

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

much valuable material has been supplied by ministries of health and IYDP committees in the larger countries, and this enabled consideration to be given to the application of the experience of wealthier countries to the needs of those at a much less advanced stage of economic and social development. Much of it is not directly relevant. Those tackling the disabilities of affluence find it difficult to adjust to the diseases of deprivation. It was one of the tasks of the survey to bridge the enormous gulf between IYDP committees who were spending their time on access by wheelchairs to public buildings, because that was what their own environment dictated, and committees who realised that one good meal a day for the villagers in their country was perhaps a higher priority in health terms than begging even a few wheelchairs which would be doubtfully useful in mountainous and remote rural areas.

22. Countries varied widely in their practical interpretation of the term "disabled person". Meeting with some national IYDP committees, I formed the impression that their almost exclusive concern was with orthopaedically disabled adults. References to the profoundly deaf and the hard-of-hearing or to the blind and partially-sighted received the answer: "They have their own arrangements". Rather more contentious were the reactions to questions about the intellectually handicapped. With notable exceptions, the implication seemed to be that nothing much could be done for them anyway, and that it was better to leave them in the loving care of their families and communities.

23. These comments suggest that in many countries, perhaps the majority, not much attention had hitherto been paid to people with spinal injuries, residual polio paralysis, amputations and other mobility handicaps, and that these people were seizing their opportunity in IYDP to call attention to themselves. These are, of course, the "visible" handicaps and it is understandable that they should receive immediate attention in a year devoted to disabled people. One result will be that this report will emphasise the need for orthopaedic surgery, physiotherapy, occupational therapy and vocational retraining leading to employment, comprehensively referred to as "rehabilitation", for the many who are threatened with a life of total inactivity following car accidents, acts of violence or mishaps such as falling from trees. Much unnecessary suffering and frustration can be relieved by the development of appropriate facilities for such people. As they become more mobile, even if only in wheelchairs, society must listen to their plea for adaptation of their homes and for access to means of transport, public buildings, etc., which forms such a large part of the conclusions of many national IYDP committees.

24. But the "invisible" handicaps, particularly deafness and mental retardation, deserve better than the lack of attention they have received in some national programmes. The balance is redressed where there are strong associations of and for the deaf and where parents of intellectually handicapped children have successfully enlisted the support of others to create organisations to provide needed services and to solicit the support of governments in the supply of hearing aids, special schooling for handicapped children and other needs.

#### **IYDP committee proposals or government programmes?**

25. Few governments had programmes of action formulated specifically for disabled people. That was a reason for declaring a special Year. This consultancy was so timed that it was possible to find out what IYDP committees were planning to recommend; but that is not to say that their recommendations were necessarily going to be adopted by governments. There were three broad sets of circumstances. Where the deliberations of IYDP committees were very much under government control, the financial or manpower difficulties inhibited bold or impracticable suggestions. In these circumstances, it was the voluntary organisations that tended to get on with their own work, relying as before on public support by their own fund-raising efforts. At the other extreme, where the IYDP committee was detached from government, it was the ministerial representatives who tended to get impatient with the discussion of matters which did not directly concern them and to which, in many cases, they accorded little priority in the realities of government's financial resources. The third category was the IYDP committee which maintained active participation by the key ministries of government and by voluntary organisations, genuinely seeking to thrash out a policy which was both practicable and advantageous to disabled people.

26. Even in the third category of committee, there was a consciousness that limited and even shrinking government funds made the implementation of many of the proposals doubtful. In

several countries, discussion in government departments away from the IYDP scene showed all too clearly that very strong (and even unwelcome) ministerial directives would be necessary if some of the proposed projects were to be carried out. This was not due to any hostility to the cause of disabled people, but to jealously guarded departmental votes already considered too small for the long-term task in hand. Why should one ministry (usually Social Welfare) plan for larger share of the national cake, which was already too small anyway? Very rarely did an inter-ministerial approach to the whole question of disablement override these departmental considerations. By no means all national IYDP committees had formulated and submitted their proposals to governments by 31 March 1982; and it must necessarily take some time for governments to decide what action they are going to take on them.

27. It is for this reason that so much of this report describes the deliberations and aspirations of IYDP committees rather than the declared policies of governments: very few such declarations have yet been made. Where the implementation is clearly going to incur continuing annual liabilities, warning notes have already been sounded. If the gathering together of the real needs of disabled people for the first time in the reports of 1981 IYDP committees are not to be wasted effort - apart from the "public awareness" impact during the Year itself, which was often considerable - some continuing mechanism is essential: it will take much more than one year, or two, to influence the policies of the several departments involved in the direction of a co-ordinated effort. This report suggests what form such a continuing body might take. It exists already in several countries and is recommended by IYDP committees in others. The problem is to make it genuinely inter-ministerial and representative of voluntary effort at the same time.

