  
15 now, but of residents who were set aside, pushed  
16 to the floor and abused. I'll close since I see  
17 I'm running out of time, just staying that in New  
18 York, too many people are in nursing homes because  
19 we continue to support the nursing home industry.  
20 Because we pit nursing homes against community  
21 based care, we will have to close nursing home  
22 beds and use those savings to have more community  
23 services. It's a shame to see New York and the  
24 rest of the country still following a system way  
25 back before 1965, a system of alms houses,

1  
2 basically, that evolved to be nursing homes. I  
3 think that the state really should support this  
4 resolution but also as Lawrence said, but more  
5 teeth in the existing programs we have and see  
6 more people out in the community. Thank you very  
7 much for your time.

8 CHAIRPERSON KOPPELL: Thank you  
9 very much. We've been joined by Helen Foster,  
10 also from the Bronx. Our next witness, please.

11 ALEJANDRA ESPINA: My name is  
12 Alejandra Espina. I'm a member of the local and  
13 disability actors community. I will also be  
14 presenting testimony on behalf of Nick Dupree, who  
15 couldn't join us today, so I thank you in advance  
16 for my six minutes.

17 CHAIRPERSON KOPPELL: I don't know  
18 if we do it that way, but go ahead.

19 ALEJANDRA ESPINA: Thank you. Nick  
20 Dupree is my partner, a 27-year-old man who uses a  
21 ventilator at all times to breathe and has for the  
22 last 15 years and a wheelchair to get around when  
23 he's not confined to a bed. He's currently a  
24 patient at the Coler-Goldwater Rehabilitation  
25 Center on Roosevelt Island where he's lived for

1  
2 the last 292 days. After years of publicly  
3 fighting to improve the quality of life for people  
4 like him in his home state of Alabama, he had to  
5 come to terms with the fact that things were only  
6 going to get harder for him there. He took a risk  
7 and made a life altering decision to come to New  
8 York City, where he felt services and support for  
9 people with severe disabilities would be more  
10 available and give him a better chance to live an  
11 independent life in a vibrant community. He  
12 wasn't wrong. New York and New York City  
13 represent opportunities for us disabled folks that  
14 are leaps and bounds over what's possible in  
15 places with more restrictive rules and policies  
16 like Alabama. All the same, here we are, an  
17 active, intelligent young man with much more to  
18 give the world around him and his partner, trapped  
19 in an institution even though he doesn't have to  
20 be there. Together, we've been fighting to get  
21 him home. If we didn't have so many hoops to jump  
22 through, he'd be home already, supported by  
23 community based doctors, nurses and attendant  
24 care. He'd be well on his way to finishing the  
25 college degree he had to put on hold back in

1  
2 Mobile, and an active member of his local  
3 community disability based and otherwise. He  
4 can't wait to get out. I can't wait for him to  
5 get out. I live in this neighborhood. On the  
6 kinds of accessible transit that are available to  
7 me, it takes an average of two hours each way for  
8 me to get to Roosevelt Island, and it will take  
9 longer once they close down the Skytram in July,  
10 but that's for another testimony. As a partner,  
11 my life, too, is on hold. I'm considered one of  
12 the lucky ones, meaning that as a person with a  
13 disability, my personal care needs are relatively  
14 minimal, and with the structures we do have in  
15 place, I can manage with minimal assistance. A  
16 few hours a day, which I'm happy to have. But  
17 people like Nick, who need consistent daily  
18 personal care, are punished for it, the way things  
19 work right now. Nick is much more of a policy  
20 wonk than I am, so his explanation would be more  
21 thorough, but fundamentally, what it means to  
22 support the Community Choice Act and things like  
23 it is to shift money that already exists away from  
24 mandatory institutionalization and into expanding  
25 community services that in many cases also already

