FUTURE PROGRAMME DEVELOPMENTS FOR PREVENTION OF DEAFNESS AND HEARING IMPAIRMENT

Report of the First Informal Consultation

Prevention of Deafness and Hearing Impairment (PDH)

World Health Organization
Report of The First Informal Consultation on
FUTURE PROGRAMME DEVELOPMENTS FOR PREVENTION OF
DEAFNESS AND HEARING IMPAIRMENT

World Health Organization, Geneva
23-24 January 1997

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EXECUTIVE SUMMARY

This informal consultation is the first in an annual series. The purpose is to review programme achievements, determine future priorities for programme development, seek opportunities for collaboration and identify possibilities for resource mobilisation.

The WHO Programme for Prevention of Deafness and Hearing Impairment (PDH) commenced in 1985 and became affiliated with Prevention of Blindness in 1991. The World Health Assembly has passed two resolutions in relation to PDH, in 1985 and 1995. These stated that hearing difficulties are an obstacle to language acquisition and education in children, and lead to major communication problems in the elderly; they affirmed that much deafness and hearing impairment is avoidable or remediable and that the greatest needs for the problem are in developing countries. The 1995 resolution estimated that there are 120 million persons with disabling hearing difficulties worldwide and urged member states to set up their own National Programmes for the prevention of deafness and hearing impairment, with the technical assistance of WHO.

A fundamental requirement for the development of a National Plan and choice of preventive strategy for a National Programme is accurate, population-based data on the prevalence and causes of the problem. The PDH programme has developed a standardised Ear disease assessment protocol to enable countries to conduct national surveys rapidly. This has already been used by several developing countries; the full protocol, including computer software for data analysis, will be distributed later this year.

A National Programme will require a set of integrated strategies to prevent deafness and hearing impairment. The PDH programme has already addressed the prevention of two causes, ototoxic drugs and chronic otitis media, by convening technical meetings. It will shortly produce guidelines for implementation of these strategies within the context of primary health care.

In order to encourage countries to address these problems and consider how to set up National Plans, regional workshops on prevention of deafness and hearing impairment have been held in 4 of the 6 WHO regions since 1991, the most recent in the Africa region in 1995. The PDH Programme has also started providing assistance to countries that wish to set up a National Plan (Turkmenistan) or conduct National Surveys (Oman, Jordan). A project proposal to encourage selected African countries to develop National Programmes has been developed.

Technical assistance and regional connections are provided through the network of collaborating centres. There are 4 currently in operation (Bangkok, Malmo, Liverpool, Copenhagen) and three in process of designation (Jakarta, Tokyo and Kumasi).

The meeting discussed possible collaborative activities between the PDH Programme and the various external organizations represented. Such activities could include assistance with setting up National Programmes and with implementing specific local projects (IMPACT, Hearing International), technical consultation especially for field situations (Hearing International, International Federation of Oto-Rhino-Laryngological Societies), human resource development for training in Public Health Otology/audiology (IFOS) and for audiological assistants in underserved areas (IALP).

The meeting made a number of key recommendations that the PDH Programme should:

- address problems in this field of major public health importance which are amenable to intervention, giving priority to developing countries. These problems are presently ototoxicity, chronic otitis media, noise damage to hearing, inherited and congenital causes, and the provision of appropriate affordable hearing aid services.
- encourage and provide technical assistance to countries in the development of national plans for the prevention of deafness and hearing impairment.
- foster the collection of accurate population-based data on the prevalence and causes of hearing impairment in countries. The data should be linked with data collection for other disabilities where feasible and should be made widely available on a regional and eventually global basis to organizations that need it. The data would be the first
element in the development of a National Plan and should also be used to determine the costs of hearing impairment and the benefits of prevention.

- encourage the development of guidelines and training for primary ear care, for human resource development and for courses in Public Health Otology/Audiology.
- develop the network of collaborating centres worldwide amongst appropriate institutions that are willing to undertake research and training of interest to the Programme for Prevention of Deafness and Hearing Impairment at WHO.
- develop linkages with other organizations for advocacy of the problem of deafness and hearing impairment and for technical and financial assistance for implementation of its programmes.

The meeting affirmed that the key requirement for this programme (and for prevention of deafness and hearing impairment itself) is human and financial resource mobilisation. To enable and enhance this demands a clear definition of goals and targets, credible information on the size of the problem and identification of effective intervention strategies. This will help to bring about the essential change in the perception of donors and the general public to the understanding that the disability caused by deafness and hearing impairment is a significant contributor to poverty and hence a brake on development.

ABBREVIATIONS

AFRO African Regional Office
AMRO Regional Office for the Americas
CSOM Chronic Suppurative Otitis Media
ECOSOC Economic and Social Council of the United Nations
EMRO Eastern Mediterranean Regional Office
EURO European Regional Office
HI Hearing International
IALP International Association of Logopaedics and Phoniatrics
IAPB International Agency for the Prevention of Blindness
IFOS International Federation of Oto-rhino-laryngological Societies
IMPACT International Initiative Against Avoidable Disability
ISA International Society of Audiology
NGO Non-governmental organization
OME Otitis Media with Effusion (serous otitis media)
ORL Oto-Rhino-Laryngology
PDH Prevention of Deafness and Hearing Impairment
SEARO South-east Asia Regional Office
UNDP United Nations Development Programme
UNESCO United Nations Educational, Scientific and Cultural Organization
UNICEF United Nations Children’s Fund
WHA World Health Assembly
WPRO Western Pacific Regional Office
1. INTRODUCTION

This *First Informal Consultation on Future Programme Developments for the Prevention of Deafness and Hearing Impairment* was convened as the first of what is intended to be a regular annual meeting. The purpose is to review programme achievements, and to determine future priorities for programme development. These meetings will also identify opportunities for collaboration and search for possibilities for mobilisation of resources.

Participants were invited from amongst the group of Members of the WHO Expert Advisory Panel on Deafness and from organizations, especially Nongovernmental organizations, with which PDH has linkages.

2. REVIEW OF THE PDH PROGRAMME

2.1 Progress made since inception

This can be best described by a number of intertwining themes, as follows.

