

Appendix B.—Medical Devices and the Veterans Administration: The Perspective of Veterans' Service Organizations

There have been veterans' service organizations in this country since before the Declaration of Independence. The first, the Society of the Cincinnati, was formed during the Revolutionary War. Today there is no accurate record of all the veterans' organizations in this country (89). They range from small groups in isolated areas to large organizations that play a role in forming national policy. Most of the organizations perform two kinds of services for veterans. They help individual veterans obtain Federal benefits and services and provide their own services to veterans. For their members as a group, they represent veterans' concerns before legislative bodies.¹

The six veterans' organizations discussed here are active nationally. They all work closely with the Veterans Administration (VA) while providing services, monitoring the VA's activities, and suggesting improvements in VA operations. OTA conducted an informal survey of these organizations' relationships with the VA by talking with their representatives. Views were sought on the VA's responsiveness to veterans' health care needs and the strengths and weaknesses of current VA programs, particularly with regard to prosthetics and rehabilitative devices. Each of the six organizations consulted is briefly described along with their viewpoints, with emphasis on problem areas and suggested improvements. Note that these organizations represent only one perspective on the issues. Their views should be considered keeping in mind that they are consumers of VA health care and therefore not impartial observers.

Paralyzed Veterans of America

The Paralyzed Veterans of America (PVA) is a national, nonprofit service organization for paralyzed veterans, founded in 1946 and chartered by Congress in 1971.² With 11,000 members and 36 chapters throughout the United States, Puerto Rico, and Mexico, PVA is the largest advocate for 25,000 paralyzed American veterans. Although membership is limited to veterans who have spinal cord injury or disease and

an honorable discharge (injury may or may not have occurred during military service), PVA also works as an advocate for the other 175,000 nonveteran paralyzed Americans, as well as all U.S. veterans (71). PVA'S emphasis is on improved medical treatment and rehabilitation for all those with spinal cord injuries.

PVA was involved in the VA establishment of Spinal Cord Injury Centers in the late 1940s to treat spinal cord injuries and diseases. There are now 19 Spinal Cord Injury Centers across the country, with PVA representatives in each (39).

PVA is also concerned with meeting the posthospitalization needs of both paralyzed veterans and other paralyzed Americans, including accessible housing, specialized transportation, high-quality education, and prosthetic aids for more independent living. PVA'S activities are organized around four major programs, for national service, advocacy, legislation, and research.

The national service program operates 46 regional service offices, corresponding to regional facilities of the VA, staffed by national service officers trained to advise veterans and their dependents on their needs, legal benefits, health care (including prosthetics, medication, and rehabilitation), education, housing, and other VA benefits. National service officers also monitor the activities of the VA medical centers in their jurisdictions, including the appearance, condition, and maintenance of the facility; the adequacy and availability of medical equipment; personnel training, retention, and levels; prosthetic availability, fitting, and distribution policies; outpatient treatment and admission procedures; and the hospital administration's long-range plans and goals (68).

PVA'S advocacy program is committed to eliminating barriers to disabled people in housing, transportation, employment, education, and rehabilitation. The advocacy department has represented PVA'S positions on numerous committees, both public and private, and has participated in several lawsuits, as a friend of the court and as a litigant.

The PVA legislative program considers how changes in laws affect disabled veterans and other handicapped persons and encourages the Government to protect and expand veterans' benefits. PVA monitors and advocates legislation both federally and locally, and testifies at legislative and administrative hearings.

The PVA research program explores ways to improve the care, treatment, and rehabilitation of spinal-

¹It is estimated that between million and 5 million, out of almost 30 million, veterans in the United States belong to veterans' organizations. It is difficult to establish a more precise figure because many, and in fact, probably most veterans who do belong to an organization belong to more than one (i'o).

²congressional charter essentially lends prestige to an organization; there are no legal benefits of a congressional charter.

cord-injured people and promotes the search for a cure for spinal cord injury. PVA is the largest private supporter of central nervous system research in the United States (68). Through the Technology and Research Foundation, established in 1975, PVA awards research grants and fellowships for research related to spinal cord injury, including basic and applied medical research and research on rehabilitation methods and aids. PVA itself conducts demographic and statistical studies to clarify problems related to spinal cord injuries (71).

