PRIMARY PREVENTION OF DISABLEMENT

99. In the words of the WHO Expert Committee on Disability Prevention and Rehabilitation (February 1981), "No other single factor can contribute as much to diminishing the impact of disability as first-level prevention. Attempts to cure, restore or rehabiliate rarely give totally satisfactory results .... First level prevention should be the overriding priority for all national health authorities and for WHO".

The Leeds Castle seminar

100 Many of the activities mentioned in the preceding sections of this report could be classified technically as secondary or tertiary prevention. They prevent an impairment becoming a disability or a disability becoming a handicap. But in layman's terms, prevention means avoiding an impairment occurring in the first place. A major IYDP initiative was taken when the British Government invited leading world authorities on the principal disabling diseases - scientists, clinicians, health administrators and ministers of health - to pool their knowledge of the principal causes of disablement and to assess practical possibilities of primary prevention on a world scale. Their findings and recommendations offer a programme of action which follows logically from the International Year and the public concern it has stimulated.

101 Known as the Leeds Castle Declaration from the historic building in Kent where the international discussions took place, the programme of action calls attention to the number of disabled people in the world and to the fact that, unless decisive action is taken now, population growth and the increasing proportion of older people will greatly magnify the problem. Much of the underlying impairment is preventable. For example, by immunisation:

> "World-wide expansion of a programme of immunisation could save five million children a year from disabilities caused by poliomyelitis, measles, tetanus, whooping cough, diptheria and, to a limited extent, tuberculosis. This could come about in ten years at a unit cost of about three dollars per immunised child.
>
> A world-wide expanded programme of immunisation would also facilitate production and effective use of vaccines against other diseases causing death or serious impairment. Among these is rubella, a prime cause of congenital blindness, deafness and mental impairment. The use of rubella vaccine should be promoted in all countries."

102. In the field of primary health care:

> "Impairment arising from malnutrition, infection and neglect could be prevented by inexpensive improvement in primary health care. Collectively these conditions now disturb the lives and reduce the productivity of at least twenty million people each year.
>
> For example, trachoma and vitamin A deficiency blind at least two million people annually; this can be controlled. Similarly, inexpensive and simple treatment can arrest impairment from leprosy (afflicting at least three million people), can restore sight to ten million people blinded by cataract, and can improve the hearing of ten million deaf people.
>
> Particular attention should be paid to the nutrition of pregnant women to prevent malnutrition of the foetus and to encourage breast feeding of the baby."

103. The Leeds Castle Declaration continues with references to the need for the education of the public and the mobilising of political will:

> "There are many oppportunities for improvement in regard to other disabilities. These depend on more effective sharing of knowledge, especially with the public.

Many disabilities of later life can be postponed or averted. There are promising lines of research for the control of hereditary and degenerative conditions. Early identification and treatment of raised blood pressure can save millions from premature disability and death due to heart disease and stroke. The toll of accidents and addiction could be remarkedly reduced.

Disability need not give rise to handicap. Failure to apply simple remedies very often increases disability, and the attitudes and institutional arrangements of society increase the chance of disability placing people at a disadvantage. Sustained education of the public and of professionals is urgently needed.

Avoidable disability is a prime cause of economic waste and human deprivation in all countries, industrialised and developing. This loss can be reduced rapidly.

The technology which will prevent or control most disablement is available and is improving. What is needed is commitment by society to overcome the problems. The priority of existing national and international health programmes must be shifted to ensure the dissemination of knowledge and technology. With proper use of modern communications this would involve modest costs and would bring great economic benefits. For instance, the world community is saving itself one billion dollars per year by the eradication of smallpox."

104. On scientific advance, the Declaration says:

"Although technology for preventive and remedial control of most disabilities exists, the remarkable recent progress in bio-medical research promises revolutionary new tools which could greatly strengthen all interventions. Both basic and applied research deserve support over the coming years".

105. The seminar welcomed the success of disabled people themselves in bringing their frustrations and their ambitions before the global community, and other achievements of the International Year. The participants regarded their programme of action as a logical and essential part of the follow-up, to ensure that the next generation does not suffer from the present degree of avoidable disablement. It has been adopted by the World Health Organisation and UNICEF, and has been written into the World Plan of Action for Disabled People, prepared by the Advisory Committee for IYDP for presentation to the UN General Assembly. Its implementation will be supported and co-ordinated by the United Nations Development Programme (UNDP). Government health ministries in Commonwealth countries will receive inspiration, guidance and help for their work of primary prevention as a consequence.