**THEME ONE: RAISING AWARENESS**

In 1985 a Resolution of the 38th World Health Assembly entitled *Hearing Impairment and Deafness* stated that there were 70 million deaf individuals worldwide. The term “deaf” was not defined. The resolution also stated that much deafness is reversible or remediable and that in developing countries, most hearing impairment is preventable at the primary level. In response to this resolution a report by the Director General was drawn up which addressed the size of the problem, its causes and their prevention. This report stated that there were 42 million persons with moderate to profound bilateral hearing impairment worldwide and that the largest needs were in developing countries. Unfortunately, consideration of this report by the 39th WHA was postponed because of other pressing business.

The next resolution on the *Prevention of Hearing Impairment* was passed in 1995 by the 48th World Health Assembly. The global number with “disabling hearing difficulties” was estimated to be 120 million. This figure is higher than in 1985 because of the larger and more elderly world population, and because of the increased recognition of the extent of the problem. This resolution emphasised the public health aspects of avoidable hearing loss and urged member states to set up National Plans and WHO to strengthen its activities in this field (see box 1).

Another opportunity for raising awareness came with the *International Symposium on Deafness and Hearing Impairment in Developing Countries*, held in Manchester, UK in July, 1995. This was organised by the Universities of Manchester and Liverpool and co-sponsored by the PDH.

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The Forty-Eighth World Health Assembly... requests the Director-General:

1. To further *technical cooperation* in prevention... including development of appropriate guidelines.

2. To cooperate with countries in *assessment* of hearing loss as a public health problem.

3. To *support... planning, implementation, evaluation of measures in countries to prevent hearing impairment*.

4. To develop further collaboration and *coordination* with nongovernmental and other Organizations.

5. To promote/support applied & operations research for prevention and treatment...

6. To mobilise extra-budgetary resources...

*Box 1: Tasks for PDH, as set out by the 1995 WHA Resolution*
Programme together with Hearing International. Substantial support was given by the Overseas Development Administration of the British Government and by Christoffel-Blindenmission.

**THEME TWO: CONSULTING WITH ADVISERS**

The Expert Advisory Panel on Deafness and Hearing Impairment was set up in 1987 and an informal meeting was held in 1989. In 1991 PDH became affiliated with Prevention of Blindness (PBL) at WHO and in the same year the Informal Working Group on Programme Planning, was held in Geneva. Several of those participants are attending the present meeting.

Members of the Expert Advisory Panel have also been consulted during the regional workshops for prevention of deafness and hearing impairment (see theme 4), through technical meetings (see theme 8), and through the collaborating centres.

**THEME THREE: FORGING LINKS WITH OTHER ORGANIZATIONS**

Currently the programme has developed links with the following inter-agency, nongovernmental, and professional organizations:

- IMPACT (An International Initiative against Avoidable Disablement)
- CHRISTOFFELBLINDENMISSION
- INTERNATIONAL FEDERATION OF OTO-RHINO-LARYNGOLOGICAL SOCIETIES
- INTERNATIONAL ASSOCIATION OF LOGOPEDICS AND PHONIATRICS
- HEARING INTERNATIONAL

Future links are envisaged, in addition, with other organizations including community service organizations such as LIONS CLUBS INTERNATIONAL and ROTARY INTERNATIONAL.

**THEME FOUR: DEVELOPING AND PUBLICIZING THE PDH PROGRAMME PLAN**

The programme will be developed and updated on a continuing and regular basis. It will be subject to in-house and external review, the latter particularly by annual review at future informal consultations.

Publicity regarding the PDH programme development was given at the XVth World Congress of Otolaryngology in Istanbul in 1993 and at the International Symposium on Deafness and Hearing Impairment in Developing Countries in Manchester in 1995.

The outline PDH Programme Plan for 1996/97 was presented at the International Congress of Audiology, Bari, Italy in June 1995 and at the International Congress of Hard of Hearing People, Graz, Austria in August 1996. Overviews have been published in ENT News and Hearing International Newsletter, and will appear in Scandinavian Audiology.

A future presentation that will incorporate the results of this meeting will be made at the XVI World Congress of Otorhinolaryngology, Head and Neck Surgery, Sydney, Australia in March 1997.

**THEME FIVE: CONSULTING WITH WHO REGIONS**

The following meetings and workshops have been organised jointly by the Regional Office concerned and assisted by the PDH Programme. All of them were attended by representatives of IFOS and Hearing International, in addition to the country representatives.

1. Workshop on Management of Programmes for PDH, SEARO, Delhi, 1991 (representatives from 8 countries attended).
2. Meeting of Task Force on PDH, EMRO, Alexandria 1992 (representatives from 5 countries
attended).

(3) Working Group on PDH, WPRO, Manila 1994. (representatives from 9 countries attended)

(4) First Meeting of regional advisory panel on prevention and control of deafness and hearing impairment, EMRO, Alexandria, 1995 (representatives from 6 countries attended) 6 countries


THEME SIX: WHO COLLABORATING CENTRES

There are currently four designated collaborating centres for the PDH Programme and three in process of designation (see map and annex 4). The designated centres have assisted PDH with various topics such as the development of the ear disease assessment form, the development of primary ear care and training, and the revision of the International Classification of Impairments, Disabilities and Handicaps.

THEME SEVEN: THE WHO EAR DISEASE SURVEY PROTOCOL

It was recommended by the Informal Working Group on Programme Planning in 1991 that a global database on deafness and hearing impairment be established. The development of the WHO Ear Disease Survey Protocol was commenced the following year. This protocol describes a method using a standardised survey form and coding instructions to enable countries to carry out prevalence and causes surveys of deafness and hearing impairment, and of ear disease.

In 1992 an informal working group convened to discuss the development of the survey form. A prototype form was field-tested in India in 1993, and survey methodology and coding instructions were completed in 1995, when a version of the Ear Examination Form was used in a pilot study in Botswana (with WHO support) to survey hearing impairment with visual impairment. Software for data entry and analysis is almost complete and the whole package will be distributed in 1997.

