Disabled people in a reorganised health care structure

This article identifies the definition of disability and an action and prevention programme. It draws attention to the health care needs of disabled people, including the need for disabled people to become members of the health team.

Disabled People South Africa (DPSA) is a national organisation of people with disabilities. It functions as an umbrella body for self-help groups.

Aims and objectives

In contrast to charity/welfare organisations, DPSA is a non- racial, democratic movement of disabled people from both rural and urban areas of South Africa, who come together to speak for themselves, about issues which affect them. This same trend is mirrored in the whole Disability Rights Movement (DRM) represented internationally by Disabled People International (DPI).

DPSA's aim at all times is to fight for equality and full participation in every sphere of our society. The handicaps which stand as barriers to this are addressed by DPSA (and member self-help groups).

Definitions

The World Health Organisation (WHO) makes the following distinction in definition:

> *Impairment*: Any loss or abnormality of psychological, physiological, or anatomical structure or function.
> *Disability*: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal

for a human being.
Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual."

(UN Action Progam, 1983:3)

Disabled people and health

In the present health system that is predominantly based on curative medicine (and a society based on the "myth of the normal healthy body"), disabled people are generally seen, at best, as long term inconveniences to the medical system, and at worst as medical failures.

The majority of disabled people in the present South African health care system face two levels of discrimination: first their long term needs are inadequately catered for (whatever the colour of their skin); secondly, whatever facilities (for long and short term care) there are, they differ in quantity and quality paralleling levels of racial discrimination.

World Action Program

The need for a re-evaluation of the global policy with respect to disabled peoples, led the United Nations, together with Disabled People International (DPI), to draw up a WORLD PROGRAM OF ACTION CONCERNING DISABLED PERSONS. The objectives of which are to be implemented by all countries during the United Nations DECADE OF DISABLED PERSONS 1983-1992.

This program identifies three levels of action:

1. Prevention (primary and secondary)
2. Rehabilitation
3. Equalization of Opportunity

Primary prevention

This looks at the precautions needed to avoid the initial impairment by the following means:

> a) ... avoidance of war; improvement of the educational, economic and social status of the least privileged groups; identification of types of impairment and their causes within defined geographical areas;

introduction of specific intervention measures through better nutritional practices; improvement of health services, early detection and diagnosis; pre-natal and post-natal care; proper health care instruction, including patient and physician education; family planning; legislation and regulations; modification of life-styles; selective placement services; education regarding environmental hazards and the fostering of better informed and strengthened families and communities.

Nutrition intervention programmes are an aspect of primary prevention

(b) To the extent that development takes place, old hazards are reduced and new ones arise. These changing circumstances require a shift in strategy, such as nutrition intervention programmes directed at specific population groups most at risk owing to vitamin A deficiency; improved medical care for the aging; training and regulations to reduce accidents in industry,in agriculture, on the roads and in the home; the control of environmental pollution and of the use and abuse of drugs and alcohol. In this connection, the WHO strategy for Health for All by the Year 2000 through primary health care should be given proper attention.

(UN Action Program, 1983:A)

Secondary prevention

This looks at measures which:

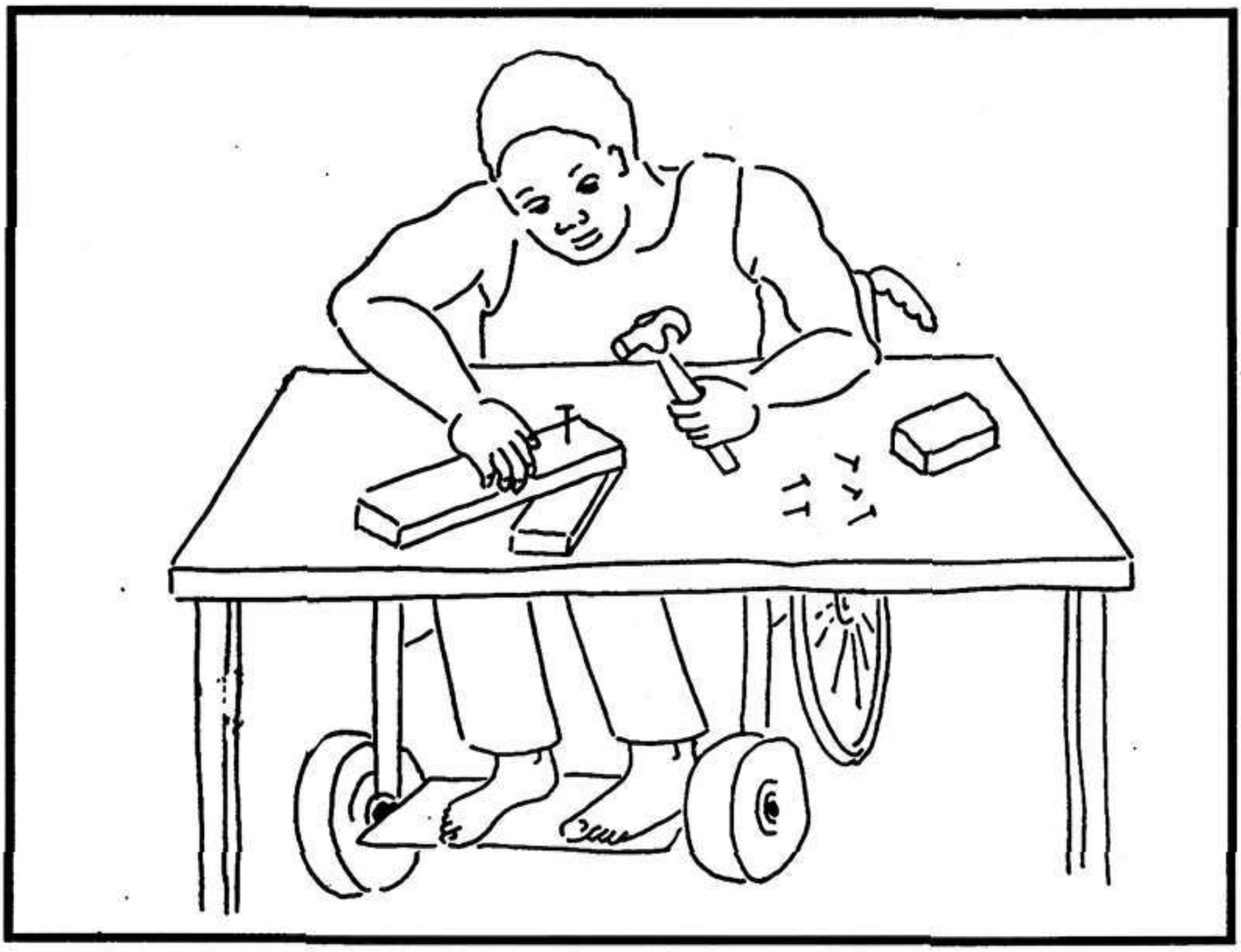
> 14. ... should be taken for the earliest possible detection of the symptoms and signs of impairment, to be followed immediately by the necessary curative or remedial action which can prevent disability or at least lead to significant reductions in its severity and permanence. For early detection it is important to ensure adequate education and orientation of families and technical assistance to them by medical social services."
>
> *(UN Action Program, 1983:4)*

Rehabilitation

The areas included under this section of the World Programme of Action are seen generally in the aims (although not the practice) of Rehabilitation in most developed countries.

However the programme goes on to stress that:

> 17. Important resources for rehabilitation exist in the families of disabled persons and in their communities. In helping disabled persons, every effort should be made to keep their families together, to enable them to live in their own communities and to support family and community groups who are working with this objective. In planning rehabilitation and supportive programmes, it is essential to take into account the customs and structures of the family and community and to promote their abilites to respond to the needs of the disabled individual.
>
> 18. Services for disabled persons, should be provided, whenever possible, within the existing social, health, education and labour structures of society. These include all levels of health care; primary, secondary and higher education; general programmes of vocational training and placement in employment; and measures of social security and social services. Rehabilitation services are aimed at facilitating the participation of disabled persons in regular community services and activities. Rehabilitation should take place in the natural environment, supported by community-based services and specialized institutions. Large institutions should be avoided. Specialized institutions, where they are necessary, should be organized so as to ensure an early and lasting integration of disabled persons into society.



Rehabilitation services are aimed at facilitating the participation of disabled persons in regular community services and activities

19. Rehabilitation programmes should make it possible for disabled persons to take part in designing and organizing the services that they and their families consider necessary. Procedures for the participation of disabled persons in the decision-making relating to their rehabilitation should be provided for within the system. When people such as the severely mentally disabled may not be able to represent themselves adequately in decisions affecting their lives, family members or legally-designated agents should take part in planning and decision-making.

20. Efforts should be increased to develop rehabilitation services integrated in other services and make them more readily available. These should not rely on imported costly equipment, raw material and technology. The transfer of technology among nations should be enhanced and should concentrate on methods that are functional and relate to prevailing conditions.

(UN Action Program, 1983: 5,6)

Equalization of opportunities

The Disability Rights Movement recognizes that rehabilitation is a time limited process, and that there are barriers in the environment which handicap disabled people. It is recognised that "a person is handicapped when he or she is denied the opportunities generally available in the community that are necessary for the fundamental elements of living ..." (*UN Action Program, 1983:6*). One of these elements is equal access to all aspects of the health care system.

The role of primary health care

Disabled people recognize that in order to live healthy active lives they need to take responsibility for the daily functioning of their bodies. In order to do this they need to understand how to look after their changed, or changing bodies. This has involved acquiring a great deal of knowledge which has traditionally been believed to be in the domain of specialized health care professionals.

This acquired "specialised" knowledge becomes "common sense" knowledge for the person with the disability, and is not generally understood by the average health care professional, nor adequately taught by specialists.