1  
2 exist and are waiting to help those who want a  
3 chance to live life like Nick and I are waiting to  
4 do together. I feel pretty important speaking to  
5 you here today, and tomorrow, I'll have a chance  
6 to discuss this issue on the radio show. But I'd  
7 much rather not be an example, a case, a study in  
8 the ramifications of healthcare policy. I just  
9 want to be living day to day with Nick and the  
10 people who are important to us, the good, the bad  
11 and the boring. Isn't that what life's all about?  
12 And now, with your permission, I will present  
13 Nick's testimony. My name is Nick Dupree. I'm  
14 glad for the opportunity to give testimony today.  
15 Unfortunately, I can't be here to give it myself  
16 because I'm stuck in bed in an institution. This  
17 is about who chooses where we live. I moved to  
18 New York City in August of 2008, hoping to escape  
19 my deteriorating situation on the Gulf Coast and  
20 have more choice and options. But because of the  
21 federal law, nursing homes are mandatory, and home  
22 care is an optional waived service. I had no  
23 option but to go into a facility. The Community  
24 Choice Act would create parity so that home care  
25 is also mandatory and then I can choose to live in

1  
2 the community. Medicaid waivers, no matter what  
3 state you're in, are hard to get onto, and you  
4 have to meet many requirements, some of which are  
5 completely at the state's discretion, not yours.  
6 Almost this entire year, my doctor has been ready  
7 to discharge me back to the community but has been  
8 unable to secure home care services from the  
9 Department of Health that would enable my  
10 transition because the Department of Health keeps  
11 adding progressively more absurd requirements.  
12 Where I live should not be their call. That's a  
13 decision to be made privately by the individual  
14 and the physician who knows them best. These are  
15 sensitive personal decisions that should be signed  
16 off on by my doctor only. The DOH should never  
17 decide that you must live in an institution  
18 against your will. But that's exactly what's  
19 happened to me. Everyone but those with  
20 disabilities are allowed to decide where they  
21 live. Monday is the tenth anniversary of the  
22 Supreme Court's Homestead decision, which declared  
23 a right to receive services in the least  
24 restrictive setting under the ADA and barred  
25 unnecessarily institutionalization. Thousands

1

2 still remain confined to institutions because of  
3 legislative inaction. The community choice act  
4 would end the years of overlooking implementing  
5 Homestead and make home care a mandatory service,  
6 too. We would be freed from the waiver trap.  
7 More people could choose where to live and who  
8 takes care of them, and their quality of life  
9 would be much higher. I and those like me could  
10 leave the institutions, pursue educational and  
11 employment opportunities, choose their own bedtime  
12 and stay with loved ones beyond arbitrary visiting  
13 hours. Please support the Community Choice Act.  
14 Thank you.

15

CHAIRPERSON KOPPELL: Thank you  
16 very much for that excellent testimony, and you  
17 only took five minutes. I think it was excellent.  
18 Very evocative and obviously out of personal  
19 experience, and at least it's good to hear that  
20 New York is better than other places in the  
21 country, even though we haven't achieved what we  
22 should achieve. I think Gale Brewer has a  
23 question.

24

COUNCIL MEMBER BREWER: Rachel,  
25 thanks for all your work and say hi to Marsha. My

1

2 question is when you are delivering meals, what is  
3 the sign and how do you deal with it to try to  
4 keep people in homes as opposed to other kinds of  
5 care that we don't want? How do you deal with  
6 that? We spend our whole life in New York and in  
7 the council. We call preservation--it could be  
8 preservation of your home, preservation of your  
9 stabilized apartment, preservation of services.  
10 It's a hard barrier to overcome. How do you try  
11 to keep people in their homes? You might be the  
12 only person in contact.

13

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RACHEL SHERROW: I think--I know  
you're a huge fan of the NORCs, and that is  
something that we'd like to expand. Because of  
the NORCs, you can keep people in their homes  
because there is a social worker. There's  
somebody there who can actually see and talk to  
the person every day and note their deterioration.  
Through NORCs, you can get home care, which would  
be less than the hours that are available, which  
would then put somebody off the Meals on Wheels  
program. There are a lot of options that are out  
there. We just have to get creative. Obviously,  
staying in the home for some older people is not



1  
2 an option. If they become completely demented,  
3 they have Alzheimer's, they forget to feed  
4 themselves, they have no supports, they might be  
5 better off in some sort of home setting, but for  
6 most people, if we give them a little extra care  
7 in addition to the meal, they can be at home. I  
8 think that we need to have a better relationship.  
9 Case management needs to have a better  
10 relationship with their clients. They need to see  
11 them more often. They need to be in touch with  
12 them more often. I know the commissioner is  
13 supportive of all of this. A lot of thinking  
14 outside the box and a lot of work with NORCs and  
15 not necessarily NORCs that are actually funded but  
16 how people have grown into the communities,  
17 especially communities like yours and in the Bronx  
18 where people stay.