THEME EIGHT: DEVELOPING STRATEGIES FOR PREVENTION

Work on the first two strategies for prevention has commenced with technical meetings on Strategies for Prevention of Hearing Impairment from Ototoxic Drugs in Geneva in 1994 and the Workshop on Prevention of Hearing Impairment from Chronic Otitis Media organised jointly with the CIBA Foundation and held in London, UK, in 1996. It is intended that each strategy will produce guidelines which can be integrated as required by countries in construction of their own National Plan for the prevention of deafness and hearing impairment.
THEME NINE: PROVIDING ASSISTANCE TO COUNTRIES

Activities during 1996 have included:

- Assistance to National Workshop on Prevention of Blindness and Deafness, Ashgabad, Turkmenistan (September, 1996)
- Version of Ear Examination Form used in the National Survey of Eye and Ear Diseases in Oman. (Assistance to Training Workshop, September, 1996)
- Assistance given to planning National Surveys of Blindness And Deafness in Jordan. (October, 1996)

2.2 Ongoing Projects: 1997

Ongoing and new projects are listed in the PDH Work Plan on page 19. New activities include two project proposals. These are:

(1) Global Epidemiology of Deafness and Hearing Impairment.

The objectives of this project are:

- To develop methodologies for rapid, small-scale population-based surveys of prevalence and causes, especially for developing countries.
- To gather population-based data from all countries especially developing countries.
- To construct a global database of the prevalence and causes of deafness and hearing impairment.
- To develop methodologies to measure the individual and societal costs of hearing impairment and the benefits of prevention.

This proposal is being submitted to the National Institute on Deafness and Other Communication Disorders, Bethesda, USA.

(2) Development of a National Programme for the Prevention of Deafness and Hearing Impairment in Selected African Countries. The objectives of this project are to assist each country:

- to conduct a population-based survey of prevalence and causes
- to determine priorities for Prevention
- to draw up a National Plan for Prevention.
- to set up a programme for primary ear care integrated into primary health care.
- to develop appropriate audiological referral and support facilities, including provision of earmoulds and hearing aids.
- to determine its training needs and strategies.

This has been submitted to CBM for funding.

Other new activities include the convening of two meetings, the first to be held in Autumn 1997 on Prevention of Noise-induced Hearing Impairment, and the second on Provision of Appropriate Hearing Aids for Developing Countries - needs and technology assessment. This latter meeting will probably be held in early 1998. It is hoped that both meetings may be held at WHO regional offices pending the mobilization of needed resources.
3. PRIORITIES FOR PROGRAMME DEVELOPMENT

3.1 National programmes for the prevention of deafness and hearing impairment including Primary Ear Care

There are 3 “actors” which link with each other: (1) Ministry of Health. This guarantees sustainability and is where the focal point or coordinator would usually be located; (2) The Local ENT/Audiology Society, this may produce the first initiatives for a programme; (3) National and International NGOs could have a significant involvement in some countries.

The programme development process occurs along two converging paths (see box 2). Key individuals in the local ENT/audiology society can address the issue of what is being done and what the needs are. The national committee should include up to fifteen representatives from the MOH, relevant professions, service deliverers, and NGOs. The national programme should focus on major public health causes of hearing impairment and develop an appropriate ear care component of primary health care including key health education messages. Children would be a priority group. It would produce technical guidelines and criteria and address human resource development at all levels and mobilisation of resources (not just from government). The programme should be integrated within the existing health care system.

The role and decision-making of the WHO Regional Offices is important, through the relevant regional adviser for PDH (not present in EURO & PAHO). Several countries in Africa and the Eastern Mediterranean are enthusiastic about the PDH Programme and there are also good possibilities for setting up National Programmes in South-east Asia and the Western Pacific (the member states in the WPR are very diverse which makes this region more complex to work in). It should also be realised that WHO cannot provide funding for this apart from occasional “seed” money.

3.2 Control of specific diseases/causes of hearing impairment

The main criteria for intervention by the PDH Programme for control of specific causes of hearing impairment would be that each such cause is:

- a major public health issue
- amenable to effective intervention
- not covered by other WHO technical programmes
- possible to be integrated with primary health care.

The major causes of hearing impairment and those that fulfill the above criteria are shown in box 3.

3.3 Training needs

Key issues were highlighted for consideration by the meeting. In setting up a programme of human resource development, it is necessary to determine the levels, categories and numbers of staff that are needed, the extent of Government commitment and funding, and integrating these with the National training policy. For developing countries, it is important to plan “bottom-up” rather than “top-down”, since the greatest staffing and training needs are at the most basic levels (see box 4). In some countries, resource
constraints will probably only allow a few of the possible categories listed in box 4. Thus ORL and audiology specialists may not be available at the intermediate level. Training for "primary Ear Care" should be emphasised (see box 5). Training should also be integrated with health education and health promotion for healthy ears and prevention of hearing impairment targeted at patients, parents, teachers and community leaders.

The developers of appropriate training should consider what skill levels are needed, (eg should minimum standards be set), how should trainers be trained and what training curricula and materials are required. Other problems in developing countries relate to the frequent shortages of staff and equipment especially in remote or rural areas. Another issue, particularly for higher-level staff, is where should the training take place (eg is it appropriate for tertiary level staff to have expensive, possibly inappropriate training in developed countries?).

3.4 Research Needs for PDH

Research should include basic, applied, and operational research which accords with programme priorities. A major task of the PDH Programme is to characterise deafness and hearing impairment as a public health problem; the main route to do this is to focus on epidemiological research and data gathering (see box 6). Research possibilities would mainly focus on the following topics:-

- Methodologies for population-based surveys of prevalence and causes
- Development of standard criteria for definition, measurement and comparison
- Field research into survey test methods particularly for children <5y
- Criteria for assessing quality of surveys
- Methods for database collection & construction
- Development of indicators of:
  - costs of hearing impairment to individuals and communities.
All surveys must include a service component for the community being surveyed.

There could also be involvement in research on interventions against major public health ear problems (eg for chronic suppurative otitis media in children in developing countries).

