HOME SWEET HOME: STILL AN ELUSIVE RIGHT A DECADE LATER

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Since 1996, University Legal Services, Inc. (ULS), a private, non-profit organization, has been the federally-mandated protection and advocacy (P&A) program for individuals with disabilities in the District of Columbia. Congress vested the P&As with the authority to investigate allegations of abuse and neglect of individuals with disabilities. Accordingly, ULS advocates and represents DC residents with disabilities to promote their civil and human rights including their right under the Americans with Disabilities Act (ADA) of 1990 to live in the most integrated settings appropriate to their needs.

HOME SWEET HOME: STILL AN ELUSIVE RIGHT A DECADE LATER

I. Introduction

June 22, 2009 marks the tenth anniversary of the Supreme Court's decision in Olmstead v.

L.C. that restated the obligation of state and local governments to provide services to people with disabilities in the most integrated settings appropriate to their needs. 527 U.S. 581 (1999). That reaffirmation in Olmstead relied on the "integration mandate" of Title II of the Americans with Disabilities (ADA) of 1990. But integration is still beyond reach for hundreds of individuals with disabilities who seek to transition to the community with the services and supports they need.

The District's failure to provide information on community services or assist nursing home residents in accessing community-based alternatives to honor their choice constitutes state-sanctioned discrimination.³ Despite the Supreme Court's ruling, bolstered by a decade of federal guidance and financial incentives, the District of Columbia continues to subject hundreds of people with disabilities of all ages to unjustified segregation in nursing facilities against their will and at far greater cost to DC taxpayers. This report summarizes the status of people with disabilities in the District in light of the District's ongoing over-reliance on nursing facilities, rather than home and community-based services preferred by people with disabilities.

Over the past ten years, participation has increased sharply in the District's Medicaid home and community-based services for people who are elderly and those with physical disabilities who

¹ The <u>Olmstead</u> case was brought by two women who were held in a psychiatric hospital for decades despite their treating physicians' determination that they could live in the community with services and supports.

² The ADA provides that "no qualified individuals with a disability shall, "by reason of such disability," be excluded from participation in, or be denied the benefits of, a public entity's services, programs or activities." 42 U.S.C. §12132. The integration regulation mandates state and local governments to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR §35.130(d); Olmstead, 527 U.S. at 592. 'Integrated setting' is defined as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 CFR pt 35, App. A, p.450 (1998); Olmstead, 527 U.S. at 592.

³ Federal Medicaid law provides that states and the District of Columbia which have Medicaid home and community based services and programs must inform individuals of feasible alternatives to the provision of services in hospitals, nursing facilities, or intermediate care facilities. 42 USC 1396n(c)(2)(C).

overwhelmingly choose to "age in place" rather than in nursing facilities. But the District's long-term care system is still driven by institutional bias that presumes eligibility for, and reflexively places, people with disabilities in nursing facilities. This institutional bias is reflected in the District's policy of generating income for empty nursing home beds through "bed taxes," soliciting a lessee to take over the exclusive-use operation of a nursing facility, and failing to offer the full range of community-based services and integrated, accessible housing for some of the most vulnerable residents with disabilities of the District such as those with dementia and those with traumatic brain injuries.

II. DC's Over-Reliance on Nursing Facilities

There are approximately 2,700 beds in nursing facilities located in the District of Columbia,⁵ 489 of which are in two facilities owned by the District of Columbia.⁶ Nursing facilities in the District maintain an average occupancy rate of 94%, despite the District's dubious distinction as first in the nation with 44% of its nursing facilities cited for deficiencies for actual harm or jeopardy of residents in 2007.⁷

As of April 30, 2009, there were 2,021 individuals in nursing facilities located in the District of Columbia.⁸ An additional 176 DC residents were in out-of-state nursing facilities,⁹ for a total of 2,197 DC residents institutionalized in nursing facilities, three-quarters of whom are DC

⁴ "Bed taxes" refer to revenue gained by the District through "taxes" levied against nursing facilities for empty beds. Reductions in the number of nursing home beds would thereby reduce the District's revenue. "Bed taxes" serve as a disincentive to the District's closure of unoccupied beds in nursing homes. The current DC provider bed tax rate is 5.5% per licensed bed. DHCF Transmittal No. 09-11 dated 5/1/09, available at: http://newsroom.dc.gov/show.aspx/agency/dhcf/section/43/release/17009/year/2009.

