

INTRODUCTION

The International Year of Disabled Persons (IYDP), 1981, was proclaimed by resolution 31/123 adopted by the General Assembly of the United Nations on 16 December 1976, and was celebrated throughout the world with the theme "Full participation and equality". The Year had as its main objectives: "promoting all national and international efforts to provide disabled persons with proper assistance, training, care, and guidance to make available opportunities for suitable work and to ensure their full integration in society".

Objectives and organisation of the survey

2. As a contribution to the observance of the Year, the Commonwealth Secretariat commissioned this survey of the achievements of Commonwealth countries in relation to disabled people during 1981. The main purpose was to identify initiatives that might be sustained, especially in relation to the smaller and more remote countries, by technical co-operation between governments and through the activities of voluntary organisations. My terms of reference as the Secretariat's consultant are given in an appendix to this report.

3. In circular letter 38/81 of 4 August 1981, the Secretariat invited all Commonwealth governments to co-operate in the survey by sending copies of information prepared in connection with their observance of the International Year and, if possible, to nominate a correspondent to whom I could write direct. As almost every Commonwealth country had sent some particulars of its national IYDP co-ordinating committee to the United Nations Secretariat in Vienna, I was able to supplement this approach by writing to the chairman or secretary of most of the committees to solicit information. This in turn was supplemented by the selection of several countries in each major region of the Commonwealth for brief visits for discussion on the spot with government ministries, IYDP committees and the representatives of voluntary organisations active among disabled children and adults. The 22 countries visited are listed in an appendix to this report.

4. The response to these approaches was, predictably, uneven. Many governments and IYDP committees sent full accounts of their activities in relation to disabled people before and during the International Year, with their plans for the future. From others the information supplied was sparse; several did not respond at all. Countries visited included some in each category. I am therefore unable to arrive at a just assessment of the achievements in each and every Commonwealth country, and shall not attempt to do so. Instead, this report will review the general principles that emerged from the observance of the International Year, the main lessons learned and the possibilities for continuing effective action so that the stimulus of the Year will not be lost.

5. There is, of course, a very great difference between the steps taken to accede to the needs of disabled people in industrialised countries, which have sophisticated health and welfare services, and the limited choice of action that can be taken in small countries with enormous health and welfare problems still unresolved and very limited financial and manpower resources at their disposal. The provision of ramps and self-opening doors for wheelchairs may be a priority need in Australia, Canada or New Zealand. A prior need in Papua New Guinea, Fiji or St. Vincent may be a rehabilitation process that will enable people with spinal injuries to leave their beds in an orthopaedic ward and enjoy some mobility if wheelchairs can be made available. The intention of the report is to suggest a few ways in which the experience of some of the industrialised countries can be interpreted and made available to countries at a less advanced stage of development.

6. During the first country visits it became apparent that a practical way of approaching the subject of disablement was under four main heads: prevalence, prevention, provision and prospects.

Prevalence

7. Discussion of prevalence revealed the main categories of disabled people requiring assistance and the causes of their disabilities. Ideally, statistics would tell the story. One day, no doubt, they will. Many countries inaugurated disability surveys as a part of their IYDP programme of action. But very few results were in by the end of the Year. Meanwhile, we rely on the experience of government officials and voluntary organisations to indicate which categories of disabled people have come to notice: polio victims, amputees, the blind, the deaf, leprosy victims, the mentally retarded. Inevitably, there are two main distortions. First, their impressions are clearer for urban and more accessible rural areas than for remote villages. Second, voluntary societies usually specialise in one particular disability - blindness or leprosy, for example - and therefore tend to seek out adults and children who need help so that their existence becomes better known than that of people in other categories - cerebral palsy or tuberculosis, for example, and most noticeable of all, poliomyelitis.

Prevention

8. Discussion of prevention indicated the relative importance the health authorities gave to each category of disablement, conditioned of course by the availability and cost of effective immunisation or other prevention activity. There are four categories of preventive action:

- (a) those which governments have already built into their health care systems;
- (b) those which take the form of special interventions which governments are able to undertake with the backing of outside (or local voluntary) bodies, e.g. the World Health Organisation Expanded Programme of Immunisation, a Rotary-to-Rotary measles or polio campaign, or the Asian eye-camps sponsored by the Royal Commonwealth Society for the Blind - the hope is that interventions in category (b) will be promoted to category (a);
- (c) those which governments know are needed but which cannot be undertaken for lack of finance, trained personnel or accessibility;
- (d) research into causes of disability for which no effective preventive action is yet known.