3.5 Programme & Technical Documentation

The current output consists of general documentation such as reports of planning and technical meetings and guidelines for different aspects of prevention, and of country-specific
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documentation such as reports of National Planning Workshops and reports on technical advice to countries (via consultancies).

The rationale of guidelines is that they should deal with topics of major public health importance and also focus on vulnerable groups. They could be variously used for incorporation into National Plans and training curricula, and used for construction of case management schedules and be a basis for health education / health promotion campaigns.

Guidelines would generally originate from the output of a technical meeting comprising topic-specific advisors. The guidelines themselves would then be developed with assistance from collaborating centres and other relevant institutions, and be field tested before general distribution and their impact subsequently evaluated. Each set of guidelines would be one package in an integrated collection of strategies that could be selected as required by countries for their national plan for the prevention of deafness and hearing impairment.

Documents that will be ready in 1997 include:

- WHO Ear Disease Survey Protocol and software
- Guidelines for the Prevention of Deafness and Hearing Impairment by the Management of Chronic Otitis Media
- Prevention of deafness and hearing impairment, EMRO Technical Publication.

Future planned guidelines and other material may include:

- Prevention of Noise-Induced Hearing Impairment
- Provision of Hearing Aids for Developing Countries
- Primary Ear Care training manuals
- How to develop and implement a National Programme for the prevention of deafness and hearing impairment
- Database of prevalence and causes of Hearing Impairment.

4 OPPORTUNITIES FOR COLLABORATION

4.1 UN Inter-Agency Initiatives.

IMPACT, an International Initiative Against Avoidable Disablement was established in 1981 following a recommendation of The UN General Assembly and sponsored by WHO, UNICEF and UNDP. Its main roles are (1) advocacy for disability, and (2) Prevention. WHO provides technical back-stopping and logistical support; UNDP provides core funding. A recent example of the way IMPACT works was the Disability Prevention "Needs Assessment" Mission to West Bank and Gaza in 1995.

Unlike the UN Agencies, IMPACT can receive contributions from many sources such as National IMPACT Foundations and other NGOs; this enables it to link the UN system with the private sector.

IMPACT wishes to develop close contacts with the PDH Programme; it could be involved with the implementation of strategies for prevention such as noise reduction or hearing aid service provision. National IMPACT Foundations could have an important role in a country where there is an initiative to set up a National Programme for the Prevention of Deafness and Hearing Impairment, and could help to finance and implement specific projects. Prevention of deafness and hearing impairment will be regarded as a priority by these IMPACT Foundations.

4.2 NON-GOVERNMENTAL ORGANIZATIONS

4.2.1 General Considerations

During the past twenty-five years, from small beginnings and initially with inadequate funds, the Global Programme for the Prevention of Blindness has become a model of effective action
resulting in significant decrease in some of the major causes of blindness in the developing world. Last year alone, 22 non-governmental organizations provided $77 million to action for the prevention of blinding.

This history has optimistic relevance to our planning here today. There is a need to define objectives, to concentrate on a limited number of “do-able” activities which in aggregate could significantly change the pattern of hearing impairment across the world. We need to agree on standards and definitions and to develop a better statistical base. The concept of public health otology needs to be fostered with its implications of multi-disciplinary co-operation and with training curricula for different levels of personnel and agreement on the extent to which skills can be delegated. Research needs to be expanded and more closely focused with greater international co-ordination.

Why has hearing impairment, which is numerically one of the largest categories of disability, not yet attracted the level of official and private funding which would be justified by size and severity? Have we failed so far to present this cause in understandable human and political terms and in relation to its economic and social consequences?

The question of co-operation, the theme of this session, is now being addressed at the highest level in the United Nations system. The new concept of this goes well beyond the traditional view of non-governmental action, and includes new partnership arrangements, multinational planning and tapping in to the global capital flow which is now becoming the most decisive factor in economic and social change. The word “non-governmental” may now be inappropriate with its negative implications and the assumption of division between public action and private philanthropy.

At the international level the International Federation of ORL Societies (IFOS) and other world-wide memberships of professionals, through their links with WHO, offer an invaluable technical resource for cooperation. The most recent addition to this partnership, Hearing International (with a constitution similar to the successful International Agency for the Prevention of Blindness) is a potentially powerful mix of professionals, service providers and service users. It should be the co-ordinator of non-governmental action and in the mobilisation of resources.

The World Federation of the Deaf and organizations of hearing impaired people - though their primary concern is with rehabilitation and human rights and sometimes are cautious about prevention - could, with their world-wide membership, play an essential role in advocacy and in achieving a change in public perception. The IMPACT Programme, though concerned with all forms of avoidable disability, regards hearing impairment as a priority and through its foundations in a number of countries is already promoting projects deliberately designed as potential international models.

WHO has, of course, the central role in co-ordination and development with its mechanisms for collaboration with its regions, centres, governments and with other specialised UN agencies (e.g. UNICEF, ILO, FAO, UNDP and the World Bank) and with the NGOs. In these difficult times the most immediate problem throughout the UN system is for core funding.

Perhaps what we need now for avoidable disability is a “grand alliance”. We need to gear aspirations to the main goals of human development policy with its emphasis on poverty reduction, equity, social change and the phenomenon of ageing. It needs to be established that hearing impairment is a significant cause of deprivation and inequity and that its prevention could provide an immediate and cost-effective means of poverty reduction.

Eventually, the decisive action must be at the national and community level. Governments must be stimulated to implement the recommendation of the World Health Assembly that, within the framework of public health care, they should prepare national plans for the prevention, control and management of major causes of hearing impairment. In principle no government will disagree with that recommendation but, in the real world of competing priorities, there is a need for public and political pressure. In the Blindness Programme, national programmes have developed in many countries but almost invariably these were preceded by the establishment of national pressure
groups prepared, often over many years, to publicise the cause and to demonstrate its practicability in economic terms. We may well need specialist institutions, but the main aim is to build action on hearing impairment into all on-going programmes of health and development.

