

*'SEMINAR ON PREVENTION OF DEAFNESS AND  
HEARING IMPAIRMENT: STRATEGY PLAN FOR  
INDIA'*

*HELD AT*

*MAULANA AZAD MEDICAL COLLEGE,  
NEW DELHI*

*ON*

*10<sup>TH</sup>-11<sup>TH</sup> DECEMBER 2010*

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## *LIST OF PARTICIPANTS*

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A seminar was held on the 11<sup>th</sup> of December 2010 at the Maulana Azad Medical College, New Delhi. The seminar was attended by the following experts:

### **LIST OF PARTICIPANTS**

#### **International experts:**

1. Dr. Bulantrina Djelantik, Indonesia, Past President, Society for Sound hearing and consultant, WHO SEARO
2. Dr. Suchitra Prasansuk, Thailand, President, Hearing International
3. Dr. Madan Upadhyay, Former, Director, Non communicable diseases, WHO SEARO, Kathmandu, Nepal
4. Dr. Rakesh Prasad Srivastava, professor of ENT, Tribhuvan University, Kathmandu, Nepal
5. Dr. Ronny Suwento, Director, WHO Collaborating Centre, Jakarta, Indonesia
6. Dr. A.H. Joarder, Professor of ENT, Dhaka, Bangladesh

#### **Indian Experts:**

1. Dr. Achal Gulati, Professor of ENT, MAMC, Delhi
2. Dr. Alok Thakkar, Professor of ENT, AIIMS, Delhi
3. Dr. Suneela Garg, Professor of Community Medicine, MAMC, Delhi
4. Dr. U. Thansein, Member, Society for Sound Hearing
5. Dr. TS Sidhu, Medical Superintendent & Head of ENT, RML Hospital
6. Dr. Vijaylakshmi Basavraj, Director, All India Institute of Speech & Hearing, Mysore India
7. Mr. Rangasayee, Director, Ali Yavar Jung National Institute of Hearing Handicap , Mumbai, India
8. Dr. Geeta Rao, Lecturer, Ali Yavar Jung National Hearing Institute for Hearing Handicapped, Mumbai
1. Ms Silvana Mehra, Regional Director, CBM SARO, Bangalore, India
2. Mr. Murali, Director, Deaf Leaders, Coimbatore, India

3. Dr. PD Vithhalani, Professor of ENT & Director, Medical Education, Ahemdabad, Gujarat
1. Dr. Anirban Biswas, President, Association of Otolaryngologists of India, Kolkata
2. Dr. Karan Sharma, Head & Professor of ENT, Govt. Medical College, Amritsar
3. Dr. Dr. JK Sahni, Professor & Head of ENT, lady Hardinge Medical College, Delhi
4. Dr. S. Ramalingam, Prof. & Head of ENT, Army Hospital Delhi Cant,
5. Dr. T. K. Joshi, Director OEM Programme COEH, MAMC, New Delhi
6. Mr. Biswajeet, Audiologist, LNJP Hospital, New Delhi
7. Ms Narayanswamy, Educator of the Deaf, Balvidyalaya, Chennai
8. Dr. MNG Mani, Secretary General, International Council for Education of Visually Impaired
9. Ms Gita Arora, Human resources expert, Delhi
10. Dr. Himanshu, Assistant Professor of Community Medicine, Maulana Azad Medical College, New Delhi
11. Dr. MM Singh, Professor of Community Medicine, Maulana Azad Medical College, New Delhi
12. Mr. Murali, Programme Officer, CBM, SARO Office, Bangalore
13. Dr. Neelima Gupta, Lecturer of ENT, University College of Medical Sciences, New Delhi
14. Dr. Rajiv Dhawan, ENT Specialist, Guru Gobind Singh Hospital, New Delhi
15. Ms Ranjana Sethi, Educator of the Deaf, Sriganaganagar
16. Dr. S. Ramji, Director-Professor & Head, Department of Neonatology, MAMC, New Delhi
17. Dr. Krishna Agarwal, Associate Professor of Gynecology-Obstetrics, MAMC, New Delhi
18. Sh. D.S. Chauhan, Secretary, Delhi Association for Deaf, New Delhi
19. Mr. Nandha Vedakkeppatte, CEO, Hearing Care India Gurgaon
20. Mr. Anup Narang, Director, ALPS International , New Delhi

21. Mr. Vikas Katoch, Programme Officer, CBM – SARO North, Bangalore
22. Ms. Shilpi Narang, Special Educator Hearing Impaired, New Delhi
23. Dr. V. P. Sah, Assistance Prof. Ali Yavar Jung National Hearing Institute for Hearing Handicapped, New Delhi
24. Mr. J.C. Gupta, ex-Principal, AYJNIHH, New Delhi
25. Ms. Ruchika Mittal, Chief Audiologist, Army Hospital (R&R), New Delhi