Rubella

106. Separate action has been taken to carry out the Leeds Castle injunction to promote vaccination against rubella. Health ministries and education authorities in most countries visited during this survey were all-too-conscious of the link between rubella epidemics and the number of deaf children in their schools at the corresponding later period. Even where vaccination against rubella had been introduced, the time-lag between the age of immunisation and the principal child-bearing age was causing fears of further epidemics before the purpose of the immunisation could become effective.

107. Rubella is often mild in its effect and sometimes passes almost unnoticed; but the effect on the unborn child if the mother contracts it in the early stage of pregnancy is devastating. Sir John Wilson, the principal instigator of the Leeds Castle consultation, has suggested for this reason that the name "rubella" is too mild; and during my visits I propagated his proposal that, for public education purposes its name might justifiably be changed to "baby blight", for it causes not only deafness but also mental handicap, blindness, heart defects, and often a horrifying combination of these impairments. I suspect, without statistical proof at the moment, that the reduction in incidence of rubella syndrome births in recent years in some industrialised countries is due not only to vaccination but also to increasing numbers of terminations of pregnancies when it is known that the baby is likely to be seriously deformed as a result of a pregnant mother's rubella. Some countries (e.g. Singapore) are following the

example of the United States by insisting on a rubella vaccination certificate for girls at high school age. In other countries, including Canada, New Zealand and the United Kingdom, rubella vaccination is the subject of periodical publicity campaigns but the cover is by no means 100 per cent.

108. In developing countries, rubella is not included in the "package" delivered under the Expanded Programme of Immunisation, partly because of the relatively high cost and partly because the congenital rubella syndrome is relatively infrequent, at least in comparison with measles, whooping cough, neonatal tetanus, polio and tuberculosis. There is also some failure to agree on delivery strategies, such as age at vaccination and whether both sexes should be included.

109. A multidisciplinary group, including representatives of WHO and UNICEF, met in London in March 1982 to consider these questions. The group concluded that an effective technology of control of rubella by vaccine is available, the limiting factor being take-up and delivery. A major collaborative effort will now be made to carry out the Leeds Castle injunction to promote vaccination against rubella. Under the leadership of the Royal Commonwealth Society for the Blind, voluntary organisations will seek, in conjunction with the health authorities, to achieve a decisive increase in the take-up of the vaccine (now estimated to be about 83 per cent overall) in the United Kingdom. In conjunction with UNICEF and the governments concerned, the Society has proposed an initial prevalence survey, followed by an immunisation programme, in Antigua, St Lucia, and in the Medak district of Andhra Pradesh, India, for which a questionnaire is being prepared for use as a part of a more general house-to-house survey. Enquiries have also been instituted with a view to similar action in The Gambia and Fiji.

GOVERNMENT POLICIES FOR THE DISABLED

Institutions or family care

110. The United Nations slogan "full participation and equality" accentuated the strong swing away from care in institutions to independent living in the family and in the community generally. Ministries of health and of social welfare, in large countries and small, insisted that resources were being diverted from the creation of new "disease palaces" (large hospitals in main centres of population) to primary health care nationwide; and from "dumping grounds" (residential homes for the disabled) to rehabilitation centres - better still to rehabilitation techniques at village level - with the objective of restoring mobility and sufficient well-being to enable disabled people to come and go in society on an equal basis with everybody else.

111. In accordance with this trend, the World Health Organisation has set its mind to find rehabilitation services which could be made available at family and community level at the lowest possible cost, with practicable methods of delivery. Where there is an infrastructure of community health workers providing basic services (immunisation, family planning, assistance over childbirth) under the supervision of medical advisers, it should be possible to introduce simple rehabilitation measures in the home or community which would materially improve the quality of life of disabled children and adults. A manual of these "appropriate technologies" was drafted in 1979 and was being field-tested in St. Lucia, Botswana, India, Sri Lanka, Nigeria and other countries during the IYDP. The community health aides who carry out this work are young people of the community who can get the confidence of their own people as no census enumerator or other outsider could. The WHO manual is being adapted so that they can use it to find the disabled people who can be helped, to identify their needs, to secure the involvement of the family and the community, to initiate the making of simple aids and supports, to arrange for referral where more sophisticated help is needed and to keep simple records of the numbers and categories of the disabled. All this is set out in the manual in the simplest (easily translatable) language: e.g. "people who have difficulty with hearing, speaking, seeing, moving and learning, or people who show strange behaviour".

112. By offering a simple service on the spot with referral of the more difficult cases, the true picture of the extent and nature of disablement in the community will gradually emerge. It