⁵See http://hrla.doh.dc.gov (listing the beds at each DC nursing facility). Some of the facilities listed do not consistently accept DC Medicaid patients. See also AARP, "Across the States Profiles of Long-term Care and Independent Living" at p.88 (2009)(noting a total of 2,982 nursing home beds in DC in 2007).

⁶ See http://hrla.doh.dc.gov (listing JB Johnson and Washington Center on Aging with combined bed capacity of 489 beds).

⁷ AARP "Across the States Profiles of Long-term Care and Independent Living" (2009) at p.88.

⁸ Email from Dept of Health Care Finance to M. Rifkin dated 6/15/009.

⁹ Email from Dept of Health Care Finance to M. Rifkin dated 6/15/009.

Medicaid beneficiaries. The average annual cost for each person in a nursing home on DC Medicaid is \$138,000¹⁰ for an average of four hours of daily care. As with all Medicaid services, the District pays 30% of the cost of nursing facilities; 70% is paid by the Federal government under the Medicaid Program.

Daily life in nursing facilities is dictated by an institutional regime. Residents are told when and what to eat, what time to wake up and go to sleep, on what conditions they may come and go for personal business and social interaction. In addition, depending on their care needs, many individuals are at the mercy of staff to assist them with bathing, dressing, toileting and transferring out of bed. Individuals' health often deteriorates as they languish in these facilities, where they develop decubitis ulcers (pressure sores) that frequently go untreated, incontinence, and loss of mobility, among other conditions.

Among the people with disabilities exiled in nursing facilities seeking to move back to the community are Mr. J. and Ms. T. Mr. J. is a 36-year-old man who was admitted to a DC nursing facility after a foot injury spread to his bone, requiring amputation of his foot and part of his leg. After a month-long hospital stay, Mr. J. was sent to a nursing home, ostensibly for rehabilitation. He lost his job and his housing in the community. Now, two and a half years later, he uses a wheelchair and remains in the nursing facility awaiting an opportunity to rent accessible subsidized housing. In the absence of assistance from his nursing home staff, ULS has assisted Mr. J. in completing and submitting housing applications to a number of accessible developments.

Ms. T., a 47-year-old woman with multiple sclerosis (MS), used to own a small gift shop and a home in the District until early 2008 when her MS progressed. She gave up her business and her home was foreclosed. After living with friends for over a year, Ms. T. was hospitalized and

¹⁰ HCFA 372 Report submitted by DC Medicaid to CMS for 2006.

¹¹ AARP, "Across the State Profiles of Long-term Care and Independent Living" at p. 88.

subsequently admitted to a DC nursing facility in April 2009 where she "compensates for the indignities with her personality." Now a wheelchair rider, Ms. T. is seeking to rent an accessible subsidized apartment in the community with her Social Security Disability Income, and secure the services she needs through the Medicaid EPD Waiver Program.

The overall number of nursing home beds in the District declined in August 2007 with the closure of Beverly Nursing Facility, a 250-bed nursing home. Rather than take active steps to expand community-based services to serve people with disabilities such as those with varying degrees of dementia and traumatic brain injuries, among others, the District issued an "emergency" directive to facilitate their placement in out-of-state nursing facilities without the need for prior authorization. These out-of-state placements make it much more difficult for individuals with disabilities seeking to maintain their ties to the community necessary to transition back to the community in the District. Moreover, in out-of-state nursing homes, their DC Medicaid is typically terminated and they are reassigned to Medicaid in the state where the nursing facilities are located. This further undermines their fundamental choice of residence, violates Federal Medicaid law, and makes their return to the District all the more difficult.