Disabled American Veterans

After World War I, some disabled veterans formed local self-help groups that eventually became the Disabled American Veterans (DAV), a national non-profit association established in 1920 and chartered by Congress in 1932. The founders of DAV worked with other organizations toward the legislation for a central Government agency to handle veterans' affairs—the Veterans Bureau, forerunner of today's Veterans Administration, DAV now has 818,000 members and a nationwide network of service programs, in addition to a Vietnam veterans outreach program, a national legislative program, and a national employment program.³ DAV places special emphasis on meeting the needs of Vietnam veterans. Approximately 25 percent of DAV'S members are veterans of the Vietnam War period and Vietnam veterans represent 95 percent of the professional staff, both at DAV'S national headquarters and in the field.

DAV'S national service program operates much the same as does PVA'S corresponding program, with approximately 250 national service officers in 68 offices across the United States, who provide free counseling and claims representation for disabled veterans and their families. In addition, since 1973 DAV has sent Field Service Units to rural and suburban areas to serve veterans and families living too far from DAV offices. All DAV national service officers are disabled veterans with service-connected, wartime disabilities who function as attorneys-in-fact, representing veterans before the Veterans Administration, the Social Security Administration, the Labor Department, and other Federal and State agencies. They provide counseling on disability benefits, rehabilitation programs, and other available services, and help in preparing claims and assembling evidence to support claims.

DAV also provides a Disaster Fund (for disabled veterans needing help because of natural disasters), an

³To qualify for membership in DAV, an honorably discharged veteran must have a disability incurred in wartime military service or under conditions similar to war (23).

Emergency Relief Fund (for disabled veterans facing financial emergencies), and a Scholarship Fund (for children of needy disabled veterans). These programs are available only to veterans with service-connected disabilities, although one need not be a DAV member to apply.

DAV'S national legislative program monitors and advocates legislation affecting benefits for disabled veterans and their families, including disability compensation, health care, employment, vocational rehabilitation, and death benefits. DAV also advocates architecture designed for handicapped people. Like PVA'S advocacy and legislative programs, this DAV program is active at local, State, and national levels.

Through its national employment program, DAV helps disabled veterans find jobs, supports local employment programs, helps employers and local government officials place disabled veterans in jobs and job programs, and files job discrimination complaints on behalf of disabled veterans. DAV works closely with the National Alliance of Business, the President's Committee on Employment of the Handicapped, and other private and public organizations concerned with creating equal employment opportunities for handicapped people.

Veterans of Foreign Wars of the United States

The Veterans of Foreign Wars of the United States (VFW) is the Nation's oldest existing veterans' service organization, and one of its largest. It originated from the veterans' groups formed in the early 1900s by veterans of the Spanish American War, the Philippine Insurrection of 1899, and the China Relief Expedition of 1900. Several of these early groups eventually banded together to form a new organization, which in 1914 became the VFW.⁴ Since 1914, the VFW has worked for compensation, pension, hospital, and bonus benefits for World War I veterans; the GI Bill of Rights for veterans of World War II, Korea, and Vietnam; and other major laws providing benefits to veterans.

The VFW now has nearly 2 million members; in the past 15 years membership has increased by more than 250,000. Membership in the VFW is open to any U.S. citizen who has served honorably in any overseas engagement for which a campaign medal or ribbon was awarded by the U.S. Government. The VFW has nearly 10,000 posts (local chapters), in the United States, Germany, Thailand, Korea, Japan, France, and other countries (45).

⁴The VFW, however, recognizes its founding year as 1899, when the first of the organizations that would become the VFW was formed.

VFW operates a nationwide service network like those of PVA and DAV to aid all veterans and their families (regardless of whether they are VFW members) in filing claims for benefits. It also promotes legislation for veterans' rights and benefits and national security, and sponsors community activities, including programs aimed at stimulating patriotism and an appreciation of national heritage.

The American Legion

The American Legion is the largest veterans' organization in the United States. It was born at a caucus of the first American Expeditionary Force in 1919 in Paris, with the goal of building an association of veterans "whose primary devotion was to God and Country" (89). The American Legion now has about 2.5 million members, of whom about 25 percent are Vietnam veterans.⁵ Its Auxiliary boasts an additional 1 million members (89). The American Legion has seven programs that have remained essentially unchanged since the organization's beginnings. The programs are for veterans' affairs and rehabilitation, children and youth, Americanism, national security, foreign relations, legislation, and economics.

The American Legion's main concern has always been the "welfare of veterans and their families." Its programs for veterans' affairs and rehabilitation, children and youth, and economics are all intended to serve veterans and their families in various ways.⁶ Its other programs—except for those of the Legislative Division,⁷ which promotes issues of interest to the organization (including veterans' rights and benefits)—do not directly benefit veterans. Rather, they further the organization's ideals of patriotism and good citizenship, and advocate its views on national security and foreign policy.

