

locally available materials. Training in making such aids has already started but my hope is that it can be very much extended on a regional basis under a recommendation I make below (see paragraph 263).

Prevention

52 Most IYDP committees put the prevention of disablement prominently on their list of objectives. The most obvious area of prevention was road safety because hospital statistics show an alarming increase in car and motor-cycle accidents, resulting in spinal injuries and amputations. Nor were industrial and agricultural accidents forgotten, and committees called attention to the need to ordain and enforce regulations for greater safety at work. Statistics suggest that home accidents, particularly burns and falls, outnumber industrial and agricultural accidents - cooking while wearing a sari can present a serious fire hazard, for example - but this takes us into very far-reaching long-term social action.

53. Medical prevention, e.g. by immunisation, received remarkably little attention, although in five countries I was told that the incidence of deafness among children had been associated during IYDP with rubella epidemics and campaigns for rubella immunisation had been inaugurated. Special attention to this subject is recommended later in this report (see paragraphs 106-109). The successful extension of the cold chain to remote villages to ensure immunisation against polio was, of course, a main concern of the medical authorities but, surprisingly, rarely impinged on the consciousness of IYDP committees as part of their responsibility or interest. I discussed perinatal care and infant nutrition with medical authorities, who recognised them as essential prerequisites for the avoidance of unnecessary disability; but most IYDP committees regarded these subjects also as falling outside their purview.

SOME PRINCIPAL CAUSES OF DISABLEMENT

Childhood infections

54. IYDP committees concerned themselves mostly with people in the community who are already disabled and with preventing road and industrial accidents, rather than with action to reduce the number of avoidable disabilities in the next generation. Government health programmes, on the other hand, are giving increased attention to this aspect.

55. Deaths from diarrhoeal diseases and preventable infections like neonatal tetanus, measles, whooping cough and diphtheria - which could be described as the diseases of deprivation - are not the direct concern of this report. The survivors are. Recurrent infection coupled with malnutrition causes grave disabilities in later childhood and adult life; so any study of the disabled in the community must take account of them.

56. Most governments are as concerned now about maternity and child health services in rural areas as they are with the traditional emphasis on hospital care and the development of complex technology in prestigious institutions. Immunisation is recognised as an essential element in primary health care and governments are assisted by WHO, UNICEF, bilateral aid and voluntary societies in implementing the Expanded Programme of Immunisation. This covers the six major vaccine-preventable diseases of childhood; and some governments are able to add rubella, at least for girls at pre-pubertal age.

57. The extent of poliomyelitis epidemics in many developing countries over the last 25 years is only now being fully realised. After the introduction of the Salk vaccine (by injection) and the Sabin vaccine (by mouth) in 1958, industrialised countries lost no time in controlling their epidemics. Although finance and the organisation of delivery mechanisms deterred the extension to developing countries for some years, notable successes can now be recorded. But the damage has been done by the severe epidemics in many Commonwealth countries in the years immediately preceding the availability of the vaccines. Many victims died, but many remain alive with varying degrees of paralysis and they now form one of the most important groups for surgical, prosthetic and orthotic help. This is one of the reasons why so many of the IYDP

committees appeared to equate "disabled people" with the orthopaedically disabled and were so largely concerned with their mobility and access to all the amenities of normal life as full members of the community.

58. In 1979 the International Year of the Child focused attention throughout the world on maternal and child care. In 1980 UNICEF received from Rehabilitation International a detailed report on childhood disabilities which it has now incorporated into its regular programme. It recognises that most physical and mental impairments suffered by children result from inadequate nutrition of mother and baby, from faulty childbearing practices and from preventable diseases. In concert with governments, UNICEF will direct its main efforts towards better preventive measures through primary health care and basic services programmes. Recognising that most impairments that do occur need not necessarily develop into serious disabilities and handicaps, emphasis will also be placed on the detection and treatment of impairments, again through existing and improved health, education, nutrition and welfare services. UNICEF is working with WHO on the development of the manual for "Training the disabled in the community" which will involve a maximum stimulation of community participation in both prevention and rehabilitation. The manpower training requirements of such a programme are formidable, especially for countries with limited and hard-pressed resources, and are the subject of comment later in this report.