There is therefore an urgent need for the inclusion of experienced disabled people as members of the health team - not as members of one of the traditional medical or paramedical professionals already in the "team", but as co-ordinators and facilitators between each of these members and the "newly" disabled person. Because disabled people actually *live with* their particular disability, their ability to teach and share knowledge (and their understanding of why this knowledge must be shared) is far more successful than highly- trained, over-burdened professionals.

DPSA's call for health for all

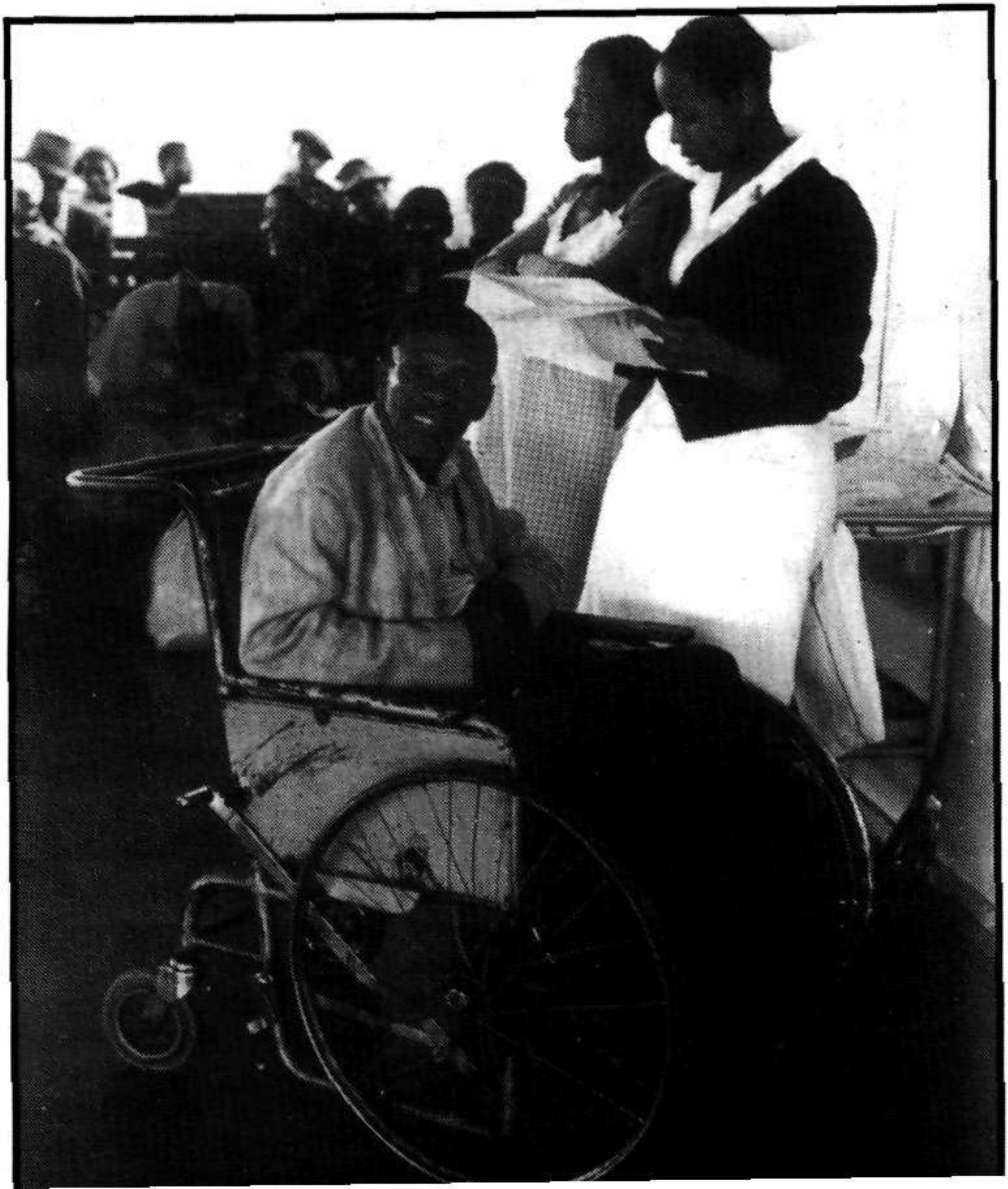
As people with disabilties looking at a new health care structure, we call for:

1. Non-racial and effective health services for all disabled people in both urban and rural areas;
2. Health services for people with disabilities to be available in the normal service delivery system;
3. A move away from the emphasis on highly trained health professionals as the only service deliveries.
   This involves a recognition of the desperate need throughout the country for rehabilitation assistants;
4. A recognition of the contribution of experienced disabled people as paid workers in the health care system.

Reference:

United Nations Decade of Disabled Persons, 1983-1992: World Program of Action Concerning Disabled Persons, United Nations, New York, 1983.

Kathy Jagoe
August 1987



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