Through its veterans' affairs and rehabilitation program, The American Legion operates a nationwide network of 16,000 service officers who provide help in preparing and filing claims for VA benefits (like the service networks of other veterans' organizations). This program also offers advice and representation in cases before the VA's Board of Veterans Appeals and

⁵Any honorably discharged veteran who served in World War I (Apr. 6, 1917, to Nov. 11, 1918), World War II (Dec. 7, 1941, to Dec. 31, 1946), the Korean War (June 25, 1950, to Jan. 31, 1955) or the Vietnam War (Dec. 22, 1961, to May 7, 1975) is eligible for membership in The American Legion.

⁶Although the objectives of the program for children and youth have grown to include improved social and economic conditions for all children, the original purpose of this program was to ensure the well-being of the children of deceased and disabled veterans.

⁷The Legislative Division is the lobbying arm of The American Legion. Although other issues also get vigorous support from this division, legislation for veterans' benefits specifically and the economic well-being of veterans generally is given priority attention.

the Department of Defense Boards for discharge review, and in correcting military records. These services are provided free, regardless of whether the veteran is a member of The American Legion. In addition, the program employs six field representatives who regularly conduct onsite visits in the VA's 172-hospital system, much like PVA'S hospital monitoring (82).

American Veterans of World War II, Korea, and Vietnam

The American Veterans of World War II, Korea, and Vietnam (AMVETS) was founded in 1944 and chartered by Congress in 1947. Although AMVETS was originally formed for veterans of World War II, in 1966 its charter was amended to include veterans of the Korean War and Vietnam. AMVETS now has about 200,000 members, of whom about a third are Vietnam veterans.⁸

AMVETS' goals and services are very similar to those of The American Legion and the VFW. As a service organization, AMVETS' primary commitment is to serving veterans and their families. Its service officers are stationed at VA regional offices and medical facilities in every State. These service officers are trained professionals who offer counseling and representation to all veterans and help them obtain the benefits to which they are entitled, including compensation, education, employment, hospitalization, and rehabilitation (162). AMVETS also participates in the VA's Voluntary Service Program (as do some other veterans' organizations), whose volunteer workers provide services for hospitalized veterans.

AMVETS also provides many community services such as drug abuse education programs, voter registration drives, programs to promote safe driving habits, and a college scholarship program for needy children. Some of AMVETS' community service projects are also intended to encourage patriotism, such as the National Americanism Essay Project it sponsors, and the AMVETS Memorial Carillons in national cemeteries and at historic sites throughout the United States.

Blinded Veterans Association

The Blinded Veterans Association (BVA) is a non-profit organization founded in 1945 by a group of vet-

⁸Membership in AMVETS is open to any honorably discharged American veteran who actively served in the Armed Forces between Sept. 16, 1940, and May 7, 1975. Those who entered the service for the first time on or after May 8, 1975, are not now eligible for AMVETS membership, but legislation is pending to open AMVETS membership to all honorably discharged veterans who served in the Armed Forces from May 7, 1975, to an indefinite future date.

erans blinded in World War II. BVA was incorporated in 1947 and in 1958 was granted a congressional charter. Almost 5,000 of the nearly 50,000 blind veterans in this country belong to BVA.⁹ Some of these blind veterans also have other disabilities such as a hearing loss or missing limbs.

BVA operates much like the other veterans' organizations by providing help to individuals through a nationwide service network and by representing the interests of blind veterans in promoting legislation. BVA has two major service programs, the Field Service Program and the Outreach Employment Program. Both are provided under contracts with the Federal Government: the Field Service Program under contract with the VA and the Outreach Employment Program under contract with the Department of Labor. There are 37 BVA regional groups that provide help at State and local levels.

BVA's Field Service Program is unique in that blind veterans are actually sought out by the field representatives and offered help. BVA obtains the names of blind veterans from the VA and hospital records and through word of mouth. A field representative then visits the veteran and encourages him or her to seek whatever assistance is appropriate. The program employs 10 field representatives, all blind veterans themselves, who help blind veterans in obtaining benefits, including disability compensation or pension, rehabilitation and vocational training, and prosthetic equipment and training in its use. The representatives also counsel the veteran's family and help them to take advantage of existing community programs. This program serves as an adjunct to the VA's 76 Visual Impairment Service Teams at VA medical centers, who are responsible for reaching as many blind veterans as possible to provide them physical examinations and rehabilitation (91).

The Outreach Employment Program makes use of regional employment representatives who help blind veterans by finding prospective employers, providing advice on resumes and job applications, keeping the veterans informed of potential job opportunities, and offering counseling in cases of job discrimination. The program also tries to convince employers, through public service advertising and directly, to hire blind veterans.

