

SICKLE CELL



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RECOMMENDATIONS FOR APPROACH AND PROCESS

Legislators should provide themselves with an opportunity to ascertain whether the elements of the proposed legislation are viewed favorably by the community the program will serve. It is doubtful if the highly objectionable (to the black community) mandatory testing laws precipitously enacted by well-meaning state legislatures would have been passed if public hearings had been held and the advisability of such laws thoroughly examined.

A body of experts such as the Scientific Advisory Committee of the National Association of Sickle Cell Disease, Inc., should be asked to review and comment upon any new or revised legislative programs for sickle cell disease.

New information is constantly being generated in the sickle cell field. The review of proposed legislation by a body of experts will help to assure legislation consistent with the latest scientific discoveries and a balanced consensus on controversial issues.

The Scientific Advisory Committee of the NASCD is in a unique position to review and comment upon proposed legislation or revisions of existing laws. Its membership is multidisciplinary and it studies and takes public positions on key medical and social issues related to sickle cell anemia and trait.

Legislation should authorize the establishment of a committee, with representation from all segments of the community, to develop a state plan for a sickle cell program.

Recommendations in the area of education and communication, social issues, technological and scientific development, counseling, vocational rehabilitation, comprehensive care, and financing must be a part of any legislative plan to create a total health care program for sickle cell. To best use resources and to assure a program that is acceptable to the target population, a committee, consisting of professionals, paraprofessionals, and community-based persons (particularly representatives from sickle cell anemia organizations) who have demonstrated expertise in these areas should specifically be charged to seek input from sickle cell anemia patients and their families. Persons with sickle cell anemia should be made eligible to receive support for medical care under Crippled Children's Acts.

SPECIFIC RECOMMENDATIONS FOR SICKLE CELL LEGISLATION

Legislation establishing services for sickle cell anemia patients should provide for the establishment of a statewide sickle cell anemia program to include public education, testing, genetic counseling and comprehensive health services.

PUBLIC EDUCATION

Education is a vital weapon in efforts to combat diseases. Progress in overcoming many once dreaded diseases, or in extending and improving the lives of the chronically ill, often has come about through creating public awareness.

An accurate and sound understanding of sickle cell anemia and trait by the public is, therefore, an essential first step in sickle cell disease programs. Additionally, the affected population needs to be aware of the nature of sickle cell trait and anemia in order to be motivated to seek testing.

TESTING

Testing is an intrinsic part of a sickle cell program. Without testing, individuals with sickle cell trait will continue to have children, unaware of the possibility that the children may be born with sickle cell anemia. This is clearly unacceptable and unnecessary, since the technology to identify carriers has been developed.

COUNSELING

When an individual has been identified as having the sickle cell trait, counseling is needed to enable him to make an informed decision in his own best interests concerning marriage to another person with sickle cell trait, and reproduction.

COMPREHENSIVE HEALTH CARE

Sickle cell anemia is a chronic condition for which, at present, there is no cure. Some measures have been developed for treating the pain crisis and other manifestations of the disease, but it is impossible to predict when symptoms will develop, or to prevent their occurrence.

While the primary effects of sickle cell are physical, the patient can also be handicapped by maladaptation to certain psychologically "stressful" aspects of the disease such as: incurability, periodic and unpredictable occurrences of pain, decreased life expectancy, growth retardation, delayed onset of puberty, decreased physical vigor, frequent hospitalization, and frequent interruption of vital activities such as school and work.

The patient's learning and thinking abilities are not impaired. His adjustment to his illness will depend on a combination of factors, including his individual personality and attitudes, school or work situation, peer acceptance, and the availability of comprehensive health and ancillary services. Social case work, vocational counseling, vocational rehabilitation, tutoring, parental counseling, child care and homemaker services may be needed by the patient and his family to assist them in coping with the disease. A health program for sickle cell anemia should enable or recommend appropriate linkage with public and voluntary agencies providing these supportive services.

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MINORITY VETS AT DEAD END

THE FIGURES tell the story.

With an unemployment rate of 6.0 per cent for the third quarter of this year, our nation is drifting toward economic difficulties. In the case of the minority Vietnam veteran those difficulties are compounded.

In the 21-34 age group that is generally used to designate Vietnam-era veterans unemployment for nonwhites stood at 10.8 per cent in this past quarter. It was 9.2 per cent a year ago.