III. Home and Community-based Alternatives to Nursing Facilities

As of March 2009, 505 individuals in DC nursing facilities such as Mr. J. and Ms. T. expressed their preference to transition back to the community with the services and supports they need.¹³ Their community preference is disregarded by the District and its nursing facilities.

¹² That Emergency 2007 directive expired at the end of 2007. Now, DHCF prior authorizes out-of-state nursing home placements. 29 DCMR 905.4.

¹³ See Minimum Data Set (MDS) Active Resident Information Report at http://www1.cms.hhs.gov/apps/mds.reports. MDS

data reflect nursing home residents' responses to questionnaires administered by nursing facilities that are reported to CMS. MDS data most likely undercounts the number of individuals seeking to return to the community. Compare AARP data (stating that 89% of people 50 years and older intend to remain in their own homes rather than go to nursing homes) available at: http://www.aarpmagazine.org/lifestyle/revolution_in_design.html?

People with disabilities in the District of Columbia may access home and community-based services in three ways: under the Medicaid State Plan, the Medicaid Home and Community-based 1915 (c) Waiver or, on a more limited basis, under the Medicare Program, depending on their level of service needs and their financial status.

A. The Personal Care Services Option under the Medicaid State Plan

The District offers up to 1,040 hours per year of personal care aide services plus additional hours based on physicians' orders and prior authorization by Medicaid. Medicaid beneficiaries may access these services by unskilled aides up to 8 hours daily to assist them with their daily activities such as bathing, dressing, toileting, transferring from wheelchairs, and eating. The number of individuals using these services has increased substantially due to outreach by disability rights advocates from ULS, DIRECT Action, and Capital Area ADAPT to individuals and staff in nursing homes and hospitals to debunk the myth that such services do not exist. Known as the "PC Option," these services are available to all DC Medicaid beneficiaries whose doctors order the service to assist them. People who need more than the eight hour daily limit, or those not on Medicaid, cannot benefit from this PC Option.

B. Medicaid 1915 (c) Waiver Services for People Who are Elderly and People with Physical Disabilities (EPD Waiver)

Following three years of advocacy efforts by ULS and Capital Area ADAPT, DC Medicaid expanded its Elderly Waiver Program to all adults who are elderly and people with physical disabilities aged 18 and older; it is now known as the EPD Waiver Program. EPD Waiver services are available to people whose income does not exceed 300% of Supplemental Security Income, ¹⁴ and who require a 'nursing home level of care,' <u>i.e.</u>, need assistance with at least two activities of

 $^{^{14}}$ SSI is currently \$674 monthly in DC x 300% = \$2022 per month.

daily living (ADLs) or at least three instrumental activities of daily living (IADLs) such as chores, laundry, and food shopping. The EPD Waiver Program offers up to 16 hours of daily aide services.

Under the Medicaid State Plan, people with disabilities are also entitled to nursing visits for skilled services such as wound care and tracheotomy aftercare. However, the home health agencies often fail to distinguish the Medicaid standard from the more restrictive Medicare standard governing nursing care visits.

As of April 30, 2009, there were 1,986 individuals participating in the EPD Waiver Program, an increase of over 50% of the reported participation rates in 2006. There is no waiting list for waiver services in the District.

The average annual cost of providing one on one, direct services to each individual in the community under the EPD Waiver Program is \$46,580 – nearly 300% less than the average annual cost of care in a nursing facility.¹⁵

C. <u>Medicare Home Health Services</u>

The Federal Medicare Program offers home health services to people who are aged 65 and older, 'homebound' and need 'intermittent' care along with skilled care such as nursing visits, or physical therapy visits. Despite the fact that the Medicare Program offers home health aide services, many of the home health agencies in the District apply unwritten service caps to restrict access to these crucial services, leaving many District seniors without the appropriate level of care at home. This forces many individuals into nursing homes against their will. The District and CMS must hold these agencies accountable for providing the full panoply of home health services to which people with disabilities are entitled.

¹⁵ HCFA 372 Report submitted to CMS for 2006.