⁹Membership in BVA is open to all veterans with service-connected blindness. Blinded veterans with non-service-connected blindness are eligible for associate membership.

Observations on the Veterans Administration Health Care Delivery System

The veterans' service organizations interviewed for this appendix believe that the Veterans Administration is doing a more than adequate job of tending to the health care needs of veterans in the United States. Some problems were noted, although in many cases efforts are already being made to alleviate them. Comments on specific VA departments follow.

Rehabilitation Research and Development Service

The VA's Rehabilitation Research and Development Service (Rehabilitation R&D) is primarily responsible for the research, development, and evaluation of new devices, techniques, and concepts in rehabilitation.¹⁰ Such activities generally focus on the three most prevalent service-connected disabilities of veterans: prosthetic aids for amputees, especially lower-limb prosthetics (which represents about 40 percent of the Service's budget); aids for veterans with spinal cord injuries, with special emphasis on wheelchairs (representing about 30 percent of the budget); and sensory aids, including aids for the visually impaired (representing about 30 percent of the budget)(5). Although the dollar amount allocated to Rehabilitation R&D rose 40 percent from fiscal year 1982 to fiscal year 1983 (a \$2.9-million increase), this Service receives only 6.4 percent of the VA research and development budget (see table 2 in ch.3).

PVA, DAV, and BVA all feel that greater funding should be provided for research sponsored by Rehabilitation R&D. However, they disagree on which areas should be emphasized. PVA would like to see more R&D conducted on aids for spinal-cord-injured veterans, DAV on prosthetics, and BVA on sensory aids for the blind (33,39,161).

All the organizations noted that positive changes have been made in the last few years, such as increased funding for Rehabilitation R&D and greater participation of veterans' organizations in setting research priorities. The VA recently held three informal sessions to discuss research priorities in upper- and lower-limb prosthetics, speech pathology, audiology and aids for hearing-impaired veterans, and functional electrical stimulation. Nearly 50 people from across the coun-

¹⁰Rehabilitation R&D and other VA programs for research and development are discussed in ch. 3 of this technical memorandum. The testing and evaluation of devices is carried out by the VA Prosthetics Center in New York City and the VA Marketing Center in Hines, Illinois (see also ch. 4).

try participated in each session, including experts in the relevant fields, VA representatives, physicians, device manufacturers, and representatives of all the major veterans' organizations.

PVA, DAV, BVA, AMVETS, and The American Legion are also represented on the VA Rehabilitation R&D merit review panel, which recommends research priorities and reviews research proposals and results.

Prosthetics and Sensory Aids Service

The Prosthetics and Sensory Aids Service (PSAS) is generally responsible for providing eligible veterans with the prosthetic and rehabilitative devices and sensory aids that they need for independent living. PSAS is also involved with the research, development, testing, and evaluation of commercial devices, as well as procurement and supply. Veterans' organizations commended the VA for increasing the size of PSAS staff, for recognizing the need for training VA field representatives and developing a comprehensive training program, and for encouraging more involvement with veterans' organizations. Some of these initiatives have already produced results, others will require more time.

Several veterans' organizations noted that some of the information available on benefits is not accurate. Inadequate training of field representatives is not the main reason for this, however, but rather that the PSAS Program Operating Manual requires much revision. The manual, which describes the process of issuing devices, including eligibility requirements and verification of eligibility, has not been revised since 1956. The field representatives' reliance on an incomplete and outdated manual resulted in the inconsistent application of national policy and arbitrariness in the representatives' interpretation of rules. The manual is now being revised, with help from all major veterans' organizations.

The most frequent complaint about PSAS concerns the long delays in providing prosthetic and rehabilitative devices to veterans. All the organizations interviewed gave examples of unacceptable delays between the order and actual delivery of devices. For example, a cane was delivered only after several months and a custom-designed wheelchair only after a year. Long delays for repairs were also noted, such as hearing aid and eyeglass repairs that took up to 5 weeks. These delays are primarily attributed to the fact that all orders must go through the Office of Procurement and Supply's Prosthetics Distribution Center in Denver, Colorado,

It is possible that a decentralized distribution system would be more effective. The VA considers it more cost effective to stock large quantities of devices at one

center. However, a complete analysis should take into account inventory costs, the costs of paperwork involved in placing orders, and the time that disabled veterans spend without devices essential to their everyday activities. The veterans' organizations suggested that PSAS have greater flexibility to contract with local suppliers in distributing devices. The VA Office of Inspector General audited the Prosthetics Distribution Center in 1983 (138) and made recommendations to improve the efficiency and economy of the distribution and repair functions of the Prosthetics Distribution Center. However, the recommended changes must be negotiated with the Department of Medicine and Surgery before taking action.

