

SUSTAINABILITY OF PROSTHETIC AND ORTHOTIC PROGRAMMES IN THE LOW-INCOME WORLD: THE CASE OF MOZAMBIQUE

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This paper examines the overall incidence of disability, and specifically of motor-disability, in low-income countries of the world. It observes the attitude of society toward those suffering from disabilities, and argues that there is a need for long term support for services to the motor-disabled by the international community. In order to generate this support, low-income countries must develop highly efficient services that minimize the call on international resources. Such services are likely to be outside government. They will be within private nonprofit organizations; ring fenced, transparent, and capable of regular audit.

MOTOR-DISABILITY IN THE LOW-INCOME WORLD

POWER was established to provide high-quality prosthetic and orthotic devices to the victims of conflict, most especially to those who had lost limbs as a result of the plague of landmines. Over the years, we have come to reassess our priorities. There is a huge global population of disabled people. Einer Helander has reported on surveys carried out in 55 countries between 1976 and 1994, suggesting that the rate of disability can vary from 0.2 percent to 21 percent. Much of the variation comes from poor definition of disability. There are problems of definition and survey method, but broadly speaking the conclusions that can be inferred from the surveys are:

- Disability increases very significantly with age.
- Rates may be lower in low-income countries because of failure to identify disability and high mortality rates amongst the disabled.
- Overall rates of moderate or severe disability amount to something of the order of 5 percent.

Based on a global population of 6 billion people, the total number of moderately or severely disabled people in the world amounts to 312 million. Of these, just over 100 million live in the western world and the remainder, 210 million – and our constituency – in the low-income world. It is reasonable to expect that most of these are dependent on others to one degree or another. Helander expects this figure to increase to 435 million by the year 2025 – as much because of increasing age as the increasing size of the population of low-income countries.

Helander's estimates of the causes of disability are not broken down by the standard groupings employed by WHO. However, I have allocated some of his categories of disability to motor-disability and derived a percentage, which I have then applied that to the figure of 210 million derived above. The result suggests a population of motor-disabled of about 125 million people in the low-income world.

Figures generally quoted for the number of landmine victims suggest that there are about 250,000 to 300,000 surviving amputees. There are thought to be 25,000 new victims every year, of whom about half die and the remainder are left severely impaired. Given that a number of those who have been previously afflicted will die from various causes during any one year, the total number of landmine survivor amputees is unlikely to increase by more than about 5,000 to 10,000 per annum.

Terrible as the landmine plague is, and the plight of landmine survivors, we cannot expect to treat them in isolation. We must treat amputee landmine victims within the overall context of motor-disability.

DISABLED PEOPLE IN SOCIETY

This paper is concerned with the problem of disability in low-income countries. My observation of people with disability is that they are marginalized. If one comes from a Darwinian stable, then the reasons for that marginalization are understandable. Survival of the fittest requires that species reject less able-bodied specimens. We can note behavioral patterns amongst other species that support this thesis. Mankind,

however, lives in a different social and cultural paradigm in which life is valued for its own sake and we are able to recognize the contribution of all human lives. We also recognize and defend the rights of all humanity to certain basic norms of existence.

Despite our intellectual capacity to recognize these rights and norms, disabled people continue to be marginalized, even in the most economically advanced countries of the world. In Great Britain, there is a huge private sector, nonprofit, support network for disadvantaged groups: the deaf, the blind, the limbless, the AIDS sufferers, those with mental impairment, the elderly, the disadvantaged young, the terminally ill, those suffering with certain types of debilitating conditions and diseases, and so forth.

The support of people with disabilities in countries such as Britain is not left entirely with government. There are sectors of society that have a strong enough conviction that the very basic services provided by the state are insufficient for the needs of these various groups and they start, run, or contribute to nonprofit organizations which will support these marginalized groups and help provide dignity in human life.

In the low-income world, the extended family has generally been seen as the fundamental alternative to the welfare society of the high-income world. But this may never have been the case, and society is changing. Whatever the truth of that matter, there is neither the culture nor the economy to support a strong nonprofit sector in low-income countries.

In my submission, the high-income world must face up to the responsibility of providing care for the disabled of the low-income world, and it must treat that as a long-term commitment. It is a responsibility that goes with globalization.