Blindness

59. The remark made in IYDP committees, already quoted in this report, that "the blind have their own arrangements" reflects the attention that has been given to the welfare of the blind for many years. A survey of the extent and causes of blindness over 30 years ago led to the formation of the Royal Commonwealth Society for the Blind (RCSB) in 1950. Since then, working with and through its partner organisations throughout the Commonwealth, the society has promoted education for blind children, vocational training and employment for blind adults, the treatment of blindness by mobile clinics and in eye camps, and major measures for the prevention of unnecessary blindness. It has founded national organisations for the blind in most Commonwealth countries, including many of the smallest, and has constantly supported and encouraged the concept that each country should make provision for its blind citizens within a national programme covering both rehabilitation and prevention.

60. These national societies have played a leading part in the creation of national councils for the handicapped, where they exist, and were represented on most IYDP committees, but not all. Indeed, the remark quoted above is an indication of a desire to seize the opportunity of the International Year to redress the balance in favour of the orthopaedically disabled, who regarded themselves as neglected by comparison, and also in favour of the mentally retarded for whom work is often of recent growth and somewhat an uphill struggle. Talks with organisations of the blind suggest that what they regard as the "wheelchair image" of IYDP in their country deprived them and the sensorially handicapped generally of the attention they merited.

61. While increasing support to national action for the education, employment and independent living of the irrevocably blind, the RCSB has led a vigorous attack on the causes of needless blindness. Fifteen million of the world's estimated 42 million blind people live in Commonwealth countries. The society's medical teams have restored sight to over one million blind people in Asian, African and Caribbean countries of the Commonwealth. Its research into onchocerciasis (river blindness) led to the major control campaign now mounted against this disease by international agencies working with nine West African governments. In 1974, on the invitation of the world organisations concerned with blindness and with ophthalmology, the society took the initiative in founding the International Agency for the Prevention of Blindness. This Agency, for which the society provides leadership and an administration, exists to mobilise interest and resources for a global effort for the prevention of blindness, which has now been recognised by the World Health Organisation as a priority of its global programme of technical co-operation. National programmes for the prevention of blindness are now in operation in many developing countries of the Commonwealth with the aim, over the next 20 years, of controlling four eye diseases - trachoma, onchocerciasis, xerophthalmia and cataract - which together account for two-thirds of the blindness in developing countries. The Commonwealth experience has proved to be an effective model for such international action which has been described by

the Director-General of the World Health Organisation as "one of the most cost-effective options in the whole contemporary range of world health policy".

62. Economic self-reliance for disabled people is an overriding aim of most IYDP committees. Sheltered workshops for the blind are tending to become either vocational training centres or commercially-run production centres giving employment to other disabled people in addition to the blind. I suggest below that this development, calling for improved techniques in management, marketing and design, is a direction in which an invaluable contribution might now be made by businessmen associated with the service clubs which do so much to provide buildings for sheltered workshops.

63. There has been a significant Commonwealth interaction in this field. Industrialised countries have contributed, and benefited from, a wider application of research, professional training and the development of sophisticated technology such as computerised and multilingual production of braille and talking books. Developing countries, with their experience of primary health care, mass low-cost surgery, rehabilitation for village life and the cheapened production of simple equipment, have influenced prevention and rehabilitation policies in industrialised countries.

64. The Royal Commonwealth Society for the Blind, in association with its partner organisations throughout the Commonwealth, has provided powerful stimulus for Commonwealth co-operation using philanthropic funds. It gives grounds for hope that similar action might now be taken for other groups of handicapped people, particularly if inter-governmental action for the disabled is recognised as an appropriate and cost-effective enterprise for Commonwealth co-operation.

Deafness

65. IYDP committees included representatives of societies for the deaf and those with impaired hearing. Statistically, such surveys as have been undertaken show that the prevalence of deafness is very high, one person per thousand being profoundly deaf (i.e. for whom amplification is of very limited or no value) and much greater numbers hard of hearing, the impairment ranging from serious handicap to genuine hindrance or social disadvantage. Yet the recommendations of national committees had little to say about the deaf in the community, apart from the need for early detection, special education arrangements and the provision of sign language on important public occasions and visible headlines for the television news. Their pleas for public awareness of disability of course included a realisation of the difficulties experienced by the deaf socially and in obtaining employment, but in general rather than specific terms. From the point of view of Commonwealth action, the concern must be for the education of deaf children, and also for effective research into the causes of preventable deafness.