The VA Prosthetics Center

The VA Prosthetics Center (VAPC) has been widely viewed by veterans' groups as having serious organizational problems, largely because of its autonomy.¹¹ VAPC now has direct line authority through PSAS, which could help solve some of these problems. VAPC'S original goals were to conduct research and development in rehabilitation engineering, to evaluate and test commercially available assistive devices, to provide direct patient care for difficult prosthetic and orthopedic cases (i. e., customized devices), and to manufacture and distribute orthopedic footwear and prosthetic and orthotic devices. These are still VAPC'S responsibilities, with the exception of R&D, but there have been problems with VAPC'S providing direct patient care.

VAPC Special Clinic Teams were intended to provide expert fitting and construction of prostheses for the most difficult prosthetic cases.¹² People from across the Nation were to be sent to VAPC when they needed special treatment. According to DAV, however, this program has not been successfully implemented. In addition, plans to introduce five additional Special Clinic Teams in other hospitals across the country have been late in implementation. These additional teams were to be trained and in place by October 1984. Instead, as of November 1984, seven teams have been identified, but the teams are not complete and more training is needed. The new target date is March 1985 (13).

The Chief Medical Director proposed that VAPC'S special patient care services be moved in January 1983 from present facilities in New York City to the Manhattan VA Medical Center, on the expectation that a hospital setting would be more conducive to direct patient care. DAV has questioned the proposed

¹¹VAPC is discussed in chs. 3 and 4.

¹²Special Clinic Teams are discussed in ch. 3.

location on the grounds that it may not be accessible to handicapped veterans. The proposal to move VAPC is still being discussed and Congress must be notified prior to any action (13,164).

Along with other VA departments, VAPC has also been involved with setting standards and evaluating commercially available devices. Prosthetic aids, wheelchairs, and aids for blind and hearing-impaired veterans are all produced mostly by private manufacturers and provided to the VA through contracts. Many commercially manufactured devices are evaluated to ensure that they meet VA standards prior to the VA's adopting them for use. PVA and DAV indicated, however, that some new products are constrained by the VA's more specific standards.

As far as the VA's evaluation is concerned, PVA, DAV, and 13VA all mentioned that inefficiencies in the system result in delays, and that the device needs of veterans are not always met because of inconsistent and restrictive policies and standards. PSAS initiated the Prosthetic Technology Evaluation Committee in early 1982 to address problems in VA evaluations, 13 PVA and DAV have permanent representatives on this committee, which is responsible "for assessing and ranking the legitimacy and appropriateness of evaluation proposals and for assessing and approving the results of clinical evaluations." Other veterans' organizations are kept informed of the committee's activities and invited to participate in its meetings. All the organizations feel that the committee is a first step in the right direction, that improvements are already evident, and that further progress will take time, but can be expected.

Summary and Conclusions

Although the veterans' organizations discussed here have different eligibility requirements, different degrees

of involvement in political issues, and different programs for veterans, all of the organizations emphasize the needs of their particular members, and these needs are often those of all veterans.

The delivery of high-quality rehabilitation services and medical care, including prosthetic and rehabilitative devices, is a main concern of these organizations. All have representatives in place at some, if not all, VA medical facilities. These representatives function like consumer representatives for the VA, determining the needs of veterans, assessing their eligibility for VA benefits, and helping them obtain the benefits. In addition, representatives of some organizations monitor the activities of VA health care facilities to promote high-quality care.

Since veterans' service organizations are so closely involved in the VA's delivery of health care, both as participants and observers, their perceptions of VA programs are valuable. These organizations generally feel that they have an excellent working relationship with the VA. Although there are still problems, the view of these organizations seems to be that the VA is increasing efforts to involve veterans' groups in planning and policy decisions and to respond to the groups' concerns. All these organizations meet regularly with the VA, and some have representatives on various VA panels. In addition, informal meetings are held between veterans' organizations and the VA as issues arise.

Not surprisingly, these organizations would like to see greater Federal allotments to the VA, as well as greater VA allotments to the programs serving their members. Another consensus view is that there are long delays in providing and repairing prosthetic and rehabilitative devices. Although a certain amount of procedure and delay has been expected because of the size of the VA bureaucracy, improvements could be made. Through cooperation and discussion between the VA and veterans' service organizations, progress is being made to improve these services as funds permit.

¹³The prosthetics Technology Evaluation Committee is discussed in ch. 4.