STATEMENT FOR THE RECORD OF FRED COWELL

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PARALYZED VETERANS OF AMERICA

FOR THE HOUSE COMMITTEE ON VETERANS' AFFAIRS,

CONCERNING THE

DEPARTMENT OF VETERANS AFFAIRS'

LONG-TERM CARE POLICIES

JANUARY 28, 2004

Chairman Smith, Ranking Member Evans, members of the Committee, Paralyzed Veterans of America (PVA) would like to thank you for the opportunity to submit a statement for the record concerning the Department of Veterans Affairs' (VA) long-term care policies.

Despite an aging veteran population and Congressional passage of P.L. 106-117, the "Veterans Millennium Health Care and Benefits Act" (Mill Bill), the VA has, once again, failed to maintain its capacity to provide extended (long-term) care services to America's aging veterans as mandated by 38 U.S.C. Section 1710B. Since 1998, VA's average daily census (ADC) for VA nursing homes has continued to decline. Additionally, as highlighted in a recent General Accounting Office report (GAO), VA has failed to ensure that all VA facilities are providing the full range of mandated non-institutional services as required by law.

VA's Assisted Living Pilot Project (ALPP) is well underway and holds promise to be an effective alternative to nursing home care for America's aging veteran population. However, VA must work to remove any existing state regulatory barriers that may discriminate against veterans with severe disabilities by restricting their access and choice of Assisted Living as an alternative to nursing home care. PVA also believes that

veteran (ALPP) consumer satisfaction information must be collected to fully appreciate the program's successes or failures.

Current VA long-term care services for veterans with spinal cord injury are inadequate to meet the increasing demand and interest for non-institutional, assisted living and nursing home accommodations. VA must move to increase its capacity to meet the specialized long term care needs of this population.

VA Nursing Home Care

VA's Veteran Population (VetPop) data adjusted to the Census of 2000 reveals aging trends that will certainly increase veteran demand for both VA's institutional and non-institutional long-term care services. For example, the number of veterans in the 85–89 age group is projected to increase from 547,735 in 2002 to 966,669 by 2010. Additionally, veterans in the 90-94 age group are projected to increase from 107,695 in 2002 to 314,167 in 2010. These aging demographics will most certainly increase demand for VA long-term care services and place a tremendous strain on existing VA long-term care resources within the next 10 years.

Despite an aging veteran population and aging trends that will increase demand for VA nursing home care, the daily census for VA nursing homes continues to decline from the baseline number of 13,391 as required by the Mill Bill. According to VA's workload data included in its 2004 budget submission, the ADC for VA nursing homes was 11,969 in 2002, 9,900 in 2003, and is projected to be 8,500 for 2004. Also, VA's ADC for Community Nursing Homes was 3,834 in 2002 and is projected to drop to 3,072 in 2004.

Yet despite this clear picture of increasing long-term care demand VA has failed to meet its statutory obligations as mandated in 38 U.S.C. Section 1710B to maintain its nursing home capacity at 1998 levels. Section 1710B states, "The Secretary shall ensure that the staffing and level of extended care services provided by the Secretary nationally in facilities of the Department during any fiscal year is not less than the staffing and level of such services provided nationally in facilities of the Department during fiscal year 1998."

VA Non-institutional Care (Home and Community-Based Services)

In addition to a decline in VA nursing home capacity, VA has done a poor job of correcting service gaps and facility restrictions that limit veterans' access to non-institutional long-term care services provided under the Mill Bill.

In May of 2003, the GAO issued a report (GAO-03-487) entitled "Service Gaps and Facility Restrictions Limit Veterans' Access to Non-institutional Care." The report addresses service gaps for six non-institutional VA services mandated by the Mill Bill. GAO found that of the 139 VA facilities it reviewed, 126 do not offer all six of these services. The services were: adult day health care, geriatric evaluation, respite care, home-based primary care, homemaker/home health aide, and skilled home health care. Of these six services, veterans have the least access to respite care.

GAO also reported that veterans access to non-institutional services is even more limited than the numbers suggest because even when facilities offer these services they often do so in only part of the geographic area they serve. The report also states that at least 9 facilities limit veterans' eligibility to receive these services based on their level of disability related to military service, which conflicts with VA's own eligibility standards. These restrictions have resulted in waiting lists at 57 of VA's 139 facilities.