D. The District's Spending on Home and Community-based Services

In June 1999 when the Supreme Court issued its <u>Olmstead</u> decision, only 6.4% of the District's long-term care Medicaid budget was spent on home and community-based services as compared to 93.6% on nursing home care. In FY 2007, the District spent 33% of its long-term care budget on home and community-based Medicaid services for people with disabilities as compared with 67% on institutional services. However, this is below the national average of 42% of states' Medicaid long-term care budgets spent on home and community-based services, and continues to reflect the District's institutional bias toward nursing facilities despite their exorbitant costs.

IV. The District's Reverse Olmstead Actions

A. Two Steps Back: From St. Elizabeths Hospital to Nursing Homes

Throughout the past ten years, the District has employed a reverse <u>Olmstead</u> approach by transferring scores of individuals with psychiatric disabilities and those with intellectual disabilities from St. Elizabeths Hospital, the District-owned and managed psychiatric hospital, to a nursing home owned by the District, among other, more restrictive, institutions. The District has made little effort to provide community-based alternatives to residents at St. Elizabeths who, like the plaintiffs in <u>Olmstead</u>, deserve the right to transition to the community with the services and supports they need. This is all the more important now as the District struggles to reduce the population at St. Elizabeths Hospital in anticipation of moving into a smaller facility in 2010.

¹⁶ "Distribution of Medicaid Long-term Care Expenditures" based on CMS-64 data submitted by DC government, available at http://www.ancor.org/issues/Data-Statistics/Data-Statistics.html.

Burwell, et al., "Medicaid Long-term Care Expenditures in FY 2007 (Sept. 2008) at 1. Available at: http://www.ancor.org/issues/Data-Statistics/Data-Statistics.html.

Simply moving individuals who would prefer community services from the hospital to nursing facilities violates their rights under the ADA as pronounced by the Supreme Court in Olmstead.

The District's Draft Olmstead Plan issued in April 2009 failed to even mention St.

Elizabeths Hospital residents, let alone prioritize their re-integration to the community. Many individuals at St. Elizabeths desperately want to leave, have the right to leave (i.e. who are not committed or being held for competency examinations in criminal matters), and want to live independently with the services and supports they need. A substantial number of these individuals who are considered 'ready for discharge' cannot leave because the District will not provide the quality services to them in the community. ULS staff has worked intensively over the past four years to assist people with intellectual disabilities and psychiatric disabilities to transition from St. Elizabeths Hospital to the community, but DDS consistently erects barriers to their transition.

The average cost of housing one individual at St. Elizabeths is astronomical at \$280,000 per year, as compared to what it costs to house an individual in the community; these resources could be much better spent on community-based services. In addition to the violations of Olmstead and Title II of the ADA, further delay in their discharge and community reintegration subjects them to ongoing unnecessary institutionalization and deterioration of their mental health conditions. The District must also assist people to transition out of "micro institutions" such as Community Residential Facilities (CRFs) and group homes on which the District relies heavily for housing individuals with mental illness.

B. Restrictions on the District's Money Follows the Person Program

In 2007, DC Medicaid received a \$26.4 million, five-year federal Money Follows the Person grant from the Center for Medicaid and Medicare Services to fund 85% of the cost of community-based services and supports to facilitate the transition from institutions such as nursing homes of over 1,000

people with a range disabilities (e.g., people with physical disabilities, mental illness and/or intellectual disabilities). ULS, together with other DC-based disability, advocacy and legal services agencies, wrote the proposal to CMS that resulted in the grant award. The District undermined the cross disability nature of this program by restricting its focus to people with intellectual disabilities in intermediate care facilities. In addition, the DC Department of Health Care Finance recently eliminated the MFP staffing.

The District apparently has no plans to fully implement the MFP Program for people with all disabilities as was originally proposed and approved by CMS. MFP now excludes many people who want to transition from institutions, and forecloses the District's access to the enhanced 85% federal matching funds.

