Prevention of Deafness and Hearing Impairment for Development of Framework of Proposed Regional Collaboration

Report of an Intercountry Meeting
Bangkok, Thailand, 27-28 November 2003

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1. INTRODUCTION

An intercountry meeting on the Development of a Framework of proposed regional Collaboration for Prevention of Deafness and Hearing Impairment was held in Bangkok, Thailand from 27–28 November 2003.

Twenty-Five participants representing governments, professional organizations, academic institutions, NGOs, private sector, manufacturers and WHO [HQ (PBD & DAR) and SEARO – DPR] participated in this meeting. (Programme and List of Participants are attached as Annex 1 and Annex 2, respectively).

Prof. Suchitra Prasansuk (Thailand) and Prof. Hendarto Hendarmin (Indonesia) were nominated Chairperson and Vice Chairperson respectively. Dr Ron Brouillette served as Facilitator and Rapporteur along with Dr Ravi Ramalingam as co-rapporteur.

Welcoming the participants Dr Madan P Upadhyay, RA-DPR, World Health Organization, South-East Asia Region Office, New Delhi, emphasized that the meeting was action oriented geared to ‘Action now’. He outlined the objectives and expected outcome of the meeting and said that a lot of discussion had already taken place and that it was time to move forward to take serious steps to make a difference to the people.

2. OBJECTIVES AND EXPECTED OUTCOME

The following were the objectives of the meeting.

(1) To review regional progress, constraints and propose future steps for prevention of deafness and hearing impairment;
(2) To obtain consensus on conceptual framework / terms of reference for South-East Asia Collaboration for Prevention of Deafness, and
(3) To identify steps / process for development and functioning of the collaboration.

At the end of the meeting the following outcome is expected.

(1) A framework for Regional Collaboration for Prevention of Deafness and Hearing Impairment, with a five-year perspective and one-year detailed plan, and
(2) Constitution of a small group charged with the responsibility of taking the initiative further.
3. CURRENT STATUS

3.1 Global and Regional Perspectives

Dr Andrew Smith – PBD/HQ and DPR SEARO, briefed the participants on the global and regional status of deafness in SEA respectively. Dr Andrew Smith informed that the WHO estimate for prevalence of deafness is currently 250 million which is markedly higher than for prevalence of deafness previous estimates.

![Figure 1. Global trends in magnitude of disabling hearing impairment](image)

He highlighted the fact that the SEA Region contributed significantly to the global burden of deafness and hearing impairment.

He also listed various reasons contributing to this increased estimate of deafness including better methods of data collection, increasing age of the population and noise-induced hearing loss, among others. Dr Smith informed the participants that according to a US study, deafness and hearing impairment, together with voice, speech and language disorders, cost the USA from 2.5 to 3% of GNP in 1999. He also updated the participants on some recent WHO initiatives. These included hearing aids and services for developing countries, and primary ear and hearing care training resources.
Dr Madan P Upadhyay, Regional Adviser for Disability, Injury Prevention and Rehabilitation, WHO/SEARO reviewed the activities related to the prevention of deafness and hearing impairment in the SEA Region. He highlighted that the SEA Region was home to every third deaf person in the world; thus this Region had a disproportionately high burden of deafness.

Prevention of deafness varied from 4 to 16% in different countries. There are an estimated 110 000 000 deaf persons in South-East Asia for a population of 1.5 billion, with an overall deafness prevalence of 7.3 percent.

He emphasized that all the available data indicated the national averages and did not reflect the distribution of disease in different geographical areas of the individual countries. The prevalence of deafness was known to vary not only between the countries but also within the countries. Disaggregated data were, therefore essential for local planning. These, however were not available currently.

Dr Upadhyay enumerated the various causes of hearing loss and ear diseases. These included ear wax, suppurative otitis media, ototoxic & noise induced deafness and congenital hearing loss. He said that a review of the
causes of deafness indicated that half of all deafness in the Region was preventable and about 30% of them were treatable. Therefore, 80% of all deafness was avoidable. This indicated the failure of the health system in so far as providing ear care was concerned.

Based on the findings of the six country survey, Dr Upadhyay emphasized the urgent need to formulate a policy for prevention of deafness in Bangladesh and India and develop tools for monitoring prevention of deafness programme in all countries. While there may be a need to enact new laws in some countries (for example against noise pollution in Nepal and Sri Lanka), there was a greater or at least as much need to strengthen the law enforcement mechanism in all countries to implement the existing statutes. The inadequacy in availability of human resources for ear and hearing care for most of the countries of the Region was also highlighted.

Dr Upadhyay identified the following as the most critical issues in the prevention of deafness:

1. Huge burden of deafness which was rapidly increasing;
2. Insufficient human resources who were inequitably distributed;
3. Inadequate infrastructure, and
4. Low Prevention and control of deafness on the priority by national governments.