Provision

9. Discussion of provision came under five main heads:

- (a) **Institutions for the disabled.** These include the old-fashioned schools for the deaf and blind, sheltered workshops and homes for the mentally retarded. IYDP policy is to spend less money on central institutions because they cost too much per head and because they tend to favour the disabled with relatively easy access to the major cities, neglecting the remoter rural areas. Also, they tend to segregate disabled people from society. Discussion shows whether it is utopian to suggest that the same amount of money, or more, could effectively be spent on realising the modern concept of family and community care for the disabled; and just what this would mean in the reality of remote rural areas.
- (b) **Prosthetics and orthotics.** The provision of artificial aids of all kinds involves first the detection of need; second, appropriate rehabilitation therapy; third, the production in quantity of appropriate aids; and fourth, fitting, training and maintenance. In the poorer developing countries, artificial limbs or hearing aids are not going to be available to those who need them if they have to be imported at great expense. A free gift of such aids from an overseas source is not very helpful if there is no local capacity to fit and service them. Local manufacture of appropriate aids presupposes an allocation of funds by a government hard pressed to maintain its basic services. Discussion showed the priority

government accords to the needs of the disabled: usually not very high because of the shortage of financial and staff resources. The priority sometimes depends upon the strength of representation made by pressure groups of the disabled themselves or of those who espouse their cause.

- (c) Vocational training. The use of the slogan "Remember our capabilities as well as our disabilities" brought out information about the extent to which governments are providing special education, whether in schools for the blind or deaf or in "open education" (by the provision of resource centres and specially trained staff), or by vocational training schemes devised to meet the special needs of disabled people so that they can use their capabilities to earn their way in life.
- (d) Employment opportunities. Some countries legislate for the employment of disabled people. In areas of high unemployment or under-employment such legislation is hardly to be expected, and would be difficult to enforce without a full official register of the disabled. Efforts are therefore concentrated on measures to assist disabled people who have a potential contribution to make to productive activity to find appropriate employment whether in sheltered or "open" conditions.
- (e) Human Rights. Questions about the human rights of disabled people, their access to public buildings, their full integration into the community - all of which form a large part of IYDP philosophy - resolve themselves in many developing countries into the simple question: "What special provision for the needs of disabled people is it fair and reasonable to expect your government to make in view of the many unsatisfied demands on your limited and hard-pressed financial and manpower resources?"

Prospects

10. Prospects for the future depend on the economic development of the country and on the priority accorded to the needs of disabled people. Without increased financial resources, or help from outside, governments will be unable to improve their primary health care or do much more than they do at present to meet specific needs. IYDP has focused attention on the fact that something like ten per cent of any population have some form of disability. Despite the real and severe financial constraints, there are provisions which can be made to enable many disabled people to lead a fuller life and to make their contribution to the economic and social well-being of the communities in which they live. Theory sometimes puts it the other way round: viz, to care for a disabled person, particularly if he is institutionalised, costs far more than to rehabilitate him so that his family can look after him or he can take care of himself. But governments cannot be expected, in their precarious financial state, to produce the money required now to include all desirable services to the disabled in their health or social welfare allocation merely in anticipation that they will be spared the expense later of caring for so many dependent disabled people. Nevertheless, it is worth reaffirming that where immunisation or other preventive measures can be introduced now, there is an undoubted saving in social welfare expenditure later.

11. Meanwhile, there are large numbers of irrevocably disabled people needing help. What is done for them is a matter of selection. Specific outside help is available government-to-government, through voluntary societies and through the UN Special Agencies. This help has been usefully focused and probably augmented by IYDP. The task now is to judge which of the IYDP initiatives in a developing country ought to be sustained permanently, and to enlist the support of outside agencies where their maintenance and development are beyond the means of the government and local voluntary societies. The tradition of Commonwealth cooperation, supplemented by the Commonwealth Fund for Technical Cooperation (CFTC), has a part to play here. Experience in one country can benefit another country by communication, by visits and by the offer of training facilities in conditions comparable to the home country of the trainee. This is already happening in many fields. The best I could hope for was to detect and portray specific areas in the whole disabilities field where assistance is most needed and might be forthcoming through the CFTC, and also through the Commonwealth Foundation; and conversely, to find possible sources of experience which might be tapped for the benefit of the poorer and more remote Commonwealth countries.

The verdict

12. In one sense, this report is being written a little too early. It is about national policies in relation to disabled persons; but very few national policies have yet been determined. It is about programmes for the handicapped; but in the countries with which the report is mostly concerned the programmes are still mainly in the hands of voluntary societies. The dialogue with governments continues; and a major purpose of IYDP was to coordinate and strengthen the advocacy of voluntary organisations for larger government grants and for the assumption by government of responsibility for the salaries of teachers of children with special needs, for better rehabilitation services and for placement in employment. Governments have not had time to respond to these representations; indeed some of them have not yet been presented to governments. In so far as they have been presented piecemeal during the course of the year, most governments of the smaller countries have been obliged to give very discouraging replies because of their financial plight (and that is not too strong a word). "Cuts wherever possible" is the order of the day in the present economic climate. And because of a world movement, strongly led by the United Nations IYDP Secretariat itself, to end the segregation of disabled people - adults or children - in institutions, pleas for larger government grants for schools for the blind and deaf, for sheltered workshops for handicapped people or for Homes for the most severely disabled children whose parents cannot cope, are not likely to find a ready response from hard-pressed governments.