INSTITUTIONAL STRUCTURE FOR SUSTAINABILITY

In facing this commitment, the international community will wish to ensure that it gains the maximum effectiveness for the minimum amount of money. And this brings us to a major reason for programs failing. History reveals that where these programs are handed over to government departments, they tend to fail, even where financial provision continues to be made.

The simple reasons for this are twofold. First, governments of low-income countries have very limited resources and huge demands on those resources. The provision of services for motor-disabled people is not a priority. Even where overseas funding is received for the service, it can easily be diverted to other purposes.

The second reason is that staff salaries within government services are frequently very low; consequently, morale is low within the service and staff leave. It is tragic to spend eight or ten years developing a service, with the provision of well-trained and competent staff, only to see that advantage whittled away as qualified personnel leave to join other industries or leave the country.

The solution to these problems is to create a body that can continue the service outside government. This body may be a local NGO, and it may be a partnership between public and private organizations. It will be a nonprofit establishment. This formula was devised by a group of international experts – many of them from the low-income world – at the 1997 Henley on Thames Technical Workshop. The communiqué from that workshop is attached as an appendix to this paper.

THE MOZAMBIQUE EXPERIENCE

The International Committee for the Red Cross (ICRC) established or developed four ortho-prosthetic centers at Maputo, Beira, Quelimane, and Nampula during the 1980s. A part of the Maputo center is a manufacturing facility, making prosthetic and orthotic components, chiefly from polypropylene. In 1990, ICRC established a training course for 24 Mozambican students to study to become Category II prosthetists/orthotists. All 24 graduated in 1993, with recognition for their qualifications from ISPO. ICRC withdrew from the country in 1994, handing over the facilities it had been running to the Ministry of Health.

Handicap International (HI) came to Mozambique in 1986 and established a further six centers, at Inhambane, Vilanculos, Nampula, Tete, Pemba, and Lichinga. For the last four years, HI has been pursuing a policy of integrating these six centers within the Ministry of Health.

In 1995, POWER arrived in the country and, with the support of USAID and UNICEF, took over partial management control of the four ICRC centers, together with the component-manufacturing operation in Maputo. Staff terms and conditions did not come within the POWER management, and this proved a considerable drawback. A requirement of the contract with USAID was that POWER would establish a local NGO and place the management of the four centers within this organization. In the event this did not prove possible.

Last year, POWER completely renegotiated its agreement with MISAU, withdrawing from direct involvement in the four centers. Mindful of the reasons for services failing, POWER has agreed with MISAU to continue providing materials for the manufacture of limbs, both to the four centers for which it had responsibility, as well as to those that HI established.

POWER is also undertaking considerable training activity to strengthen management and professional capacity in the centers. Two Category II prosthetists/orthotists will attend a four year course in Strathclyde University, Glasgow, Scotland, to upgrade to Category I. Meanwhile, HI has arranged for three staff members to attend a course in Lyons to upgrade to Category I. Thus, of the 24 Category II prosthetists/orthotists, five will be overseas training from September onward. In addition, one has been promoted to an administrative position, one has been fired, and one has moved occupation. Only 16 will be available in the forthcoming year to service the requirements of the 10 centers.

Absolutely central and critical to POWER's new program is an agreement with the Associação dos Deficientes Moçambicanos (ADEMO), to strengthen its management and financial capacity, and to jointly initiate the Council for Action on Disability (CAD) which, it is hoped, will eventually take over POWER's program in Mozambique. CAD is open to any organization working for the benefit of the disabled in Mozambique to join, and five or six organizations currently attend board meetings as observers.

Also central and critical is the development of a new ortho-prosthetic center in Chimoio in Manica province. This will be within the private, nonprofit sector and will be managed by CAD. It is intended that this center will lead the way in demonstrating that high levels of productivity and quality can be achieved when staff are properly and fully incentivised.

In 1999, the Mozambique Red Cross Society (MRCS) is opening a center at Manjacaze in Gaza Province, with support from the Jaipur Limb Campaign and the Diana Princess of Wales Memorial Fund. The center is in the private, nonprofit sector and will fit Jaipur limbs, using staff trained in the technique in India.

It is now MISAU policy to maintain one ortho-prosthetic center in each of the 10 provinces. The center at Vilanculos in Inhambane province is to be closed down. With the opening of the POWER center in Chimoio, Manica province, and the MRCS center in Manjacaze, Gaza province, this policy will be fulfilled.