Although the District's Draft Olmstead Plan reported that the Department on Disability Services (DDS) transitioned 136 individuals with intellectual disabilities from intermediate care facilities (ICFs) in the past year, as of April 2009, only 23 people had been transitioned under the MFP Program since implementation began last year. Even these few reported community transitions are suspect because DDS appears to have simply relabeled many of the institutional ICFs as "waiver homes." The District has not shared any data about how many individuals under the MFP Program were transitioned to their own apartments, as distinct from "waiver homes" that were previously their intermediate care facilities. Neither CMS nor the disability community will tolerate this sort of sleight of hand.

C. <u>Lack of Consumer-directed Services</u>

Consumer- or participant-directed service programs enable people with disabilities to select as personal care aides individuals they know – family members, friends or acquaintances -- and to train them and manage the services they provide without resorting to home health agencies. The care givers are typically paid and administrative time records processed by a third party fiscal

intermediary. Such programs are common in many states as a way of offsetting personal attendant workforce issues, and enabling consumers to fully direct their care.

Although the District's 2002 EPD Waiver Program included these services which were approved by CMS, the District has never implemented consumer direction despite years of advocacy by disability rights and consumer advocates. After years of consultation with other states, costly consultants, there is still no such program in the District, even on a pilot basis.

Notably, DHCF recently announced its intention to remove these services entirely from the EPD Waiver. People with disabilities who demand to hire, train and manage their own personal care aides must do so under the auspices of home health agencies which, in turn, employ the aides and assign them accordingly at much greater expense to the District.

D. Failure to Reform the System to Eliminate Institutional Bias

The District has failed to implement a mechanism for realigning funding from institutional care to home and community based care. On the contrary, the District has reversed course on long-term care systemic reform.

For example, the DC Office on Aging (DCOA) recently issued a Request for Offers to find a firm to lease and operate a 259-bed nursing facility on the site currently used by the Washington Center on Aging. The RFO cites the 'exclusive' use of the property as a nursing facility. It was issued without any community discussion or consideration of the site use for more integrated settings, even though the American Association of Retired People (AARP) opened a community residential facility (CRF) on the site of the facility last year. This is a reflection of the District's blatant lack of commitment to compliance with the Olmstead decision.

¹⁸ Nevertheless, the Olmstead Plan cited self-directed services as a goal, overlooking the seven years of implementation planning, and the recent announcement by DHCF.

As people move back to the community, the District must begin to close beds in nursing facilities, intermediate care facilities and psychiatric hospitals. The District must reduce or eliminate the "bed tax" that fosters the illegal segregation of people with disabilities, and redirect to community services the cost savings that the District can realize through restructuring its long-term care system.

V. The District's Inertia

The District's April 2009 Draft 'Olmstead' Plan is by no means an "effectively working plan" to actually move people who choose to transition from institutions to the community.

The Plan failed to prioritize institutionalized populations seeking to transition to the community. It *excluded* the very populations the <u>Olmstead</u> decision and Title II of the ADA were designed to address, <u>i.e.</u>, people with disabilities in institutions – psychiatric hospitals, nursing homes, intermediate care facilities and residential treatment facilities – who want to move back to the community with the services and supports they need.

A. Failure to Conduct Outreach in Nursing Facilities

Neither the Aging and Disability Resource Center (ADRC) nor the Department of Health Care Finance, nor the DC Center for Independent Living outreaches directly to residents of nursing homes or other institutions. Inasmuch as ADRC is a "single point of entry" and "a major piece" of the Olmstead Plan, this is problematic. To make matters worse, DMH typically removes from its rolls individuals who are in nursing homes or in jail. To fill this void, ULS and disability advocates conduct regular trainings for nursing home residents that include presentation of a video featuring DC consumers who explain what the 'next steps' are in transitioning, <u>i.e.</u>, how to apply for housing and community-based services.

Arising from this outreach and from ULS' role as class counsel in Young v. DC Housing

Authority, 19 ULS staff has directly assisted over 60 people with disabilities to transition from

nursing homes back to the community in the past nine years. This transition work includes serving

as liaison between individuals with disabilities and housing providers in the first instance. Once

housing is secured, ULS staff work alongside individuals to ensure that nursing home staff and

home health agencies arrange for their services, medications, physician appointments and orders,

and medical equipment prior to their discharge.