13. Another world movement, led by WHO, to train the disabled in their own communities, is still in its infancy. It holds out the best hope, since it aims to reach the many millions of disabled people at present untouched by rehabilitation techniques. But it is too early to say how effectively it can deliver these techniques. The field-testing of WHO's manual on rehabilitation for developing countries is not much more than a year old. The preliminary results are encouraging, and this is the policy for the future. But discussions in many countries suggest that it may be embraced for the wrong reason: a saving of money. It is being assumed that great savings can be made on expenditure on institutions. The cost of training the very large numbers of village-level workers - community aides or whatever they are called - is not so far being taken into account. These essential people need not only training but also supervision; and it is the middle-level supervision that, in my view, is going to present the greatest difficulty, as well as costing a lot of money. Moreover, top-level professionals in rehabilitation and therapy will still be necessary and very few of the smaller countries have anything like the full team.

14. We have not yet reached the stage when we can make reliable estimates of the cost of switching from institutionalisation to care within the community. It is a great mistake to assume that it will cost less than the present meagre grants to institutions. It is an even greater mistake to plan on the assumption that institutions can be done away with altogether. A middle path will have to be found. By all means let us get away from the present limitation of medical and social rehabilitation to those within reach - geographically or financially - of services in urban areas. But these services will still be needed, whether they be orthopaedic wards and therapy specialists, training colleges for teachers of the deaf and blind or vocational training centres for open or sheltered employment. It is too soon to say just how the right balance is going to be found in the smaller countries.

15. In another sense, the report is timely. IYDP has focused world attention on the fact that something like 500 million people in the world - one in ten - suffer from some considerable disability. Ways have been thoroughly explored of easing their burden and accentuating their capabilities so that far more of them can become contributors to society instead of liabilities, which they do not want to be. All Commonwealth governments appointed national committees to observe the special Year and also, presumably, to guide them towards a national policy. In so far as these committees stressed public awareness of disabled people and their needs - and most of them regarded this as their major function - some measure of public demand has been created that there should be such a policy, and that it should be implemented. While this is fresh in the minds of politicians and administrators, it is appropriate to survey what was done in 1981 and to produce a view, however subjective, about the implications of working out a policy in countries with very limited financial and manpower resources.

16. There are, of course, no instant remedies. What is important is that the opportunity should not be lost of considering realistically what can be done in each country. A report on

Commonwealth IYDP experience generally, deliberately kept as short and uncluttered with detail as possible, may help each government to make up its own mind and get the problem of disabled people into some sort of perspective. It is also my hope that outside agencies, whose help the smaller countries so much need, will realise the immensity of the problem and concert with individual governments in selecting projects for assistance. This applies not only to major programmes of multilateral and bilateral technical cooperation, but also to the voluntary agencies on whose staff and money much of the work, particularly among handicapped children, must continue to rely for many years to come in many of the smaller Commonwealth countries.

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SETTING THE SCENE

18. The assumption of the International Year was that one person in ten throughout the world suffered from some degree of disability. This assumption was based on a 1968 estimate by Rehabilitation International that the number of disabled people in the world was 450 million, increasing by some 3 million annually. While it is not possible to verify this figure, it is significant that it was not seriously challenged during the Year. When the General Assembly of the United Nations reviewed the Year on 7 and 8 December 1981, the figure of between 450 million and 500 million was still accepted as the best estimate of the number of disabled people in the world. The figure of course depends upon the criterion of disability. The definition of "disabled" implies an inability, because of some physical, sensory or mental impairment, to lead a full and satisfying life in the community.

Rehabilitation, social integration or prevention

19. The juxtaposition of the figure and the definition raises two questions: "What is being done to enable the individual to develop his capabilities so as to lead a fuller and more satisfying life?" and "What can society do to make life easier and more satisfying for the disabled person?". The answer to the first question lies in medical rehabilitation, special education, vocational training and employment opportunities. The answer to the second question lies in creating public awareness, changing traditional attitudes and inducing social action. It is the second of these questions that dominated the work of IYDP committees in most industrialised countries. In countries with fewer financial and manpower resources, attention tended to focus on the rehabilitation and employment aspects.

20. There is a third question: "How much of this disablement could be avoided in future by preventive action?". This received scant attention, except in some industrialised countries which emphasised the mounting toll of traffic accidents, and also in medical circles where the potential of the WHO Expanded Programme of Immunisation and other measures to reduce disablement dramatically in the next generation was already recognised and received some impetus from the International Year.

Who are the disabled?

21. This report will assess, in broad terms, the contributory elements which make up the totality of disablement, but specifically in smaller and more remote Commonwealth countries. To attempt to do so for major developed countries would be pretentious and self-defeating. But