An immediate opportunity may be in India. Following many years of successful advocacy, the proposal now being considered is that disability and its prevention should be one of the priorities of the Government's ninth Five-Year Plan and of UNDP's Country Programme.

The difficulty is to reconcile the view of the international planner, the view of the national politician, and the view of the community including the victim and his/her family.

People do not really become deaf by millions but individually in families and communities. Eventually, at that level, will be judged the success of the action resulting from meetings such as this. Perhaps we can take comfort that in science and in health, the optimists are more often right than the pessimists.

4.2.2 Hearing International (HI)

HI is a wide-ranging umbrella organization which includes people with deafness and hearing impairment, volunteers, advocates and professionals.

The 1996 Graz resolution proposed the establishment of a series of standard small-scale district projects to reduce the burden of hearing disability through activities such as development of primary ear care and early detection programmes, provision of equipment and hearing aid services. Implementation would be assisted by the IFOS/ISA/HI Centres. Three projects in three regions would be established by 1998 and six by 2000. Unlike the IAPB, Hearing International does seek to raise funds for its projects. It is also taking part in Rotary International's Volunteer Programme.

Possibilities for PDH collaboration with Hearing International could be (1) advocacy (complementing or working alongside IMPACT), (2) technical consultation, (3) helping create National Programmes, (4) participation in Primary Ear Care projects.

4.2.3 International Federation of Otorhinolaryngological Societies (IFOS)

IFOS is the global, political, advocacy arm of National Societies of Oto-rhino-laryngology (ORL) and head and neck surgery. Its main role is to organise a 4-yearly World Congress. It also emphasises the importance of global ear care, and has set up a network of designated centres around the world. It carries out fund-raising, primarily to assist the centres. It was one of the founders of HI. In relation to WHO, it has had an important role centrally but has been less prominent in the regions. It is a strong supporter of the PDH Programme.

IFOS recognises that the main impact of the PDH Programme should be in developing countries throughout the world especially in the African, Eastern Mediterranean and South East Asian regions (in more developed regions such as in Eastern and Central Europe where there are significant problems of training and supply, IFOS and the European community could more appropriately take the lead).

A key role of IFOS is in lobbying within countries. WHO and the PDH Programme need the local generation of commitment and support in order to raise the profile of the problem with the

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1 The IAPB, which is equivalent to Hearing International in the Blindness field, also has an advocacy role in persuading countries to set up national programmes for prevention and appealing to professional to merge their individual with their societal responsibilities. It is an umbrella body with NGO members. It leaves all fund-raising to them to avoid potential conflicts of interest. IAPB is not an implementing body, nor does it confer status on particular centres.

2 For a list of current IFOS/ISA/HI Centres and their Directors see Hearing International Newsletter No. 17, December 1996, page 3.
National Government. IFOS can also help bring together other adjacent professional groups (e.g. audiologists, teachers of the deaf) in order to enhance the effectiveness of this lobbying.

IFOS supports the need for the PDH Programme to address urgently:-(1) the problem of noise damage to hearing; (2) the provision of hearing aid services in developing countries; (3) the promotion of the concept of public health otology/audiology through encouraging the setting up of specific training courses. IFOS can also help coordinate a “time-bank” of developed-country professionals willing to volunteer to work in developing countries (including collection of epidemiological data). IFOS would wish to see an otologist working in the PDH Programme, in support of present staff.

4.2.4 International Association for Logopaedics and Phoniatrics (IALP)

IALP was founded in Vienna in 1924. It now has 120,000 members through its member organizations. It promotes prevention and rehabilitation in all countries and at all age levels.

Its most appropriate link with the PDH Programme would be through its Applied Audiology Committee, which promotes minimum standards of training. It has recently advocated a proposal for the development of an audiological assistant training programme for countries or districts without other audiological expertise. The programme would train persons with a health-knowledge background in basic auditory screening, diagnosis and treatment and selection referral and sometimes fitting for amplification.

It would be important for a detailed curriculum for this course to be developed and implemented with proper local recognition and evaluation. It was proposed that IALP should collaborate with IFOS, HI and the ISA to move forward on this.

4.2.5 Christoffel-Blindenmission (CBM)

CBM is concentrating in Prevention of Blindness, Education and Rehabilitation of blind and otherwise handicapped people. During 1997 CBM is going to support more than 1,000 projects in 105 countries with a total budget of about DM 83.3 million. These projects include support to 75 schools for the deaf, three ENT departments, one deafness prevention programme and support for the WHO Programme for Prevention of Deafness and Hearing Impairment. Support for deafness and hearing impairment occurs in 48 countries for a total budget of over DM4 million.

The available data suggests that the number of hearing impaired people in the world continues to increase. CBM appreciates its close collaboration with the World Health Organization and with other NGOs in our joint efforts to try and decrease the problem of global hearing impairment and deafness.

The Prevention of Deafness and Hearing Impairment is a new area of work for CBM, which considers this field important for the future years. It is hoped that some of the lessons learnt over the last 20 years in Prevention of Blindness can be applied in the field of PDH.

4.3 Collaborating Centres

The importance for the PDH Programme to develop a viable, evenly-distributed network of collaborating centres was stressed (this had also been stated in general by the January 1997 WHO Executive Board). They should have good technical competence in different but relevant areas and adopt a public health approach. Government concurrence is required and the designation process usually takes up to 2 years. The performance of collaboration is evaluated. Designation may enhance a centre’s ability to secure funding. Existing IFOS/ISA/Hi centres could also be WHO centres but there would still need to be a full process of designation.

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3This section was contributed after the meeting.
5 MOBILISATION OF RESOURCES

The main obstacle to the prevention of deafness and hearing impairment is a lack of resources, and specifically money, at every level from the community to the global.

5.1 Reasons for lack of resources

- The public’s perception is that hearing impairment is less disabling than blindness or physical or mental impairments. Governments give PDH a low priority in the allocation of funds.
- NGOs find it difficult and costly to obtain donations from the public.
- Publicity to prevention of deafness and hearing impairment has often been promoted in too technical terms to be readily understood by laypersons (including those who run charities).
- Some organizations of deaf people have advocated themselves to be a linguistic rather than a disabled minority.