19 CHAIRPERSON KOPPELL: Thank you,  
20 all three of you very much, and we're now going to  
21 go to the next panel, which is our final panel.  
22 We have Thomas Small, Julie Maury, Betti  
23 Weimersheimer, Marvin Wasserman and Nadina  
24 LaSpina. Since that's all that remain, I thought  
25 we'd have one final full panel. For those who've

1  
2 come here with some difficulty because of their  
3 disability, we really appreciate your effort to  
4 come and testify, and thank you very much. It's a  
5 wonderful testimony to your interest and  
6 commitment not only to yourself but to the entire  
7 disabled community. You want to start in the  
8 order that I called? Thomas Small first.

9 THOMAS SMALL: Council Member  
10 Koppell and Chairwoman Arroyo, thank you for the  
11 opportunity testify today. My name is Thomas  
12 Small. I'm at attorney, and I work on a  
13 contractual basis for the New York State  
14 Independent Living Council. I'm also on the board  
15 of directors of the Disability Network of New York  
16 City, Independence Care Systems, which is a  
17 Medicaid managed care, long term care  
18 organization. I am very pleased to ask for your  
19 support of the Resolution of 1783A. The Community  
20 Choice Act is critical in integrating people with  
21 disabilities throughout society on a national  
22 basis. As you've heard testimony today already,  
23 New York state and New York City do a fairly  
24 decent job of getting the services that people  
25 with disabilities need. But nationally, the

1  
2 services are absolutely awful. If I lived in any  
3 other state, there is a high degree of probability  
4 that I would be stuck in a nursing home and being  
5 forced to make the incredibly courageous decision  
6 that Mr. Nick Dupree made of picking up, leaving  
7 his family and moving here to New York in an  
8 effort to do things that most of us take for  
9 granted. Also, I would like to say that it is  
10 amazing that this young man gave a really cogent  
11 discussion of the legal issues at stake here in  
12 terms of implementing the Supreme Court Decision,  
13 Homestead, which is the case that says that people  
14 with disabilities have a right to live in the  
15 community, decided ten years ago. I had the  
16 privilege of actually being at those arguments and  
17 heard this argument at the Supreme Court. I  
18 participated in an all night vigil and then in a  
19 sleepless state actually went in to hear the  
20 arguments. In hearing this young guy with less  
21 than a college degree make the arguments about the  
22 importance of the Homestead decision and only once  
23 before Mr. Nick Dupree testified did we hear the  
24 word Homestead mentioned at all. It's really  
25 remarkable that the city government and other

1  
2 national figures haven't figured out that this is  
3 the law of the land. Council Member Koppell, as  
4 an attorney yourself, you would appreciate that  
5 there should be a parallel between Brown v. Board  
6 of Education and the Homestead decision. And yet,  
7 we are forced to have people pick up and leave  
8 their families and travel all the way across the  
9 country just to receive services that they should  
10 be getting in their own state. This is personal  
11 to me. If I was stuck in any other state, I would  
12 be stuck in a nursing home, and thankfully, I grew  
13 up here in New York State and I had the  
14 opportunity to go to law school, to be a taxpayer,  
15 and I would encourage you absolutely to support  
16 Resolution 1783A. Thank you.

17 CHAIRPERSON KOPPELL: You're a  
18 wonderful example of why the bill is important and  
19 how people with disabilities can lead very  
20 productive lives. It's a very important example,  
21 and we appreciate you coming and participating.  
22 I've had colleagues in the law who also have a  
23 series of different disabilities, and it's  
24 wonderful to see them overcome them, but it's also  
25 a lesson for everybody that they can be overcome.

1  
2 THOMAS SMALL: Well, the great  
3 thing about being a lawyer is it's indoors and  
4 there's no heavy lifting.