A review of the recommendations of the last intercountry consultation held in the year 2002 in Colombo was presented by Dr Bulantrisna Djelantik. She apprised the participants of the general guidelines for formulation of national policy programme and human resources requirements as agreed by Member States at the Colombo meeting. She also highlighted the priorities for disease control in the represented countries as firstly being control of middle ear infections and congenital deafness. Functions of, and resources required at, the primary, secondary and tertiary levels were enumerated. Action pointers for WHO, NGOs and Professional societies were also reviewed.

### 3.2 International Nongovernmental Organizations (INGO)'s Perspectives

Presentations were made on behalf of the NGOs: Christoffel Blinden Mission (CBM); IMPACT; Hearing International (HI), and Lions Club International Foundation (LCIF).
Professional Organizations represented were International Federation of Otolaryngological Societies (IFOS), SAARC ENT Society, and International Society of Audiologists (ISA).

3.2.1 Christofel Blinden Mission - South-Asia Regional Office

Ms Silvana Inselmann and Mr John Tressler, Regional Representatives of Christofel-Blinden mission (CBM) reviewed the activities of CBM which was active in 73 countries. They outlined the priorities of CBM which included prevention, early intervention, training and rehabilitation, and also highlighted their work in the SEA Region, especially in North-East India, Southern India and in Sri Lanka. Mr John Tressler spoke at length about the work being done by CBM in North Eastern India (a relatively underserved area) with Sister Merly Tom Kizhakhayil, Director, Ferrando Speech and Hearing Centre, Meghalaya.

3.2.2 Commonwealth Society for the Deaf

Dr Navnith Shah, Vice-Chairman, Commonwealth Society for the Deaf, emphasized that diseases of poverty cannot be altered by doctors in the healthcare systems. He spoke about CSD’s role in prevention of deafness and hearing impairment and their current projects in various parts of the world, especially HARK! (Hearing Assessment and Research Centre - Audiology Clinic). He emphasized that many causes of deafness could be eradicated or reduced by national governments working closely with public health departments and stressed the need for health education in schools and for the public. He also emphasized immunization as an important goal along with genetic counselling, antenatal care, control of ototoxic drug use and prevention of noise induced deafness.

3.2.3 IMPACT International

Prof Rakesh Prasad Shrivastav briefed the participants about the Affordable Hearing Aid Project (AHAP) of IMPACT. He emphasized the objectives of the AHAP in making the hearing aids affordable, acceptable, appropriate and available. He also spoke about the activities of IMPACT including the Life Line Express in India and also the River Boat Project in Bangladesh as well as the microsurgical ear camps in Nepal taking ear care to the doorsteps of people in remote areas in these countries.
3.2.4 **Lions Club International Foundation (LCIF)**

Mr K M Goyal, representative of the President of Lions Club briefed the participants of the work being done by the Lions in the social sector, including health. Sightfirst for prevention of blindness is the flagship project of the Lions International Community. Dr Goyal expressed Lions Clubs' interests in prevention of deafness for their future activities.

3.2.5 **Hearing International**

Dr Suchitra Prasansuk, President of Hearing International highlighted the main objectives of Hearing International and its promotional role in mobilizing resources, networking, manpower development and improving education. She said that Hearing International worked with the IFOS and the respective national chapters and national committees. She also enumerated the existing HI - IFOS - ISA Centres worldwide and discussed in detail the role of Hearing International in various countries. She also highlighted the activities of the Otological Centre, Bangkok which has been operational since 1972.

3.3 **Professional Organizations**

The following presentations were made by Professional Organizations:

3.3.1 **International Federation of Otolaryngological Societies (IFOS)**

Prof Jan J Grote, Secretary-General of IFOS spoke on the worldwide perspective of deafness and hearing impairment. He highlighted that the current focus of IFOS was to develop a sound plan in order to raise money and formulate an action plan for all countries in the world for prevention of deafness and hearing impairment. He assured the participants of the strong support which the IFOS was prepared to offer for the development of regional collaboration for the prevention and management of deafness and hearing impairment.

3.3.2 **SAARC (South Asian Association for Regional Cooperation) ENT SOCIETY**

Prof. Alauddin, Secretary-General of the SAARC Otolaryngologists Association highlighted the objectives of the SAARC Otolaryngologists’ Association and the success of the association in conducting various conferences, panel discussions and teaching programmes thus enabling better awareness and better treatment for patients with deafness and hearing impairment.
3.3.3 International Society of Audiologists (ISA)

Prof William Noble from the International Society of Audiology briefed the participants on the aims and functions of the ISA and also their current projects in this field. He informed that the International Society of Audiology was a very small organization and their role on a regional scale was limited. He, however, spoke of one of their projects which was the development of a very comprehensive website to help in the better awareness and communication with all those concerned with the problem of hearing impairment.

3.4 Group Discussion

Following the presentations, the participants were divided into three groups. These three groups discussed the following separately.

1. Vision, mission, terms of reference and name of the initiative;
2. Administration of initiative;
3. Finances for the initiative, and
4. Regional priorities for prevention of deafness projects.

The main outcomes of the group discussions and plenary session following the group discussions are summarized as follows.