GAO said, "VA's lack of emphasis on increasing access to non-institutional long-term care services has contributed to service gaps and individual facility restrictions that limit access to care." GAO added, "Without emphasis from VA headquarters on the provision of non-institutional services, field officials faced with competing priorities have chosen to use available resources to address other priorities."

PVA supports the two GAO recommendations issued to correct VA's access barriers to non-institutional care:

- VA ensure that facilities follow VA's eligibility standards when determining veteran eligibility for non-institutional long-term care services.

- VA refine current performance measures to help ensure that all facilities provide veterans with access to required non-institutional services.

VA Long-Term Care Workload

The following data is taken from VA's FY 2004 budget submission and is expressed in Average Daily Census (ADC) numbers.

Institutional Care:	2002	2003	2004	Increase/Decrease
VA Domiciliary	5,484	5,577	5,672	+ 95
State Home Dom.	3,772	4,323	4,389	+ 66
VA Nursing	11,969	9,900	8,500	- 1400
Community Nursing Home	3,384	4,929	3,072	- 1,857
State Home Nursing	15,833	17,600	18,409	+ 809
Subacute Care	1,122	956	860	- 96
Psych. Residential Rehab.	1,349	1,429	1,508	+ 79
Institutional Total	43,363	44,714	42,410	- 2,304

Non-Institutional Care	2002	2003	2004	Increase/Decrease
Home-based primary care	8,081	10,024	13,024	+ 3,000
Contract home health care	3,845	3,959	4,070	+ 111
VA adult day care	427	442	458	+ 16
Contract adult day care	932	1,352	1,962	+ 610
Homemaker/home health aide	4,180	4,247	4,315	+ 68
Community residential care	6,661	6,821	6,821	0
Home respite	0	1,284	1,552	+ 268
Home Hospice	0	0	492	+ 492
Non-institutional care total	24,126	28,129	32,694	+ 4,565
Long-term care total	67,489	72,843	75,104	+ 2,261

These VA workload numbers show a clear decline in VA nursing home care and contract community nursing home care and an overall decline in capacity for VA institutional care services. While VA non-institutional care reflects a modest increase in ADC the projected increase in 2004 services remains to be seen.

Recommendations:

- Congress must provide the necessary resources to enable VA to meet its legislative mandate to maintain its long-term care services at the 1998 levels and meet increasing demand for these services. In accordance with the recommendations of *The Independent Budget* for FY 2005, PVA calls for an additional $600 million to enable VA to provide comprehensive high quality long-term care services.

- VA must meet its statutory obligation to provide long-term care services in its facilities.

- VA must work to identify and incorporate additional non-institutional services and programs that can improve and bolster VA's ability to meet increasing demand as required by law.

Paralyzed Veterans of America also supports the following GAO recommendations regarding VA non-institutional care:

- VA must ensure that its facilities follow VA's eligibility standards when determining veteran eligibility for non-institutional long-term care services.

- VA must refine current performance measures to help ensure that all facilities provide veterans with access to required non-institutional services.

SCI Long-Term Care

Thousands of veterans with spinal cord injury (SCI) are at a disadvantage when it comes to the availability of specialized VA long-term care in their geographical area. Currently, VA operates four designated SCI long-term care facilities for persons with spinal cord injury. These are located at Castle Point, NY, Hampton, VA, Brockton, MA and at the VA residential care facility (RCF) at the Hines VAMC in Chicago, IL. PVA documentation and experience shows high demand and long waiting lists for these VA specialized long-term care programs. The December 2003 VA SCI Center and Staff Survey report shows 23.9 staffed SCI long-term care beds with a 23 patient census at Brockton; 15.4 staffed SCI long-term care beds with a 13 patient census at Castle Point; 47.1 staffed SCI long-term care beds at Hampton with a patient census of 51; and 26.7 staffed SCI long-term cared beds at the Hines RCF with a patient census of 27.

Veterans with SCI, who are eligible for VA nursing home care and who live west of the Mississippi River, have no local access, let alone a choice, of VA facilities for VA specialized SCI long-term care. To its credit, the VA's Draft National CARES Plan (DNCP) calls for the addition of SCI long-term care beds at several VA locations. The DNCP calls for 30 SCI long-term care beds in Tampa, FL, 20 SCI long-term care beds in Cleveland, OH, 20 SCI LTC beds in Memphis, TN and 30 SCI long-term beds in Long Beach, CA. While this is a step in the right direction, additional SCI specialized long-term care capacity must me made available to west-coast veterans.