It is worth noting that the DC-owned nursing homes, Washington Center on Aging and JB Johnson, apparently pose the most significant barriers to community transition for residents by, for example, not allowing residents to leave their facilities to seek housing and other preliminary steps such as obtaining their IDs and other documents. The District must address the practices of these nursing homes in order to resolve rights violations by directing staff to honor choices of individuals who seek to pursue more independent living opportunities.

B. Failure to provide services for people with traumatic brain injuries

The District must develop and implement services for people who sustain traumatic brain injuries (TBI), many of whom are not currently served by any District programs because they do not fall clearly within the purview of the Department of Mental Health or the Department on Disability Services or the Office on Aging. Consequently, they often end up unnecessarily institutionalized in nursing facilities and in St. Elizabeths Hospital.

TBI is not a mental illness with symptoms treatable solely with medications; it manifests itself with myriad cognitive, physical and emotional symptoms. Individuals whose TBI occurs

¹⁹ ULS filed <u>Young v. DC Housing Authority</u> in 2001 to remedy the failure to build or renovate at least 5% public of public housing units wheelchair accessible as required by Section 504 of the Rehabilitation Act of 1973. As a result, the DC Housing Authority is under a Federal Court Consent Order to produce 565 fully wheelchair accessible units of which approximately 500 are completed and occupied.

after the age of 18 or who do not meet the strict DDS eligibility I.Q. criteria have no recourse for treatment or therapy for the symptoms of their TBI. In light of the fact that people with TBI fall between the proverbial cracks, and the high incidence of TBI in the District,²⁰ the District must implement a waiver program to provide services such as independent living skills training and development, structured day programs, intensive behavioral programs, among other support services that address the needs of this population along the lines of model programs in our neighboring states.

C. Failure to provide services for people with dementia

DC's Office on Aging (DCOA) has acknowledged that there are currently very limited community-based day program services or specialized community-based housing for people who develop dementia and/or Alzheimer's, regardless of their age. Some of these individuals are under 65 years old and thereby do not qualify for DCOA services. DCOA providers do not provide the wrap-around services that are needed for these individuals or for senior citizens with dementia to live safely in the community, rather than in institutions. Nursing homes or homeless shelters are therefore the only options for DC senior citizens with varying levels of dementia.

The District must develop services and offer them to individuals as an alternative to nursing home placement. At present, many of these individuals, particularly those who are not senior citizens, are lost between the gaping cracks in DC service networks because neither DMH nor the DCOA recognize or fulfill their obligation to serve them.

VI. Housing

Accessible, affordable, integrated housing is essential for people seeking to transition back to the community. While such housing opportunities are limited in DC, they exist. Nevertheless,

²⁰ www.CDC.gov, Preliminary Estimated Annual rates and numbers of TBI by state (2000).

District government and nursing home staffs often fail to make any efforts on behalf of people seeking to transition from nursing homes, reflexively citing as their rationale the lack of available housing.

People with disabilities in District nursing homes typically receive only \$70 per month as a 'personal needs allowance.' Upon release, their full monthly SSI benefits of \$674 are restored. Housing costs in DC outstrip these fixed income (SSI) benefits by 177.6 %.²¹ Therefore, many people with disabilities in nursing facilities rely upon subsidized housing in public housing developments, privately-owned subsidized housing or, to a lesser extent, group homes.

The District must develop integrated, affordable (for people in the very lowest income strata), wheelchair accessible housing for people seeking to move out of institutions. The DC Housing Authority's completion of nearly 500 accessible public housing units under the federal court mandate in ULS' Young v. DC Housing Authority lawsuit has enabled hundreds of families with individuals of all ages, from across the disability spectrum, to move into accessible, integrated communities from institutions and from inaccessible housing.