4. MAJOR OUTCOMES OF THE INTERCOUNTRY CONSULTATION

4.1 Vision

To prevent, care for and (Re)habilitate hearing loss so that no one is needlessly deaf and has equal opportunities with other to lead a dignified life, if deafness can't be prevented or cured.

4.2 Mission

To eliminate avoidable hearing loss by 2030.

Reports of the different groups will be provided to the Steering Committee as inputs from the group discussion. The Steering Committee will draft the final versions of Vision and Mission.
It was decided that a Steering Committee representing various stakeholders will be constituted to refine these. In addition, the responsibilities of the Steering Committee were identified.

**Administrative structure**

The initiative will be a two-tier structure consisting of a] General Body and b] a smaller core group called Steering Committee.

### 4.3 Terms of Reference for the Steering Committee

1. To identify network partners regionally and internationally for technical and financial support;
2. To identify good practices and prime movers in the Region and elsewhere;
3. To develop a business and funding proposal for organizational start-up and for future implementation of identified projects;
4. To raise awareness of prevention among potential partners, donors and governmental agencies;
5. To draft a constitution of the Regional Collaborative working group;
6. To formally register the regional organization in a suitable country, and
7. To convene a general body meeting of the regional organization and transfer authority to the formal body.

**Time frame**

All above to be accomplished by 31 December 2004.

**Funding requirement**

It was estimated that US$ 80,000 will be required for organizational development including meetings of the Steering Committee, advocacy initiatives, formalization of the organization and the General Body Meeting at the end of 2004*. An amount of US$ 500,000 was estimated to be required for implementation of the projects.

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* It is expected that the organization deputing their representatives to the Steering Committee will meet their own expenses. Therefore, only a small amount for travel budget is expected for the Steering
Funding sources

- Christoffel Blinden Mission Office in South Asia pledged to provide financial inputs if other NGOs and partners also made their contributions.
- WHO was requested to provide a seed fund of US$ 10 000.
- Other participants, while pledging their support, would communicate after consultation with their decision-making authorities.

Composition of the Steering Committee

The Steering Committee will consist of a representative each from:

1. Christoffel Blinden Mission
2. Impact International
3. Hearing International
4. International Society of Otalaryngological Societies (IFOS)
5. SAARC ENT Society
6. International Society of Audiologists (ISA)
7. WHO SEARO (DPR) and WHO HQ (PBD & DAR) as special invitees

Organizations will be requested to send their nominees who have one or more of the following competencies:

1. Business planning and management
2. Fund raising expertise
3. Experience in governance and stewardship
4. Understanding of international health
5. Ability to work in groups / teams
6. ENT / audiology / special education skills

Coordinator of the Steering Committee

WHO will nominate the co-coordinator of the Steering Group after DPR’s informal consultation with various groups.

Committee. The required expenditure is mainly for remuneration to the secretary, the coordinator, secretariat, advocacy initiatives and for the process of formalization.
Secretariat localization
The secretariat of the Steering Committee will be located in proximity to the selected co-coordinator.

Constitution of the Regional Forum / Initiative
This shall be drawn up and completed by the Steering Committee and reported to the General Body to be organized before the end of 2004.

Registration
The steering committee is also entrusted with the responsibility of registering the forum in a suitable country.
Annex 1

PROGRAMME

Thursday, 27 November 2003
0900–0930 hrs Opening of the Meeting
0930–1230 hrs Technical Session
0930–1000 hrs Global Burden of Deafness – Dr Andrew Smith
1000–1030 hrs Status of Deafness in SEAR countries – Dr Madan Upadhyay
1030–1045 hrs Summary of recommendations of Colombo meeting – Dr Bulantrisna
1100–1200 hrs INGO and professional organizations’ perspective – CBM / IMPACT / IFO S / ISA / SAARC ENT Society / World Federation of Deaf / HI / CSD / LCIF
1200–1230 hrs General Discussion – I
1400–1630 hrs Specific Discussion 1 (3 separate Groups)
1400–1440 hrs **Topic 1:** Structure of regional collaboration: Vision, Mission, TOR and Name of Initiative
1440–1500 hrs Plenary Summary of the Discussion on Topic 1
1515–1600 hrs **Topic 2:** Administration of collaboration
Group 1: Composition and member officials
Group 2: Secretariat and localization
Group 3: Constitution and formalization
1600–1700 hrs Plenary Summary of Discussions on Topic 2

Friday, 28 November 2003
0900–1130 hrs Specific Discussion 2 (3 separate Groups)
**Topic 3:** Finances: One-Year Plan, identifying needs and resources for the one-year plan
**Topic 4:** Identifying global and national bodies and linking these to the regional forum. Suggested structure, timeline and function of national bodies.
**Topic 5:** Regional priorities for prevention projects
1130–1230 hrs  |  Plenary Summary of Discussion on Topics 3, 4 and 5
1330–1630 hrs  |  General Discussion – II
•  Conclusion and recommendations for action
•  Follow-up for implementation – next steps
•  Closure
Annex 2

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