5.2 Possible strategies to attract inter-governmental and national funding:

- Mount a public relations campaign to change public attitudes, coordinated by UN agencies or the International Public Relations association
- Translate global strategic planning objectives into national and local community level projects, for which funds are often easier to obtain
- Pass resolutions on prevention of deafness and hearing impairment by national delegations to other UN agencies (World Bank, UNDP, UNICEF, UNESCO, ECOSOC).
- Link the goals of the PDH Programme as far as possible with the general priorities of poverty reduction and empowerment of minorities.
- Quantify the contribution that deafness and hearing impairment make to the causes and consequences of poverty
- Develop a clear policy, credible goals and targets with acceptable time spans, and clearly defined short and long-term funding requirements for the PDH Programme

5.3 General points on funding applications

- Approaches for funding should be according to the philanthropic mandate, and areas and preferences of operation of the donor (in the case of corporations, according to their commercial interests). For example a focus on children, adults in the workplace, citizens of a particular country or region, links with ageing.
- Most NGO donors are unlikely to fund international coordination and general core costs and will only support specific projects.
- the applicant for funds should preferably be a national of the country where the donor organization has its main interests and should be known personally or professionally to the donor’s decision makers.
- professional fundraising is expensive and should generally be used for large capital projects rather than for recurrent or core costs

5.4 Possible sources of funding

- International agencies such as the World and Regional Development Banks (especially if the economic costs of deafness can be demonstrated). The approach has to come from the recipient country.
- Bi-lateral aid agencies of national governments (these may have specific geographical interests)
- Foundations and Trusts. Vary in scope (global, regional, national, district).
- Community service organizations. Examples are Rotary, Lions, Kiwanis, Giants. Fundraising is primarily through their membership network often with personal involvement of members and local clubs, sometimes through an annual appeal. These organizations can also be powerful advocates and provide local accountability and management skills.
Commercial organizations⁴. Multi-nationals have a responsibility to invest in development; they may also benefit from such investment. Philanthropic giving is linked to commercial interests. Thus donation is more likely if the funding target benefits the workforce, customers, or work-area of the commercial organization (eg medical equipment and drug manufacturing, telecom and music industries). Funds for direct charitable support are usually limited although advertising and public relations budgets may provide support through sponsorship. This should be approached more cautiously.

6 CONCLUSIONS AND RECOMMENDATIONS

6.1 PROGRAMME PRIORITIES

6.1.1 In addition to the priorities of other WHO Programmes which have a hearing on hearing impairment⁵, the Programme for the Prevention of Deafness and Hearing Impairment should address problems of major public health importance which are amenable to intervention. Thus the presently identified areas for disabling hearing impairment and deafness should include ototoxicity, management of chronic otitis media, prevention of noise-damage to hearing, genetic hearing loss, and provision of appropriate, affordable hearing aid services.

6.1.2 The work of the PDH Programme should, as a general rule, give priority to developing countries where there is the greatest need, but keeping in mind the need for appropriate work opportunities.

6.2 DEFINITIONS

6.2.1 The detailed, accurate definition of hearing impairment and deafness should always be stated in survey reports. Different surveys should use the same definition to enable comparison of results.

6.2.2 Disabling hearing impairment in adults should be defined as a permanent unaided hearing threshold level for the better ear of 41 dB or greater; for this purpose the "hearing threshold level" is to be taken as the better ear average hearing threshold level for the four frequencies 0.5, 1, 2, and 4 kHz."

6.2.3 Disabling hearing impairment in children under the age of 15 years should be defined as a permanent unaided hearing threshold level for the better ear of 31 dB or greater; for this purpose the "hearing threshold level" is to be taken as the better ear average hearing threshold level for the four frequencies 0.5, 1, 2, and 4 kHz."

6.3 EPIDEMIOLOGY

6.3.1 The PDH Programme should foster the collection of accurate population-based data on the prevalence and causes of hearing impairment in order to assist individual national governments to determine priorities within their health programmes; to select and monitor preventive strategies; to predict treatment and rehabilitation needs; to set up regional and global databases; and to determine the individual and societal costs of hearing impairment and the benefits of prevention, with their implications for poverty reduction and equity.

6.3.2 The WHO Ear Disease Protocol should be publicized and disseminated as widely as possible, not only through the WHO official channels. Members of the informal advisory group agreed to attempt to publish and publicize information about the protocol's availability and use when the PDH Programme informs them that it is ready.

⁴ EDITORIAL COMMENT: It should be noted that WHO does not accept direct funding support from commercial organizations.

⁵ Such as the Global Programme for Vaccines and Immunization (GPV), Occupational Health (OCH), Urban Environmental Health (UEH), Maternal and Newborn Health/Safe Motherhood (MSM), Child Health and Development (CHD), and Rehabilitation (RHB).
6.3.3 Accurate population-based data on the prevalence and causes of hearing impairment should be made available by the PDH Programme to hearing aid manufacturers to encourage the development and manufacture of good quality, affordable hearing aids which are commercially viable by manufacture on a large scale.

6.3.4 Prevalence surveys for hearing impairment and visual impairment should be carried out together, wherever feasible.

6.3.5 Recognising that hearing impairment may be associated with other disabilities, the assessment of hearing impairment in a country could include the collection of relevant, general public health information, including other major causes of disability, where feasible and appropriate.

6.3.6 The method used to calculate the current estimates of the global and regional prevalence of deafness and hearing impairment should be published in a peer-reviewed journal.

6.4 PROGRAMME DEVELOPMENT

6.4.1 The PDH Programme should seek assistance for its development through:
- extra-budgetary funds from linkages with other appropriate organizations, such as NGOs,
- specific project funding,
- expansion of the network of collaborating centres,
- secondment from other institutions.

6.4.2 It is of critical importance that more staff be made available to the PDH Programme. All possible options should be considered, including secondment of personnel from other interested institutions.

6.5 RAISING AWARENESS

6.5.1 The PDH Programme should search for ways of raising the public profile and enhancing the public perception of the problem of disabling hearing impairment. Linkages with well-known deaf and hard of hearing individuals and Organizations should be developed to facilitate this process.