Most severely affected have been the young minority veterans of 20 to 24 year of age. Their rate of unemployment for this past quarter was an astounding 23.2 per cent, up from 8.5 per cent in the final quarter of 1973. Their non-veteran counterparts had a 14.1 per cent unemployment rate.

Employment, or rather the lack of it, is undoubtedly the number one problem confronting the black veteran. But it is not the only one. Some 350,000 Vietnam-era veterans left the service with less-than-honorable discharges. Of this number, most have been black and poor, and with limited educations.

Again, the numbers tell the tale. In 1972, black veterans represented 32.6 per cent of the dishonorable discharges, 20.7 per cent of the bad conduct discharges, 16.1 per cent of the undesirable discharges and 20 per cent of the general discharges.

And less-than-honorable discharges and a veteran's opportunity for employment are directly related. The overwhelming majority of less-than-honorable discharges are administrative in nature. They have been meted out for petty offenses, frequently by commanding officers who disliked a particular individual.

VIETNAM VETERANS have experienced disproportionate discrimination when seeking a job simply because of their association with the most unpopular war in our nation's history.

The employers' doors have not been thrown open wide as was the case for World War II's warriors. On the contrary, today's prospective employers frequently view Vietnam reentrants as drug addicts or even murderers. Many men admit to removing any mention of military service from their resumes.

Men like Leon Coates. Leon is 28, black and a Vietnam war veteran who had an undesirable discharge until it was upgraded through the efforts of the American Veterans Committee. Leon explained how he was finally able to find employment after leaving the service with his less-than-honorable discharge: "When they asked, I told them I had no military experience."

A report prepared for the Department of Labor in October of 1972 concluded that "although many (employers) appeared to be favorably disposed to the idea, few employers in the private sector indicated having any preferences, services or programs specifically for veterans."

WITH A less-than-honorable discharge, a veteran's chances for employment are miniscule. The National Urban League, among others, has found that employers who would hire civilians who had been convicted of misdemeanors would not hire veterans with administrative discharges.

As June Willenz, executive director of the American Veterans Committee, has written in the October issue of THE CRISIS, the official publication of the National Association for the Advancement of Colored people:

Among the casualties of the Vietnam War hidden from public view are approximately 350,000 veterans who got other than honorable discharges. The stigma of a "bad" discharge will haunt these veterans for the rest of their lives - a "wound" of military service that will continually cripple, psychologically, socially and economically, as surely as a physical injury. Blacks, Chicanos, Puerto Ricans, native Americans carry the burden of the casualty list far out of proportion to their numbers, as they did in the list of combat casualties in Vietnam.

In that conflict, blacks accounted for approximately 20 per cent of combat fatalities, although they comprised only 12.6 per cent of the military personnel.

THE BLACK VIETNAM veteran certainly does deserve something better. Many of today's veterans are confronted with the multiple problems of employment, education and less-than-honorable discharges. The black veteran has additional problems.

He has generally felt alienated from the mainstream of society. His military experience frequently has done little to change this viewpoint. He is confronted by a sterile bureaucracy in the form of the Veterans Administration that has no program aimed specifically at the black or minority veteran.

Veterans' benefits and assistance are grossly inadequate to help him achieve the upward social mobility that he may have sampled to some extent in military service. Training programs for blacks have not been readily available and many end up in semi-skilled or unskilled jobs. There is little opportunity to transfer the skills he may have picked up in the military to a civilian occupation.

Indeed, the discrimination that many black veterans sought to escape by joining the military may have pursued them in the service. The unequal justice meted out to minority veterans was documented in a report issued by the Department of Defense in 1972. The combined pressure of groups such as the NAACP and increasing reports of minority group problems with the system of military justice led to the appointment of a Task Force on the Administration of Military Justice in the Armed Forces.

The Task Force found that "the military services are influenced by broad societal practices, including racial discrimination."

The Task Force fully documented differences of punishment and kinds of punishment administered to blacks and whites. One difference discussed was the counseling given to blacks and whites. Of whites accused of major crimes, 23.3 per cent received counseling. Only 8.3 per cent of the blacks reported for similar offenses were counseled. Minority servicemen lacked confidence in military defense counsel. A larger proportion of blacks suffered pre-trial confinement. When incarcerated they endured longer periods of confinement.

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