28. It is, of course, theoretically possible to extract from the departmental records of each department of government those aspects of its work which have a bearing on disabilities and to make an inventory of them. The section of this report dealing with government policies for the disabled (paragraph 110 et seq) set out with the hope of being something of this sort. But it was soon realised that the report would run to several volumes and even then would be incomplete because the relevant information cannot be obtained in a short space of time. Where IYDP committees have prepared lists of services available to disabled people, these are a useful guide; but they rightly list large numbers of small voluntary associations and often overlook the main relevant government provision in hospitals, health centres and educational establishments which tend to be taken for granted or at least to be common knowledge. For the sake of brevity, if for nothing else, the section on government policies has become a mere shadow of its intended self. It merely gives a few significant facts from policies advocated by IYDP committees and programmes being carried out in a few countries to illustrate the problems of devising a national policy for disabled people. In that section, and throughout the report, the realities of economic possibilities in the smaller Commonwealth countries with few resources were kept very much in mind.

### Country visits

29. It is dangerous to make judgements after visits to any country of no more than three or four days unless there is balancing documentation to support or justify impressions gained on the spot. I went to learn; unexpectedly, a main benefit of some country visits was the chance they gave to local IYDP committees to explain the reasons for their own activities, to discuss their difficulties and to hear what other countries were doing for their disabled. Ministries of health are accustomed to having representatives of WHO and UNICEF in their midst and to receiving visits from their consultants. Ministries of social affairs (social welfare, social development, social security), who had responsibility for IYDP arrangements in most countries, seldom receive international visitors. They received large doses of literature and encouragement from UN sources initially, but they had not hitherto been visited by someone whose exclusive concern was the whole range of disabled people. They found with relief that the visitor understood their problems and spoke their language: the Commonwealth mystique worked.

30. But "speaking their language" all too often meant the language of social welfare. There was everything from surprise to open disagreement when I suggested that there was a medical dimension to what they were doing. In their view, IYDP was a social welfare concern. It had been assigned to them and IYDP was a jealously-guarded social welfare preserve. Wherever possible, I tracked back from welfare to health. Discussions with health officials on the

preventive aspects of disablement were welcome and profitable; but in several countries the local view was that they had little or nothing to do with IYDP. After all, was not IYDP really about social integration and equal access to facilities? It was about people who were irremediably disabled. They deserved equal treatment and their rightful place in community life. Therefore it was a social welfare matter. The injection of the questions "Is everything possible being done to mitigate the disabilities of individual people?" and "Is all this disablement really necessary? How much of it could be avoided for the next generation? Is not WHO's Expanded Programme of Immunisation a vital part of IYDP, or at least of the Decade of the Disabled which follows it?" - either led to nothing or was referred to the ministry of health.

31. In one country my written and oral briefing by the Ministry of Social Welfare contained no mention of the admirable new rehabilitation institute and hospital for the disabled, opened by the President to mark the inauguration of the International Year. In another country the proposal of the IYDP committee was to create, on a fresh site, a centre for the disabled without incorporating or maintaining the existing rehabilitation machinery associated with the main hospital or the day centre for severely handicapped children. In a third, money raised by public subscription for the disabled was to be spent mainly on social welfare handouts to ease the way of life of disabled people and to subsidise their organisations.

32. In a fourth country, India, it is only fair to add, the central government budget for IYDP was controlled by the Social Welfare Ministry but spent on remedial, preventive or social objectives as need dictated. It proved possible and acceptable to discuss prevention and medical rehabilitation within the Social Welfare Ministry, which commanded the IYDP vote but recognised from the outset that the needs of the disabled had a large medical component. In concert with the Ministry of Health the Social Welfare Ministry was prepared to release money for physical rehabilitation and also for the prevention of disablement.

33. Much depended, of course, upon the medical representative on the national IYDP committee and the hearing he received in its deliberations. With notable exceptions, representation of the ministry of health in most countries appeared to be anything but compelling. This is perhaps not surprising as the committee was discussing matters far from medical professional concerns. This comment relates, of course, mostly to my "smaller and more remote" clients and particularly to committees which were firmly the responsibility of a government department. Where the committee was in effect a national council for the handicapped, operating at one remove from government, cooperation between Welfare and Health - and also with Education, Labour and Information - was more easily achieved.