It is the responsibility of the Ministry for Coordination of Social Action (MICAS) to make patients aware of the availability of prosthetic and orthotic services and to assist their journeys to the centers. MICAS has available a number of transit centers, where patients can stay free of charge while they are receiving treatment at the centers. Currently, this system is not working well, largely as a result of an inability of MICAS to resource its responsibilities.

MICAS also undertakes a means test of all patients and makes charges appropriate to their circumstances for the services that they receive.

I believe that the service in Mozambique is now moving slowly towards the optimum. The establishment of CAD and the collaboration of organizations working for the service of disabled people, are huge steps in

the right direction. The development of centers in the private, nonprofit sector will give excellent opportunity to make comparisons between services delivered through the public sector and those available within the private sector.

CONCLUSIONS

What I have sought to demonstrate in this paper, in the case of motor-disability only, is that:

- There is a huge number of motor-disabled throughout the low-income world.
- Landmine survivors represent a small proportion of this number, and their treatment must be subsumed within the broader need.
- Disabled people in general are marginalized and their needs are rarely met, either in whole or in part, by state provision.
- If the needs of the motor-disabled in the low-income world are to be met, it will tend to be as a result of financial support from the international community.
- Such financial support is likely to be required for the very long term.
- In order to minimize the demand on international financial resources, it is necessary to set up effective and competent services within the low-income world.
- Such services are not likely to be within government. The best model will be in the private, not-for-profit sector, wherever possible in partnership with government.
- Mozambique can provide a model for the rest of the world.

1997 HENLEY TECHNICAL WORKSHOP

STRUCTURES FOR LONG TERM SUSTAINABILITY OF PROGRAMMES FOR REHABILITATION OF DISABLED PERSONS IN LOW-INCOME COUNTRIES

FINAL COMMUNIQUÉ ON BEST PRACTICE

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PREAMBLE

The Henley Technical Workshop has come together to attempt to define a model or models which will deliver high-quality services for the rehabilitation of disabled persons in low-income countries on a sustainable basis. The workshop received information on a very wide range of delivery systems and structures. It is apparent that there are occasions and circumstances which will merit the adoption of a structure entirely within the government of a country, or entirely within a private, nonprofit foundation or company, or under the aegis of a major non-governmental institution. However, in other cases it is

important to establish or identify a national implementing agency. In addition to its role in rehabilitation of the disabled, a major function of this implementing agency must be to facilitate the flow of funds to the programs from funding agencies, particularly international agencies. The preferred model for this purpose is a private/public partnership.

NAME

This preferred structure would be known as the Council for Action on Disability (CAD).

MISSION STATEMENT

To facilitate the implementation and development and maintenance of coordinated sustainable services for disabled people.

FUNCTION AND OBJECTIVES

The function of the CAD is dependent upon the existing structure within a country, but will include such actions as to devise, finance, facilitate, coordinate and implement a program (possibly additional to existing programs) of effective services accessible to all disabled people.

Its particular objectives are:

- To involve disabled people in the decision-making process.
- To promote technical sustainability of rehabilitation programs.
- To promote organizational sustainability of rehabilitation programs.
- To promote financial sustainability of rehabilitation programs.
- To access international finance.
- To access local finance.
- To establish and maintain acceptable standards of service.
- To monitor and evaluate the success of programs in delivering their objectives.

COMPOSITION

A public and private partnership with membership from government, implementing agencies and organizations of disabled people and other groups having a concern with disabled people.

BENEFITS

- Gives to disabled people the security of a coordinated and long-term program that is well conceived and implemented to meet their needs.
- Whilst governments retain oversight of programs, they gain access to increased funding, a mechanism for increased efficiency and evaluation of program, organization and staff performance.
- Gives NGOs the clear indication of their individual roles and the extent of their agreed undertakings, together with access to funds, which might not otherwise be available.
- Gives to donors and funding agencies the assurance that their funds will be ring-fenced and managed transparently with the benefit of accountability.
- Gives credibility to the program for all.

FLEXIBILITY

Very often, such an organization will already exist in a country and be entirely satisfactory for the purpose: or there may be a need to slightly redefine its role and function. Otherwise, a new entity may be formed by mutual agreement among the parties. There must be complete flexibility in implementation, and this will also apply to the boundaries of the program.