66. In industrialised countries, children with impaired hearing are being helped, some by surgery, some by the devotion of parents and trained teachers, some by hearing aids. The profoundly deaf can go to special schools, where they can get almost individual attention, but this is probably the most expensive form of education in the world. In the developing countries, only a very tiny minority are at present within reach of any help. Generous gifts of hearing aids do little to remedy the situation. They break down all too quickly and the supply of batteries creates a problem, especially if foreign exchange is involved. Few batteries last more than a week or ten days. Often, the aids have to be left at school when the child returns home for holidays or on completion of a course: a measure of hearing has been restored, only to be taken away again. Nevertheless, a good deal has been achieved by voluntary societies in many developing countries. Their efforts need all possible support to increase the tiny proportion of deaf children at present receiving the special education they need.

67. Much of this support will have to come from outside. The Commonwealth Society for the Deaf was started in 1959 and continues to offer help and guidance; and Australia and New Zealand have for many years supplied technical assistance in the education of deaf children and their teachers in Papua New Guinea and the Pacific islands. The Ghana Government established a training college for teachers of the deaf in Mampong as long ago as 1964 and this is a main centre for training specialised teachers for other African countries, often with CFTC support.

68. The Commonwealth Society for the Deaf helped to develop an excellent teacher training complex in Malawi with the support of the Commonwealth Foundation. It has also fostered projects in Nigeria (where there is a strong local Society for the Deaf) and in The Gambia, where an audiologist from Australia has been supplied through the CFTC. The society sent a team of four to India early in 1982 to conduct short courses for teachers for the deaf in Madras, Calcutta and Bombay under the title "The modern educational treatment of deafness". But there is a great deal more for the society to do in conjunction with local organisations who need guidance, equipment, financial support and, above all, training for teachers of both the profoundly deaf and those with impaired hearing.

69. At present, in the less developed countries most deaf children pass through the primary school without any special provision for their difficulty in learning, or they do not go to school at all. With improved primary health care, and with more and more teachers on the look-out for learning difficulties, the profoundly deaf or children with impaired hearing are being brought to notice in greater numbers; and the waiting lists for government and private special schools for the deaf are growing far beyond the financial resources available to provide for them. The ideal, of course, is not to segregate handicapped children in special establishments but to educate them together with children without disabilities; but it can be argued that deafness is the greatest barrier to learning because of the high proportion of the normal schooling process the deaf child misses. Early detection is essential and special skills are necessary to enable him or her to communicate. Clearly, the day is far off when the village primary school can be equipped with either the skill or the apparatus to cater for the needs of children with impaired hearing, let alone the profoundly deaf who have not learned to speak. As these disabilities are detected, there must be special schools to which the children can be referred. The work of local voluntary bodies should therefore be encouraged and governments should see the necessity to assume responsibility for their educational work as circumstances permit.

70. This pessimistic but, I think, realistic assessment dramatises the urgent need for research into the prevention of unnecessary deafness. If it is true that in some communities as much as 70-80 per cent of hearing loss is due to genetic factors and consanguinous marriages are the custom, we can think only in terms of genetic evaluation and counselling. But elsewhere we are told that more than half the causative factors are potentially preventable. Otitis media is the most common cause of hearing loss in children, and this is often reversible by medical and surgical treatment, given early identification and early intervention. Already, the spread of the Expanded Programme of Immunisation is giving protection against measles and other diseases of childhood which can lead to hearing impairment.

71. A Commonwealth Society for the Deaf study in Ibadan, Nigeria, has shown that about two-thirds of the deaf children, where a cause was attributable, were deafened by measles, meningitis and rubella in about equal proportions. As noted later in this report, a consequence of the Leeds Castle seminar on the prevention of disablement is that rubella immunisation is being stepped up in many Commonwealth countries. With more concentrated attention to the causes of avoidable deafness, delivery mechanisms might well be devised which would reduce the incidence. Since there is so little we can realistically plan for the education and social well-being of the vast majority of the deaf and hearing-impaired in developing countries, a deliberate policy of prevention should be urgently explored and put into effect. Prevention is not only better than cure: it can turn out to be far, far cheaper.