5 CHAIRPERSON KOPPELL: Thank you  
6 again. Nadina LaSpina?

7 [PAUSE]

8 NADINA LASPINA: I'm Nadina  
9 LaSpina. I thank the members of these committees,  
10 and I think Council Member Nelson for introducing  
11 this resolution. I'm an activist and organizer  
12 with the grassroots disability rights group ADAPT.  
13 ADAPT has been fighting since 1990 to free our  
14 people who are imprisoned in nursing homes and  
15 other institutions. Yes, I said imprisoned.  
16 Virtual prisoners of an antiquated system that  
17 uses them as cash crop to draw down dollars for  
18 others to enjoy. Even the best nursing homes are  
19 prisons. Your freedom is taken away when you  
20 check in. You are told when to get up, when to go  
21 to bed, when you can have a shower, when you can  
22 go to the bathroom. That's when they allow you to  
23 go to the bathroom. Most nursing homes, even if  
24 you have full control of your bladder will put you  
25 in diapers for the staff's convenience. Many of

1  
2 my ADAPT fellow activists served time in  
3 institutions and now live in freedom in the  
4 community thanks to ADAPT's work. I know several  
5 people, some of them dear friends, who died in  
6 nursing homes of infections, of bed sores, of  
7 neglect. I know several freed people who say  
8 they'd rather die than go back to a nursing home.  
9 As the New York City ADAPT contact person, I get  
10 calls all the time, sometimes in the middle of the  
11 night, from people crying on the phone--get me out  
12 of this hell hole. All of us with disabilities  
13 live in fear of ending up in a nursing home. All  
14 of you here should because it can happen to anyone  
15 of any age. My aging parents made me promise I  
16 would never put them in a nursing home. I kept my  
17 promise. I've made that same promise to my life  
18 partner, who's quadriplegic due to MS and  
19 ventilator dependent, and I will keep that promise  
20 if it kills me. ADAPT has made considerable  
21 progress through the years in the struggle to free  
22 our people. We've had victories such as the  
23 passage of money follows the person and of course  
24 the Homestead decision that others have talked  
25 about. Throughout the country, the Homestead

1  
2 decision has been used often in court, many times  
3 by our own TK Small to free people from  
4 institutions. But that is not enough. We need to  
5 put an end to the bias that's in the Medicaid  
6 system. We need to put an end to it once and for  
7 all. As thing are now, states are mandated by the  
8 Federal Government to provide services and  
9 institutions. However, providing home based and  
10 community based services is optional for the  
11 states. Therefore, we have good states, like New  
12 York. You heard New York is a good state, and bad  
13 states like Alabama, where Nick came from. But  
14 even in good states like New York, people get  
15 stuck in nursing homes just like Nick is stuck  
16 right now, fighting to get out. The Community  
17 Choice Act would end the bias and fundamentally  
18 change our long term care system. It would  
19 establish a national program of community based  
20 attendant services and supports for people  
21 regardless of age or disability. This is not the  
22 first time this bill is in Congress. It was  
23 introduced back in 1996 with the title Medicaid  
24 Community Based Attendant Services Act. It was  
25 introduced in every Congress through the years.

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2 The name changed to MICASSA with two s's,  
3 attendant services and supports. The same bill  
4 then was introduced in 2007 as the Community  
5 Choice Act. The name was changed to make it clear  
6 that all we want is choice. That if anyone really  
7 prefers to be in a nursing home, they can have the  
8 choice to be in a nursing home, though I have yet  
9 to meet anyone who would prefer to be in a nursing  
10 home. When Obama was elected and he talked  
11 passionately about healthcare reform, we really  
12 thought this bill was going to get passed, but we  
13 went to Albany in April, and 200 of us were  
14 arrested after Nancy - - told us that long term  
15 care was off the table and CCA would not be  
16 passed. We are still fighting, and we will  
17 continue to fight, but we need all the help we can  
18 get. We urge this city council to please pass  
19 this resolution. Thank you very much.

20 CHAIRPERSON KOPPELL: Thank you for  
21 coming today. Marvin Wasserman?

22 MARVIN WASSERMAN: Good morning.  
23 I'm Marvin Wasserman. I'm Executive Director of  
24 the Brooklyn Center for Independence of the  
25 Disabled. We are a voice of the more than 600,000



1  
2 people who according to the 2000 census have one  
3 or more disabilities who live in Brooklyn. I'd  
4 like to thank our own Council Member Ron Nelson  
5 for bringing this to the attention of all of you,  
6 and I'd like to correct a previous testimony. We  
7 have virtually all our Brooklyn Congressmen on the  
8 bill, including Congressman Weiner, Congresswoman  
9 Clark, Congresswoman Velazquez and I was told that  
10 we were informed by Congress Member Towns' office  
11 yesterday that he is signed on. This issue is a  
12 matter of institutional bias, of imprisonment of  
13 people in nursing homes. In Nick Dupree's case,  
14 he's oftentimes not allowed to get out of his bed  
15 for many days at a time because the staff doesn't  
16 want to take the bother to get him out of bed. He  
17 is not allowed to eat with other patients in the  
18 communal dining areas. He's not allowed to leave  
19 Coler Hospital, and this is not unusual even for  
20 someone less disabled. We have a volunteer from  
21 BCID who is currently in the Bishop Mugavero  
22 Nursing Home in Brooklyn who is not allowed to  
23 leave the nursing home without a pass and without  
24 an escort. She's only there for rehabilitation  
25 purposes and nevertheless, she is incarcerated.