In 2007, a group of advocates including ULS staff asked Mayor Fenty to allocate federal Home funds and local housing production trust funds to subsidize 250 housing subsidy vouchers for people with disabilities seeking to transition from nursing homes, intermediate care facilities and psychiatric facilities under the Money Follows the Person. People with disabilities in these facilities are still awaiting earmarked subsidy vouchers to enable them to live in the community.

In early 2008, 100 housing choice (Section 8) subsidy vouchers were allocated to the DC Office on Aging through its role on a citywide long term care coalition. However, despite ULS' advocacy, it remains to be seen whether *any* of these vouchers will be prioritized for people who

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²¹ http://www.tacinc.org/Pubs/PricedOut/2008.html

want to move out of institutions. The Office on Aging has failed to disclose critical eligibility or selection criteria for these vouchers. The District's heavy reliance on HUD Section 202 and Section 811 Programs is unfortunate as these are *segregated* housing programs for people at least 62 years old and for those with disabilities, respectively. The lack of wheelchair accessible housing through the DMH provider network is particularly problematic. Some DMH providers actually lease units in various buildings, and therefore, *could* very well ensure at least some accessible units are available, but there are few, if any, available. District agencies must commit to maintain at least 5% accessibility in all housing programs, regardless of the type of primary disabilities among the people they serve. This will ensure that people with psychiatric disabilities and intellectual disabilities who also have mobility limitations have the same options afforded to others.

VII. The National Front

As President Obama convenes policy discussions on national health care reform, disability rights advocates and senior citizens stress the urgency of incorporating long term care reform into the agenda. As of now, however, the focus remains on the restructuring of the deeply flawed private health insurance industry which typically fails to cover long-term care services that are crucial to the well-being of people with chronic health conditions.

Investment in a more comprehensive, universal home health service structure would be tremendously beneficial in this national economic climate by yielding substantial savings from reduced reliance on nursing home care, ²² and by creating and retrofitting jobs in the home health sector.

²² See Kaye, LaPlante & Harrington, "Do Noninstitutional Long-term Care Services Reduce Medicaid Spending?" available at http://www.pascenter.org/publications/publication_home.php?id=913.

Companion bills collectively called the Community Choice Act are currently pending on Capitol Hill, spearheaded by ADAPT and introduced by Senator Tom Harkin (D-IA) and by Congressman Danny Davis (D-IL). ²³ If enacted, this legislation would mandate all states to provide Medicaid home and community-based services for people with disabilities who qualify financially and functionally, and choose to receive their services in the community. In light of the political entrenchment of the nursing home industry, the likelihood of Congressional enactment of the Community Choice Act remains in doubt. In any event, CMS may "pilot" such a mandatory program in a select number of states to demonstrate its effectiveness. Such a pilot demonstration project may be an important first step in unifying the disparate Medicaid State-based long-term home health services that often lead to upheaval in the lives of people when they become disabled.

VIII. Conclusion

To fulfill its mandate under <u>Olmstead</u> and the ADA, the District must reform its long-term care system across the board to presume and act upon the choices of individuals with disabilities to live in the community with the services and supports they need, rather than in institutions. The critical elements of systemic reform are:

- Active promotion, expansion and presumptive eligibility for access to communitybased services and supports by individuals with disabilities
- Expansion of Money Follows the Person for all disability groups in 2010
- Implementation of waiver services for people with traumatic brain injuries
- Development of wraparound community-based services and supports for people with dementia regardless of age

 $^{^{23}}$ The Community Choice Act is S 683 in the Senate and HR 1670 in the House.

- Restructuring of existing nursing facilities in favor of small scale accessible housing with shared services and supports
- Adoption of consumer direction in all home and community based services
- Elimination of 'bed taxes' and reduction in the number of nursing home beds
- Issuance of housing subsidy vouchers earmarked specifically for people with disabilities seeking to move back to the community from nursing facilities, intermediate care facilities and psychiatric hospitals.

Through these efforts, among others, the District must commit to spending *more* of its long-term care Medicaid budget on home and community services than it does on nursing facilities, intermediate care facilities and psychiatric hospitalization by 2012. People with disabilities will not wait another decade to realize their civil rights.

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