Orthopaedic handicaps

72. Many IYDP committees gave the impression that their principal concern was with people in wheelchairs rather than the generality of disabled people. Their main drive was towards the removal of barriers, physical and social. Ramps (not always welcome to people with artificial legs) should replace steps. Curbs should be abolished where pedestrians cross at road intersections (not always acceptable to blind people). Doors should be wide enough to admit wheelchairs and they should open automatically whenever possible (hardly a high priority in third world countries). Washrooms in public places and at work should be adapted so that disabled people can use them. Reasonable solutions should be found for the transport of physically handicapped people on buses, aeroplanes and all forms of public transport. Housing standards should be developed which reflect the needs of disabled people, and government grants should be made available for adaptations. Sports and leisure facilities should cater for the needs of

disabled people. (My overseas tours ended at the Boston Marathon, where 22 "wheelies" completed the course, to the great delight of the one and half million spectators, two of them in a faster time than the course record for those running on two feet).

73. The use of the "access" symbol (a wheelchair in profile) in so many public places may well have been the greatest single means in some countries of creating public awareness of the disabled in their midst. It tended to reinforce the ideal that "disabled" means "wheelies", but it contributed to the removal of the other kind of barrier to which IYDP effort was calling attention: social attitudes which failed to recognise that wheelchair and other disabled people could function independently within society if they were accorded their right to "full participation and equality".

74. So the emphasis on the orthopaedically disabled served its purpose in countries where the main need was for public acceptance and recognition. There were echoes of this approach in less developed countries but the real priorities were utterly different. The ability to lead a full life in the community although confined to a wheelchair presupposes orthopaedic surgery and a rehabilitation process involving physiotherapy, occupational therapy and vocational retraining. These are available to a minute minority of the people of many of the smaller Commonwealth countries. One of the main purposes of this report will be to open up possibilities of bringing such help to more of those who need it.

75. Inevitably, there are regrets about the conduct of this survey. One of them is that I spent so much time with IYDP committees and the social welfare departments to whom they were responsible and so little time, comparatively speaking, with ministries of health, orthopaedic surgeons and rehabilitation technologists and technicians. It is true that ministries of health were represented, at least nominally, on IYDP committees. But hard-pressed medical officers concerned to improve and spread primary health care to remote villages can hardly be expected to spend time on committees discussing self-opening doors and wheelchair access to public lavatories. But I did see and hear enough to realise that, just as some IYDP committees paid a great deal of attention to the social needs of the orthopaedically handicapped, so this report should call attention to their surgical and rehabilitation needs in less developed countries.

76. In March 1970, the Commonwealth Foundation sent Professor Ronald Huckstep, then Professor of Orthopaedic Surgery at Makerere, Uganda, on a lecture tour of thirteen Commonwealth and four non-Commonwealth countries. It was much more than a lecture tour and its beneficial effects were still perceptible in several countries eleven and a half years later.

77. It started a process of considering how both developing and developed countries could tackle the vast problem of many thousands of untreated orthopaedically disabled people. Professor Huckstep's influence over the whole rehabilitation process, including the production of prosthetic and orthotic aids, had already been felt in Eastern and Central Africa. The next step was a symposium on orthopaedic training in developing countries, which took place at Oriel College, Oxford, in 1973, and a second symposium in 1976, also at Oriel College, on appropriate technology and delivery of health and welfare services for the disabled in developing countries. This series is now badly needed all over again: the inspirational and fact-finding visit, followed by joint consideration of the two vital subjects, appropriate technology and training at all levels. India was not included in the 1970 tour, although there was Indian participation in both Oriel College conferences. India has a great deal to offer, with centres covering the whole field of rehabilitation from orthopaedic surgery through therapy to vocational education and employment, with increasing production of simple prosthetic and orthotic devices made from local materials*. These they are now effectively taking to rural areas.

*A comprehensive review of these production facilities, as they were in 1979, by Mr. David N. Condie of Dundee, is available through the British Council.

78. Some continuing arrangement for Commonwealth consultation and action might have been expected to result from the Oriel College conferences, which were assisted by the Commonwealth Foundation. The nearest approach to such a Commonwealth organisation is World Orthopaedic Concern, a network of some 400 surgeons who keep in touch with each other and do all they can to improve the orthopaedic services in the most needy countries either by offering their own expertise or by organising training programmes in selected areas. Their activities are an inspiration to orthopaedic surgery and to the whole rehabilitation process, including the production of prosthetic and orthotic aids. They can advise and help governments towards the establishment of rehabilitation teams at professional level, which in turn will make possible the training of rehabilitation assistants, orthopaedic technicians and primary health care aides with a rudimentary knowledge of help to be given to the physically handicapped in their families and their community.