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2 The Community Choice Act will enable personal care  
3 services throughout the country, including states  
4 that don't have it currently now that Nick would  
5 not have to come to New York and conversely,  
6 people in New York who want to live elsewhere who  
7 cannot survive without personal services don't  
8 currently have the option. I encourage the  
9 council to go beyond this bill and do things in  
10 New York City that will enhance community choices.  
11 Number one, as Commissioner Sapolin noted, Section  
12 8 vouchers, nursing home diversion housing  
13 vouchers are not considered part of income in the  
14 set asides in HPB housing. People with  
15 disabilities are not oftentimes getting the  
16 housing that's set aside. In part because they  
17 don't meet the minimum income requirement. If  
18 these vouchers are considered part of their  
19 income, then they will qualify for this housing.  
20 The second thing is to expand the consumer  
21 directed personal care services in New York City.  
22 Less than 2,000 receive them now. In Los Angeles  
23 County, more than 100,000, so people who are  
24 capable of supervising their personal care  
25 services are able to do so. Thank you.

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CHAIRPERSON KOPPELL: Thank you.

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Good suggestions, and thank you for coming. Julie Maury.

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[PAUSE]

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JULIE MAURY: May I present two testimonies today, one from Melina Cowan, who's not able to be here today, and one from myself? They're both quite short.

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CHAIRPERSON KOPPELL: Yes, of

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course. Go ahead.

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JULIE MAURY: Okay. I'm going to

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start with Melina Cowan's testimony. 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 with 25 hours per week of personal attendant care. Twenty-five 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 care attendant for 15 years. However, the last couple of years, his health has deteriorated rapidly, so he could not help me with my personal needs such

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2 as bathing, dressing, etcetera. The only options  
3 I had was either to end up in a nursing home or to  
4 move to a state that provides the hours of  
5 personal attendant care I need. About two years  
6 ago, we moved to New York City in order for me to  
7 be able to live at home. The quality of the help  
8 at home cannot be compared to the help offering in  
9 a nursing home, and for this reason, despite all  
10 of my serious disability, my health is very good.  
11 I take no medicine or do I need any medical care.  
12 Yet in a nursing home, not only my health but also  
13 my very life would be in danger. I do not  
14 understand why people are segregated in nursing  
15 homes when they can have the help they need at  
16 home. Thank you for listening to my testimony.

17 CHAIRPERSON KOPPELL: Thank you.  
18 You're going to read someone else's statement,  
19 too?

20 JULIE MAURY: This is my statement  
21 now. It's short. My name is Julie Maury. In  
22 2006, I had a boyfriend named Michael of six years  
23 who died of a bedsore that caused sepsis, which  
24 then caused organ failure and pneumonia. He was  
25 in a nursing home. It was preventable. He did

1  
2 not have to die. He was a reasonably young man,  
3 and he had a long life left to live. But it is  
4 very hard to prove nursing home neglect when one  
5 already suffers from paralysis and other chronic  
6 health issues, as Michael did. He was  
7 hospitalized for health issues, and while there,  
8 the staff, like bad car salesmen, convinced him to  
9 go into a nursing home. They sold him the idea of  
10 living in a nursing home like it was going to be  
11 heaven. However, the nursing home was a nightmare  
12 from hell. While in the nursing home, everyone--  
13 he would say why is everyone telling me it's okay  
14 to let go? I love life. I love the trees. I  
15 love the birds. I know that if passed, the  
16 Community Choice Act will help Americans choose  
17 where they want to live. Choice is an unalienable  
18 human right. Most animals hate cages and crave  
19 freedom. Humans don't want to be in a cage,  
20 either. Passing the Community Choice Act would be  
21 like opening the door of a gigantic cage and  
22 giving freedom to many people to live their lives.  
23 People in nursing homes want to be out working,  
24 shopping, having families, just living normal,  
25 healthy lives. Letting them be free would help

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2 the economy. The paradigm must be shifted.  
3 People with disabilities and the elderly more than  
4 deserve to live in the community with whatever  
5 services would help them do so. Thank you.