6.5.2 The PDH Programme, through its linkages with professional organizations, should encourage professionals in ORL and Audiology to work with a greater perception of the public health needs and of their societal responsibilities for prevention of deafness and hearing impairment.

6.6 COLLABORATION WITH OTHER ORGANIZATIONS

6.6.1 The PDH Programme should collaborate with other interested organizations for
- advocacy of the problem of deafness and hearing impairment,
- technical consultation,
- development of National Programmes for the prevention of deafness and hearing impairment,
- input into ear and hearing health care programmes with emphasis on primary ear care,
- mobilisation of resources.

6.6.2 The PDH Programme should develop small-scale projects, which could be funded and/or implemented together with organizations such as IMPACT, Hearing International, Lions Clubs International, and Rotary International. Examples would be screening assessment for children, development of a Primary Ear care model for countries, and development of a hearing aid and ear mould facility suitable for developing countries. A catalogue of such projects should be developed.

6.6.3 The PDH Programme should develop the network of collaborating centres by identifying viable institutions with a public health approach who are willing to undertake research and training of interest to the PDH Programme.
6.6.4 The PDH programme should encourage the development of and collaboration in courses and training in public health otology and applied audiology.

6.6.5 The training of audiological assistants is of interest to a number of developing countries. The draft curriculum as developed by IALP should be evaluated in its application in selected countries. Other suitable training opportunities should be identified.

6.7 PROGRAMME ACTIVITIES

6.7.1 Informal Consultation on future Programme Developments for the Prevention of Deafness and Hearing Impairment should be held annually.

6.7.2 The PDH Programme should carry out the items given in the attached work plan during the year from February 1997 to January 1998.

6.7.3 Future Activities. The PDH Programme should plan to carry out the following activities in the future:

- draw up guidelines and training materials for primary ear care in conjunction with other individuals and organizations working in this field and using currently available material, as appropriate;

- develop guidelines for human resource development, particularly in relation to the needs for developing countries;

- encourage countries to develop their own National Programmes (i.e. nation-wide) for the prevention of deafness and hearing impairment. Where possible, this process could be assisted by linking with local chapters of organizations such as IMPACT and Hearing International.
<table>
<thead>
<tr>
<th>No.</th>
<th>Category</th>
<th>Work Item</th>
<th>Start Date</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>1. EPIDEMIOLOGY OF DEAFNESS AND HEARING IMPAIRMENT</td>
<td>Completion of development of software for the Who Ear Disease Survey Protocol and dissemination of the protocol to all countries</td>
<td>Jan 97</td>
<td>July 97</td>
</tr>
<tr>
<td>2</td>
<td>Ongoing Activity</td>
<td>Advise and assist countries to conduct and analyse national prevalence surveys of deafness and hearing impairment (2 countries in EMR, 4 countries in SEAR, 3 countries in AFR, and 1 country in WPR).</td>
<td>Sept 96</td>
<td>Jan 98</td>
</tr>
<tr>
<td>3</td>
<td>New Proposal</td>
<td>&quot;Research Proposal on the Global Epidemiology of Deafness and Hearing Impairment&quot; Submission to National Institute on Deafness and Other Communication Disorders, Bethesda, USA</td>
<td>Dec 96</td>
<td>Sept 97</td>
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<tr>
<td>5.</td>
<td>5. STRATEGIES FOR HEARING IMPAIRMENT PREVENTION</td>
<td>Completion of “Guidelines for the Prevention of Deafness and Hearing Impairment by the Management of Chronic Otitis Media” and Dissemination to all countries.</td>
<td>April 97</td>
<td>June 97</td>
</tr>
<tr>
<td>6</td>
<td>Ongoing Activity</td>
<td>Evaluation of “Guidelines for the Prevention of Deafness and Hearing Impairment by the Management of Chronic Otitis Media” in selected countries.</td>
<td>Jun 97</td>
<td>Continuing</td>
</tr>
<tr>
<td>7</td>
<td>New Activity</td>
<td>Convening of Meeting on Prevention of Noise-induced Hearing Impairment.</td>
<td>late Oct 97</td>
<td>June 98</td>
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<tr>
<td>9.</td>
<td>9. TECHNOLOGY DEVELOPMENT FOR HEARING AND EAR CARE</td>
<td>Convening of Meeting on Provision of Appropriate Hearing Aids for Developing Countries - needs and technology assessment.</td>
<td>early Dec 97</td>
<td>June 98</td>
</tr>
<tr>
<td>10.</td>
<td>10. SUPPORT TO PLANNING OF NATIONAL PROGRAMMES</td>
<td>Assistance with planning of the National Programme for Prevention of Blindness and Deafness in Turkmenistan</td>
<td>Oct 96</td>
<td>Jan 98</td>
</tr>
<tr>
<td>11</td>
<td>Ongoing Activity</td>
<td>“Development of A National Programme for the Prevention of Deafness and Hearing Impairment in Selected African Countries&quot; Obtaining funding and commencing implementation in 3 countries.</td>
<td>April 96</td>
<td>Jan 98</td>
</tr>
<tr>
<td>5.</td>
<td>5. PDH PROGRAMME DEVELOPMENT</td>
<td>Designation of three new Collaborating Centres</td>
<td>Feb 97</td>
<td>Jan 98</td>
</tr>
<tr>
<td>5.1</td>
<td>Ongoing Activity</td>
<td>Convening of Second Informal Consultation on Future Programme Developments for the Prevention of Deafness and Hearing Impairment, WHO-HQ, Geneva</td>
<td>Jan 97</td>
<td>March 98</td>
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</table>
ANNEX 1: WORKING SCHEDULE

Thursday 23 January 1997

08.30 - 09.00 Registration

09.00 - 09.30 Opening of the meeting (Welcome speech by Dr B Thylefors)
   Introduction of Participants
   Election of officers
   Adoption of the Agenda and Working Schedule

09.30 - 10.30 Agenda item 1: Review of PDH Programme
   - Progress made
   - Current and planned activities
     Presentation by Dr A Smith, WHO
     Discussion

11.00 - 12.15 Agenda item 2: Priorities for Programme Development
   - National programmes including Primary Ear Care
   - Control of specific diseases/causes of hearing impairment
   - Training and research needs
   - Programme/technical documentation
     Presentation by Dr B. Thylefors and Dr A Smith, WHO
   - UN Inter-agency initiatives - priorities for collaboration
     Presentation by Dr H. Nabulsi, Coordinator, IMPACT

13.45 - 14.00 Speech by Dr R.H. Henderson, Assistant Director-General, WHO.