79. The regionalisation of their activities, which they are now contemplating, would facilitate the training of these rehabilitation teams on the job in their own countries, where they are needed, instead of running the risk that, as at present, a proportion of those sent away for training acquire disproportionately sophisticated skills and are reluctant to return home where more simple methods are appropriate.

80. While poliomyelitis immunisation is protecting the next generation in the developing world, the numbers of untreated paralytic polio cases have been grossly under-reported in West Africa, South Asia, the Pacific islands and probably elsewhere. Some may be content to crawl or to beg, but thousands need and deserve attention. In Papua New Guinea, the Solomon Islands and Fiji, there are people in bed for years on end after having fallen from trees, been injured in their ferocious game of rugby football or even kicked by cassowaries (three such were entered in the orthopaedic ward records at Lae Hospital). Add to this the growing concern in most countries about traffic accidents, seriously injuring at least 15 for every one they kill, and it will be seen that in communities covered by this survey, the real IYDP concern is not about access to buildings for wheelchairs but about people who cannot get into wheelchairs even if there were wheelchairs to put them in.

81. The Expanded Programme of Immunisation and better perinatal care are slowly but steadily attacking major causes of disability from birth mishaps and major childhood diseases which have a crippling effect, particularly polio and measles. But accidents to young people and adults will still occur, and a bedridden life with bedsores should not be the inevitable penalty. For the blind, for the deaf and for the mentally retarded, voluntary associations now exist almost everywhere. For the category of disabled people which IYDP seemed in some countries to be all about - the orthopaedically disabled - the Commonwealth initiative of 1970 to 1976 in this field needs to be resumed.

82. I have recommended accordingly later in this report (paragraphs 259-261). Since those recommendations were worded, they have been reinforced by reports from "Malawi against Polio" which might well be the pilot project for countries with large numbers of untreated poliomyelitis victims and other orthopaedically disabled people. While the Malawi Ministry of Health and the Save the Children Fund are carrying out a five-year immunisation programme against poliomyelitis, Rotary International has mounted, in conjunction with local service clubs, a major project to reach the untreated cases, which include over 17,000 children under 15 years of age. The project involves visits by orthopaedic surgeons with experience in the developing world and a considerable expansion of the local production of calipers and other supports. Professor Huckstep, who devised the project during his Commonwealth Foundation tours in 1970, 1978 and 1980, re-visited it in April 1982, just one year after the project started. His report will be a guide to other countries who decide to invite a strong external intervention of this kind to tackle the backlog of poliomyelitis victims and other orthopaedically handicapped people as a result of the programme I have recommended.

Mental retardation

83. Many IYDP committees did not include mentally handicapped adults or children in their purview. "As there is so little we can do for them, it would be cruel to remove them from the loving care of their family and community". "They cannot speak for themselves, and so lose out". "We do not want the public to think that the mentally retarded or the mentally disturbed are the sort of people we want them to think of when we draw attention to the needs of the disabled people in the community". These were typical of the reasons given for their exclusion.

84. Fortunately, if the mentally retarded cannot speak for themselves in committees, there are others to speak for them. Parents of mentally handicapped children in country after country have developed a pattern of action leading to the establishment of action groups, some of them now very strong, to influence the community and the government in favour of making at least some basic provision for children with intellectual handicaps. Concern for their own child leads to simple home-based activities, the inclusion of other children with similar needs, the seeking of professional help and the formation of associations to act as advocacy groups demanding the whole range of services: medical attention, schooling, vocational training and employment opportunities. Where this process is far advanced (New Zealand and St. Lucia come to mind, and there are many others) the groups concerned with intellectual handicap were in the IYDP process from the outset and played a major part in the Year's activities. They made sure, for example, that the mentally retarded were not excluded from Sports for the Disabled or from trips to Disneyland in the USA with groups of blind, deaf and orthopaedically handicapped children.

85. Special schools or day centres for the mentally retarded now exist in most Commonwealth countries. Many are of very recent growth. Inevitably, they tend to cater for children in urban areas or within bus-reach of towns. They rely heavily on voluntary assistance for funds and for staff. Governments are gradually assuming responsibility for the salaries of the few trained staff, and making small hard-won annual grants-in-aid; even, in a few cases, providing buildings. But this work is not given much priority and the current drives for economy in public spending give little hope of an early increase in government support. Meanwhile the dependence on voluntary help with the teaching and care of the children, including the wives of transient expatriates and short-term volunteer attachments, make the whole operation precarious. Fund raising does not get any easier, and although service clubs help a great deal, their contributions are usually once-for-all in the form of new buildings or the supply of equipment. Expansion of facilities cannot in most countries keep pace with increased demand; and few governments are at this stage able to contemplate taking a larger share in work of this kind.