#### **Ministerial responsibility**

34. Enough has been said already in this section of my report to show that policies and programmes for disabled people in the community cannot be the exclusive concern of any one ministry of government. Internationally, the stimulation and supervision of the International Year was assigned to the Centre for Social Development and Humanitarian Affairs in Vienna. Understandably, the Centre stressed the General Assembly's theme for the Year, which was "Full participation and equality", i.e. the second of the basic questions already posed in paragraphs 19-20 above. The goal was to integrate disabled persons into community life by removing barriers of all kinds, including unhelpful social attitudes. In accordance with this assignment at the international level, most Commonwealth governments designated their social affairs, social development or social security ministry as the responsible department of government. Just as the UN Centre for Social Development and Humanitarian Affairs had not only an international advisory committee but also inter-agency consultative machinery, so Commonwealth governments appointed national IYDP committees consisting of relevant government departments and voluntary societies working with and for disabled people. However, such is the nature of departmental responsibility within a government that a genuine inter-ministerial approach was all too often not achieved, and the social aspects tended to predominate.

35. Close cooperation with relevant voluntary organisations was the general rule; indeed, where governments had little or no money to spare, the Year's activities resolved themselves into attempts to coordinate and support their work. Perhaps the most surprising feature of the constitution and practice of many IYDP coordinating committees was a strange reluctance to admit into their councils the representatives of groups of disabled people themselves. This led in some countries to dissatisfaction with the traditional "service providers", whether government or voluntary, and some degree of militancy. The desire of disabled people to speak for themselves was reflected internationally by the creation of Disabled Peoples' International, which held its first Congress in Singapore in November 1981.

36. The first lesson to be learned from the experience of the Year is, therefore, that continuing work with and for the disabled should be on a genuine inter-ministerial basis, in the closest cooperation with voluntary agencies and with organisations of disabled people themselves. Where the social welfare aspect dominated, the impact tended to be intangible and possibly ephemeral. My first recommendation therefore is that the continuing national council for the handicapped, or whatever it is called, should be one stage removed from the confines of any one government department, be able to supplement official grants by raising more money from the public and be free to get on with its job, subject of course to independent audit. There are several models for such a permanent body in Commonwealth countries where these principles have been successfully applied. They will be mentioned in "Notes on some significant developments" below (see paragraph 132 et seq).

## IYDP ACTIVITIES IN COMMONWEALTH COUNTRIES

### Public awareness

37. Almost every national IYDP committee put public awareness of the existence and needs of disabled people at the head of its list of objectives. Presidential or ministerial statements opened the Year's proceedings. The press, radio and television were used to publicise the purposes of the Year and to present features about the achievements of disabled people as well as their needs. At least 17 Commonwealth postal authorities issued special postage stamps. There were sponsored essay competitions for schoolchildren and exhibitions of work done by disabled people. The widespread appearance of the IYDP symbol and slogans was impressive: on posters, on T-shirts, on car bumper stickers, on the covers of telephone directories. "Full participation and equality", the official theme, was supplemented by local slogans such as "Enable the disabled", "Disability is not inability" and "An equal chance is all they ask". Sports events for disabled people were doubly effective in publicising the special Year and giving great encouragement to the participants. The International Abilympics in Japan stimulated local skill contests - a stimulus to the disabled competitors and a public demonstration that "disability is not inability". A great deal of local ingenuity and the expenditure of a considerable amount of money left few members of the community unaware that 1981 was the Year of Disabled Persons.

### Surveys

38. As many IYDP committees started their work by saying "We do not know who the disabled are nor how many there are in each category: therefore we must put in hand national surveys to establish the categories and figures as a basis for our planning", a recommendation to this effect appeared early in their proceedings. Some tentative results began to appear by the end of the Year. In Canada, for example, Health and Welfare "attempted to develop a picture of the extent of disability and estimated that in 1979 there were approximately 2.3 million disabled persons in Canada or 9.8 per cent of the Canadian population". This is remarkably close to the "One in ten" adopted by UNICEF. In many countries I was told either that the survey had been done but the results had not yet been collated, or that the survey was being put in hand but would take a long time, or that the manpower was not available and the projected survey had been deferred for the time being.

39. Even sample surveys cannot be conducted without a quite precise definition of "disability" which it is usually beyond the ability of, for example, a census enumerator to apply; and in many communities there is still a strong tendency to hide handicapped children as though they were a disgrace, an indication of wrongdoing on the part of the parents or a visitation from angry spirits. Health authorities in many countries took the view that to count disabled people, particularly children, without offering any remedy, was immoral. The way to ascertain their numbers and categories was to offer a service as, for example, in Indian eye camps where people come forward from considerable distances because treatment, including cataract surgery, is available. When such "camps" are multi-purpose, the records kept by the organisers are an invaluable and sometimes unique source of factual information about the numbers and categories of disabled people who are conscious of their need for help, or parents with children who need help.