14.00 - 15.30 Agenda item 3: Collaboration with Non-Governmental Organizations
   - Specific areas of collaboration
   - Mechanisms of collaboration at global, regional and country levels
     Presentation by Sir John Wilson on General Considerations
     Presentation by Prof Y. Kapur, President, Hearing International*
     Presentation by Prof P. Alberti, General Secretary, IFOS*
     Presentation by Dr A. Muller, Past-President, IALP*
     Presentation by Representative of Lions Clubs International*
     (*: each of these presentations will be followed by a brief discussion on specific areas of collaboration)

16.00 - 17.00 Agenda item 3 (Continued)

18.00 - 19.30 Reception in Staff Lounge (8th Floor, main building)

Friday 24 January 1997

09.00 - 10.30 Agenda item 4: Mobilisation of Resources
   - Needs
   - Sources
     Presentation by Lady Jean Wilson
     Discussion.

11.00 - 12.00 Agenda item 5: Tentative Work Plan for the Programme in 1997
   - Main activities and targets
   - Planning of detailed timetable
     Presentation of Work Plan by Dr A Smith, WHO
     Discussion

12.00 - 13.00 Agenda item 6.
   - Any other matters
   - Conclusions and Recommendations

14.00 - 15.00 Agenda item 6 (continued).
   Date and place of next meeting

*unable to attend
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Blindness and Deafness

Dr A. W. Smith, Medical Officer
Prevention of Deafness and
Hearing Impairment
ANNEX 3: THE ASSISTANT DIRECTOR-GENERAL’S MESSAGE
BY DR R.H. HENDERSON, ADG

Friends and colleagues,

It is a great pleasure for me to speak to you at this Informal Consultation on Future Programme Developments for the Prevention of Deafness and Hearing Impairment. This is the first of what I hope will be a regular series of meetings in which we consult you, our advisors, on the priorities and tasks for the Programme for Prevention of Deafness and Hearing Impairment.

Deafness and Hearing Impairment have often been neglected and forgotten even though they are major causes of disability in the world. The burden is especially heavy in developing countries. All of you well know that these impairments lead to poor language acquisition and delayed school progress in children, occupational problems in adults and social isolation at all ages.

The numbers of persons in the world estimated to have this impairment are rising, both because of the ageing of populations, and because of the increasing recognition of the problem. However, there is still a striking dearth of accurate, population-based data on the occurrence and causes of hearing impairment, especially in developing countries. There is also considerable ignorance of the possibilities for prevention, and uncertainty about the most appropriate methods for treatment and rehabilitation. This knowledge is essential for governments to determine priorities within their health programmes, to set up and monitor preventive strategies and to predict the needs for health care provision within the framework of primary health care.

Activities at WHO to do with deafness and hearing impairment actually began in the mid-eighties in the rehabilitation unit, but in 1991 became affiliated with Prevention of Blindness. An important event that year, as far as prevention of deafness and hearing impairment at WHO was concerned, was the convening of the Informal Working Group on Programme Planning. This meeting addressed the key problems and tasks in this field. Some of you here today were participants.

After that meeting, WHO Regional Offices became interested in the problem, and between 1991 and 1995 workshops were held in four WHO regions, namely South East Asia, Eastern Mediterranean, Western Pacific and most recently in the Africa Region.

A seminal event for the cause of Deafness and Hearing Impairment was the adoption in 1995, by the 48th World Health Assembly, of a resolution on Prevention of Hearing Impairment. This was a conspicuous message to re-kindle global interest in this problem; and the resolution is of particular importance to show to governments that this problem must be given increased priority in their programme planning. A key task of the work in Prevention of Deafness and Hearing Impairment by WHO will be to persuade Member States to implement National Programmes for Prevention of Deafness and Hearing Impairment.

With the strengthening of this programme in WHO, I believe there is now a window of opportunity to address this problem worldwide. It is therefore essential to determine the objectives, priorities and tasks for the programme, and for this we shall appreciate your help. We also need to develop innovative collaborations with organizations such as those you represent, and we need to proceed rapidly to mobilise the necessary resources for an effective programme delivery.

I am very grateful to all of you for coming to this meeting and I am looking forward with great interest to the outcomes of your discussions. We will do our utmost to follow up your recommendations.

Thank you very much.
ANNEX 4: WHO PDH COLLABORATING CENTRES

Currently Designated

Otological Center: Bangkok Unit, Dept of Oto-Rhino-Laryngology, Mahidol University, Bangkok, Thailand.
Head: Dr Suchitra Prasansuk. First designated 1988

Ear, Nose and Throat Department, Malmö General Hospital, University of Lund, Sweden.
Head: Dr Inga Bastos. First designated 1989.

Hearing Impairment Research Group, School of Tropical Medicine, Liverpool, U.K.
Head: Dr Ian Mackenzie. First designated 1993

Department of Audiology, Bispebjerg Hospital Copenhagen, Denmark
Head: Prof Agnete Parving. First designated 1997

In process of designation

Department of Otorhinolaryngology and Ear Health Care Centre, University of Indonesia, Jakarta.
Head: Prof Hendarto Hendarmin.

Department of Otolaryngology, Teikyo University, Tokyo, Japan.
Head: Prof Jun-Ichi Suzuki.

Department of Ear, Nose and Throat Diseases and Hearing assessment Centre, University of Science and Technology, Kumasi, Ghana.
Head: Professor George Broddy.
ANNEX 5: PDH BIBLIOGRAPHY (copies available from PDH)