86. In any case, fundamental questions are now being asked about the wisdom of expanding special institutions for the mentally handicapped. Governments are beginning to say that they will spend no more money on specialised institutions, without, in many cases, saying how the special needs of mentally handicapped children are to be met. The theory that these children should be cared for in the community and attend their local primary school is becoming accepted policy; but it presupposes that some of the teachers in primary schools should be trained or at least prepared to cope with slow learners; also that education ministries in even the smallest countries should have a special education division - or at least one officer - specialising in techniques and equipment for children with special needs. It is all too easy to say that more local people should be trained for this special work, to meet the growing need and to replace expatriate and local volunteers; but governments are often not only unwilling, but also financially unable, to increase the number of posts or to pay for the special training of staff.

87. Visits of qualified and experienced people under technical assistance arrangements seem to be the most acceptable answer; but they will bring permanent benefit only if the opportunity can be taken of in-service training for local people while the qualified practitioner is working in the country with a counterpart alongside to take over at the end of the technical assistance assignment. That again is easy to say, but it has been found difficult, if not impossible, in practice to provide local counterparts for expatriate volunteers, either because local candidates do not come forward or because adequate salaries or wages cannot be found (the second being probably the cause of the first). My recommendation therefore is that agencies of technical co-

operation, particularly those operating joint venture arrangements with voluntary organisations, should seek to supply experienced teachers of children with learning difficulties. Their presence would act as an inspiration to local people engaged in the work, improve their capabilities as teachers of the mentally retarded, introduce or improve local aids to learning, give new people in-service training and help both government and voluntary agencies to develop a long-term strategy.

88. Developments along these lines would be encouraged if there were a Commonwealth panel of consultants in mental retardation who would in turn create and inspire regional Commonwealth associations. On the recommendation of the New Zealand Society for the Intellectually Handicapped, I went to see Professor G. Allan Roeher of York University, Toronto, who in August 1982 becomes President of the International Association for the Scientific Study of Mental Deficiency at its Sixth International Congress. I discussed with him the possibility of asking the Commonwealth Foundation to help key people in this field to take part in the congress, which has as its theme "World-wide sharing", so that they could benefit from the discussions and the contacts. The thought was that, while they were there, individuals might be selected to serve as a panel of consultants and possibly as generators of regional institutes or associations to encourage and inspire local practitioners - medical and educational - in the field of mental retardation.

89. Professor Roeher has already done a good deal to stimulate and support the formation of local and regional institutes, not only in Canada but also in New Zealand, India (Trivandrum), Hong Kong and Australia (Queensland). He also fostered a Caribbean Institute on Mental Retardation and Developmental Disabilities with headquarters in Jamaica and a Caribbean-wide association stretching down to Trinidad and Guyana affiliated to it. Investigations on the spot suggested that although the institute in Jamaica appeared to have gone over very largely to the important narrower specialisation of early stimulation, the Eastern Caribbean unit of the association is effectively reaching the smaller islands with much-appreciated seminars and workshops on teaching mentally retarded children and on vocational rehabilitation generally. Similar work is done in the Pacific islands by the Asian and Pacific Action Committee of the New Zealand Society for the Intellectually Handicapped and a special education adviser provided under official Australian aid.

90. Because so many of those undertaking the care and education of mentally retarded children in the smaller and more remote islands have little prospect, for financial reasons, of formal teacher training and no other exposure to special education techniques, movements such as these, on a regional basis, are very much needed. There is already a move to form a Commonwealth Association for the Scientific Study of Mental Deficiency, following a successful First Asian and Commonwealth Congress on the subject, held in Bangalore, India, in May 1981. Although such an association might be expected to place its main emphasis on the important aspect of primary prevention, the Bangalore conference also stressed parent-professional partnership in the care, education, training and rehabilitation of mentally handicapped children and adults. Professor Roeher has invited the chief organiser of the Bangalore conference, Dr. V.R. Pandurangi, to promote the concept of a Commonwealth consultative panel during the Toronto Congress in August 1982.