During the recent work of the CARES Commission, PVA has become increasingly concerned with Commission dialog that blurs the distinction between SCI acute and long-term care. The CARES Commission seems to be under the opinion that there is no difference between an SCI acute care bed and an SCI long-term care bed.

PVA must draw attention to this misconception. An SCI Center acute bed is designed to treat the rehabilitation needs and serious secondary medical conditions associated with SCI. An SCI long-term care bed is a residential environment designed to maximize the independence and dignity of the SCI veteran and is a spoke in the SCI hub and spoke design. When a medical condition becomes a serious treatment issue the SCI long-term care resident is referred to the appropriate SCI Center for medical treatment.

PVA supports the DNCP plan for additional SCI long-term care beds to be added to the SCI system but feels additional SCI long-term care capacity must be soon developed and implemented to meet the growing demand for these VA specialized long-term care programs.

Recommendations:

- VA must expand its specialized SCI long-term care capacity.

- PVA is hopeful that the CARES Commission will support the additional VA SCI long-term care capacity as outlined in the DNCP and that VA will move quickly to implement these recommendations.

- Congress and the VA must not allow the CARES Commission to blur the distinction between an SCI acute bed and an SCI long-term care bed. These are distinctly different environments and must not be confused.

Assisted Living

Assisted Living (AL) is a special combination of individualized services that include housing, meals, healthcare, recreation, and personal assistance designed to respond to the individual needs of those who require assistance with the activities of daily living (ADLs) or the instrumental activities of daily living (IADLs). A key feature of AL is the delivery of services in a home-like setting. Assisted Living can range from renovated homes serving 10 to 15 individuals or high-rise apartment complexes accommodating 100 people or more. The philosophy of AL emphasizes independence, dignity, and individual rights.

Therefore, AL can be a viable alternative to nursing home care for many of America's aging veterans who require ADL or IADL assistance and can no longer live at home. However, there are some AL regulatory barriers that must be overcome before it will be open to many disabled veterans. Currently, AL is an industry that is regulated by state law, and many states have regulations that do not support the needs of disabled veterans or other people with disabilities. Before VA becomes an AL provider or establishes relationships with private providers, solutions to these regulatory barriers must be found to enable full participation in any VA or private AL program.

VA has argued that it should not become an AL provider because it is not in the business of providing housing to its veterans. However, PVA would point out that VA has long been in the business of providing housing for veterans who use VA domiciliary programs, VA nursing homes and VA contract nursing homes. VA could easily harness its vast long-term care expertise and building resources to become an efficient provider of AL services. These services could be provided through an expanded VA domiciliary care program if modifications were made to serve this population.

VA medical centers have already looked into public-private partnerships to provide AL on VA property through VA's enhanced-use leasing authority. Under this program, VA leases unused land to private AL providers in exchange for services to veterans at a negotiated rate. Additionally, VA's Capital Asset Realignment for Enhanced Services (CARES) initiative has called for the broad use of AL in its Draft National Cares Plan.

Public Law 106-117 authorized VA to establish a pilot program to determine the "feasibility and practicability of enabling eligible veterans to secure needed assisted

living services as an alternative to nursing home care." VA's Northwest Veterans Integrated Service Network, VISN 20, is implementing the Assisted Living Pilot Program (ALPP) in 7 medical centers in 4 states: Anchorage, AK; Boise, ID; Portland, OR; Roseburg, OR; Spokane WA; Puget Sound Health Care System (Seattle and American Lake, WA); and White City, OR.

The following highlights reflect a preliminary review of the implementation of the program and the first year of program operation, through December 2002. The Final Report, as mandated by law, will be provided to Congress in October of 2004. VA finding thus far include:

- The implementation of the ALPP has been successful: Despite significant challenges, ALPP has negotiated contracts with a total of 89 vendors. All sites are actively recruiting and enrolling veterans for the program. From January 29, 2002, through December 31, 2002, a total of 181 veterans were placed in ALPP facilities.

- A new computerized database is allowing efficient recruitment, processing of payments, high quality data collection, and data analysis for ongoing management feedback and evaluation.

- The average ALPP veteran is a 69 year-old unmarried white male who is not service connected, was referred from an inpatient hospital setting, and was living in a private home at referral.

- ALPP veterans show significant functional impairment and a wide variety of physical and mental health conditions.