6 CHAIRPERSON KOPPELL: Thank you  
7 very much. That was very moving testimony and  
8 very important, and I want to thank everybody.  
9 We're not going to take a vote today, but we don't  
10 need to have you come back. I'm sure that the  
11 members will support this, and there will be a  
12 vote taken shortly, and then once the committee  
13 votes, the matter will come before the council. I  
14 think it's been a very important testimony today  
15 and has certainly impelled me to do more to lobby  
16 with the Congress. Since we have no further  
17 witnesses--there is? I didn't see you. I'm  
18 sorry. Please go ahead.

19 BETTI WEIMERSHEIMER: Good morning.  
20 I'm Betti Weimersheimer, the Executive Director of  
21 FRIA, which is a not for profit organization over  
22 30 years old that advocates on behalf of seniors  
23 in long term care. Thank you for allowing us to  
24 present testimony this morning. We strongly  
25 support resolution number 1783A, calling upon the

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2 US Congress and the President to sign the  
3 Community Choice Act which would allow seniors and  
4 persons with disabilities increased access to  
5 community based services, thus avoiding nursing  
6 home placement. As seasoned advocates on long  
7 term care issues affecting older Americans, we  
8 hear a consistent theme from caregivers and senior  
9 citizens. Older Americans would prefer to age in  
10 place rather than enter a nursing home, but  
11 remaining in the community is often not affordable  
12 or sustainable without adequate assistance. The  
13 Community Choice Act would greatly facilitate  
14 keeping older adults in their communities.

15 Medicaid funding for long term care services  
16 currently reflects an institutional bias, with 63%  
17 of Medicaid dollars being spent on nursing homes  
18 and other institutional services and only 37%  
19 going toward community services such as home  
20 healthcare, personal care or waiver programs. The  
21 CCA would allow individuals eligible for skilled  
22 nursing facilities to choose the alternative of  
23 community based attendant services, which would  
24 provide Medicaid dollars for health related  
25 services and assistance with activities of daily

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2 living to a person in their own home or a  
3 supportive housing environment. Since FRIA's  
4 inception, we have advocated for the right of the  
5 frail elderly to access care in the least  
6 restrictive environment possible. Older Americans  
7 utilizing long term care services need equitable  
8 funding opportunities with no programmatic or rule  
9 disincentives to community services in order for  
10 them to be supported in the most appropriate  
11 environment for care. FRIA respectfully urges you  
12 to support this resolution calling for the passage  
13 of the Community Choice Act which would improve  
14 the quality of life for all older Americans and  
15 persons with disabilities by giving them the  
16 resources they need to remain in their  
17 communities. Thank you.

18 CHAIRPERSON KOPPELL: Thank you.  
19 Please.

20 CHAIRPERSON ARROYO: I just want to  
21 say thank you to FRIA for the work that you do. I  
22 happen to be one of the members in this council  
23 that support the work that you do through a member  
24 item and encourage all of my colleagues to do the  
25 same.



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CHAIRPERSON KOPPELL: There being

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no further witnesses, the hearing is adjourned.

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Thank you all very much.

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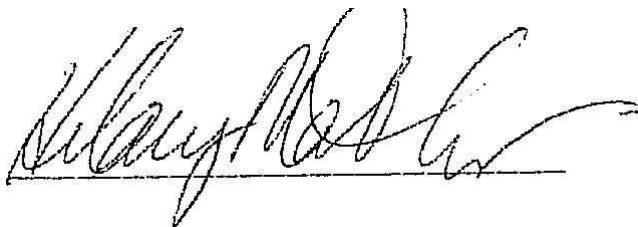
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C E R T I F I C A T E

I, Hilary Mathis, certify that the foregoing transcript is a true and accurate record of the proceedings. I further certify that I am not related to any of the parties to this action by blood or marriage, and that I am in no way interested in the outcome of this matter.

A handwritten signature in cursive script, appearing to read "Hilary Mathis", written over a horizontal line.

Signature

Date July 23, 2009