91. The brief mention above of the importance of the concept of early stimulation provides an opportunity to emphasise the need for early detection and assessment. Every individual, however retarded, has a certain potential, and this will be reached only by maximum stimulation from babyhood within a secure family unit. That is easy to write but difficult to achieve. Many smaller countries are perforce having to wait until children get to school before attention is called to difficulties in learning, but improved perinatal services and the experiments now being conducted in some countries under WHO and UNICEF auspices raise hopes that access to children in need will become possible at an earlier age. I gather that a great deal more experience will be necessary before we are able to say that family-administered dietary treatment and additional mental stimulation can improve the capability of the retarded child to cope with self-care and a share in community living.

92. My comment from observation and discussion in many countries is that this is an area of research deserving a great deal of support. The process of bringing out, instead of hiding, mentally retarded children has started and we cannot pretend that the least developed countries have any prospect at present of multiplying (and ruralising) the meagre specialist services they now provide for their education.

93. In rural communities in developing countries, a considerable degree of mental retardation can easily pass unremarked and causes little social or economic handicap to the individual. The standard IQ tests are of little relevance here and a child may acquire a satisfactory degree of social competence in his own community, whereas in formal schooling or in a more sophisticated community he would be classified as mentally retarded; the mere labelling has an adverse effect on his prospects for development.

94. Maybe the IYDP committees were right in saying that for the time being there is so little they can do for mentally retarded children that it is kinder to leave them in the loving care of their families and communities. But better primary health care is not only keeping more of them alive; it is also tackling the problem of devising appropriate training for the child within the family and also for the family itself. This makes a great deal of sense, since the provision of special institutions is financially impossible, and is universally condemned anyway because segregation aggravates the handicap. It is too soon to judge the success of booklet BIII of the WHO manual on rehabilitation for developing countries ("For the training of persons who have difficulty with learning") but something of this nature must be attempted in many of the countries I have visited because there are long and growing waiting lists for existing institutions which are already struggling for existence for lack of finance and trained staff.

Leprosy

95. Although leprosy is still a major cause of disablement in many Commonwealth countries - because impairment from leprosy is still not being prevented by early detection and sustained treatment - very few IYDP committees mentioned people suffering from leprosy as beneficiaries of their activities. The numbers and facts are well-established: there are probably about 15 million people in the world suffering from leprosy, of whom about a quarter have some degree of disability attributable to the disease. Of the four-fifths who are still not being reached for treatment, something like a quarter - three million people - suffer from deformities of hands, feet and face and slow impairment of vision leading to blindness. These disabilities are in the main not part of the original infection but the consequences of neglect. They still give rise in many countries to ostracism and discrimination of all kinds - social, physical, religious and legal - and leprosy patients might therefore have been regarded as ranking high among the beneficiaries of a national programme aimed at "full participation and equality".

96. But only a few governments accord the priority to the control of leprosy or to the rehabilitation of those suffering from the disabilities associated with the disease that its prevalence and severity merit. Fortunately, there is a strong international Federation of Anti-Leprosy Associations active in this field; but they concentrate on early detection and sustained treatment rather than on the rehabilitation of impairments already caused by the untreated disease, in the knowledge that early diagnosis and adequate treatment could lead to a marked reduction in deformity and disability. Ideally, the early detection and treatment of leprosy should form an integral part of the growing primary health care provision of governments; but this will be slow to achieve in some countries where leprosy has long been regarded as a disease for "vertical" interventions and where community education and experience have not yet removed the age-old stigma attached to leprosy.

97. The first disability of leprosy is insensitivity; and it is a matter of health education to assist patients to live with it and not to aggravate their condition unnecessarily. Protection is necessary for the insensitive feet, and I was told in Malawi that ordinary "sneakers" were satisfactory. Where they are not available or are too expensive, special sandals can be devised using old car tyres. The need for these and other aids for leprosy patients should be borne in mind when governments are considering the expansion of their prosthetic and orthotic workshops. Farmers must guard against friction on their hands, and there are ways for women to protect their hands while cooking and doing housework.

98. The days of lazarettos and segregation villages are over. Occupational therapy and vocational training can make a leprosy patient a better farmer than before and enable him to compete successfully with his fellow men. For some established deformities, surgery, physiotherapy and prostheses can help and are needed. The point for this report is that people who have been disabled by leprosy should not be overlooked or snubbed in the rehabilitation and vocational training provision of governments.