- 36 Adult Family Homes, 39 Assisted Living Facilities, and 14 Residential Care Facilities have been contracted with to date. The average vendor has 25 rooms or apartments.

- Preliminary data on the cost of ALPP placements are available. Initial findings suggest that the mean cost per-day for the first 160 enrolled veterans (not including bed hold days) is $75.10.

- ALPP's implementation will allow VA to obtain an accurate picture of the feasibility of these services in VA based on the high quality managerial and clinical staff with commitment to the goals of evaluation, the new data base, and a wide variety of important issue arising from a multi-site demonstration.

PVA believes that based on the highlights of VA's ALPP that Assisted Living can be a cost effective alternative to nursing home care for many of America's veterans. PVA also believes that an expansion of the Pilot Project to additional VISN's will benefit veterans and provide useful information to VA regarding other AL markets. However, additional information is needed to better understand how the ALPP is accommodating

veterans with severe disabilities. PVA also recommends that VA develop, collect and disseminate ALPP consumer satisfaction information before its final report is submitted to Congress in October of 2004.

Recommendations:

- VA must expand and broaden the ALPP authorized by P.L. 106-117.

- VA must investigate and eliminate state regulatory barriers that prevent disabled veterans from enrollment and full participation in any VA ALPP, VA Assisted Living program, or any other AL arrangement or contract for private services utilizing VA property.

- VA should aggressively pursue development of AL capacity within existing VA programs that are adaptable to AL and through enhanced-use lease opportunities with private sector providers and partnerships.

- Congress must pass permanent legislation and provide funding to allow VA to provide AL.

- VA should develop, collect, and disseminate AALP consumer satisfaction information for inclusion in their final report due to Congress in October of 2004.

Summary

Over the next ten years an aging veteran population will have an increased demand for VA long-term care services. Despite mandating legislation, VA has failed to meet requirements to maintain long-term care capacity at 1998 levels and to provide the full complement of non-institutional long-term care services system wide. VA's capacity to provide VA nursing home care continues to decline despite increased appropriations from Congress. In 2003, the GAO reported that VA has failed to provide mandated non-institutional long-term care services in a comprehensive manner. It is clear that VA must do more to meet the increasing demand for VA long-term care services.

VA has attempted to amend Congressional language mandating VA long-term care capacity at 1998 levels by allowing VA to count nursing home care furnished by private providers and state veterans nursing homes. PVA is adamantly opposed to this suggestion and continues to believe that the only true measure of VA capacity is one that counts only the services provided directly by VA.

Sadly, it appears that VA would prefer to offload America's aging veterans who require nursing home care to the private sector or other federal payers. It also appears that VA is allowing its facilities to provide non-institutional long-term care as they see fit instead of providing these services as mandated by Congress. Non-institutional long-term care services can be a great benefit to America's veterans and in some cases can reduce the

timing and need for nursing home care. But the availability of these services must be nationwide and unrestricted by the manipulation of eligibility standards.

Regarding Assisted Living, The VA ALPP holds a promise of an environment that fosters increased independence and dignity for Amerca's aging veterans, but VA must pay attention to discriminatory state regulations and collect consumer satisfaction information before its final report is submitted to Congress.

PVA must emphasize the importance for VA to expand its SCI long-term care capacity to meet existing and growing demand for these services. An aging veteran with SCI has specific long-term needs that must be met by specially trained staff in a properly designed VA SCI long-term care facility.

PVA believes that VA must move to embrace its aging veteran population by improving its mindset and current culture which seems to see these men and women as a financial burden rather than a national treasure.

Paralyzed Veterans of America appreciates the opportunity to express our views on these important programs. We look forward to working with the Committee to ensure that the VA is providing adequate long-term care as required by law.

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Fred is a graduate of Southern Illinois University with degrees in Marketing and Anthropology. Fred has an extensive background in advocacy for health care, personal assistance services, transportation, housing, and employment issues for persons with disabilities.

Fred is a veteran of the United States Navy. He served two tours of duty in Vietnam while attached to the Naval Security Group.

Information Required by Rule XI 2(g)(4) of the House of Representatives

Pursuant to Rule XI 2(g)(4) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2003

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $220,000 (estimated).

Fiscal Year 2002

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $179,000.

Fiscal Year 2001

Court of Appeals for Veterans Claims, administered by the Legal Services Corporation — National Veterans Legal Services Program— $242,000.