Special Invitees:

1. Dr. Vinay Aggarwal, President, Indian Medical Association
2. Dr. A.S. Bais, ex-Principal, Lady Hardinge Medical College and Professor of ENT, New Delhi
3. Dr. S.K. Kacker, ex-Director AIIMS & Prof. of ENT, New Delhi
4. Dr. Sara Varughese, Regional Advisor, Disability Prevention, WHO SEAR Office, New Delhi

## *OBJECTIVES*

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The Objectives of the seminar were: (Discussed in session 1 of the programme)

1. To emphasize the need for the country level strategy paper.
2. To seek sector specific inputs from experts in various fields.
3. Drafted strategy paper was circulated among panel of experts.
4. To discuss the methodology adopted for drafting the strategy paper: The salient features of which are
  - Formation of task force and discussions among members
  - Review of literature
  - Formal and non-formal meetings with stakeholders
  - Participating in training and workshops

## PROGRAMME

SI.NO.	Time	Session	Speaker/Participant
<b>0900-0930: Registration</b>			
1	0930-0940	Welcome and Introduction	Dr. A.K.Agarwal
2	0940-0950	Objectives of the Workshop	Dr Himanshu Chauhan MAMC
3	0950-1010	Need for country strategy paper	Dr Bulantrisna Djelantik, SSH
4	1010-1030	Draft Strategy Paper for India: Salient points	Dr Suneela Garg, SSH
5	1030-1050	Barriers and Challenges to effective hearing care: A Community health experience	Dr Shelly Chadha, SSH & MAMC
	1050-1110	<b>Coffee Break</b>	
6	1110-1130	Role of education sector in combating hearing impairment & its ill effects	Dr MNG Mani, ICEVI
7	1130-1150	Role Of ENT Professionals in Strengthening ear care	Dr Agarwal, SSH & MAMC
8	1150-1210	Role of IEC in combating hearing impairment	DR GK Ingle, MAMC
<b>Inauguration: 1210-1240</b>			
<b>Lunch break (1240-1330)</b>			
9	1330-1350	Community based Rehabilitation: A strategy	Ms Lisa Johnson, CBM
10	1350-1410	Role of CBOs towards Rehabilitation of Hearing impaired	Ms Silvana Mehra, CBM & SSH
11	1410-1430	Strategies of Rehabilitaion Council Of India For comprehensive Mgt of hearing Impaired	Dr. J.P. Singh, RCI
12	1430-1450	Role of Disabled Person's organisations	Mr. Murali, Deaf Leaders
	1450-1545	Open House, Comments and Discussion	All experts
<b>1545-1600: Valedictory &amp; Tea</b>			



## *PROCEEDINGS OF THE MEETING:*

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The meeting was chaired by Dr. Madan Upadhyay, Senior Vice-President, Society for Sound Hearing and Suchitra Prasansuk, Past President, Hearing International & Executive Body member, Society for Sound Hearing

### **I. OBJECTIVES OF THE WORKSHOP: DR. HIMANSHU CHAUHAN**

**To begin with, the Objectives of the workshop were outlined as follows:**

1. To highlight the need for country level strategy paper
2. To seek sector specific inputs from experts in various fields
3. Review of draft strategy paper by panel of experts
4. To formulate the next steps based on the proceedings

**The Expected Outcomes of the workshop:**

1. **Evaluation of strategy paper**
2. **To receive inputs from experts on the strategy paper**
3. **To delineate resources required for drafting of the strategy paper.**

The methodology of development of strategy paper was outlined with aim to develop a multi-sectoral approach to address the numerous issues related to hearing impairment

- Formation of a task force within India: formal and non-formal meetings were held. Task force member Dr. Chauhan and Dr. Rajiv Dhawan attended the Course on 'Public Health Planning for Hearing Impairment' at Hyderabad in October 2010.
- Doing a literature review and learning from the experience of other countries of the region. This included:
  - Reviewing published literature in journals
  - Reviewing unpublished literature
  - Extensive search on internet
- Organizing a consultative workshop of all stakeholders
- To prepare a roadmap for integration of promotive, preventive, curative & rehabilitative components into the national program based on the results of the workshop.

- To develop a strategy plan in concurrence with national and international experts and validate the strategic actions.

## **II. NEED FOR STRATEGY PLANNING: THE COLOMBO RECOMMENDATIONS : Dr. Bulantrisna Djelantik**

**The origin, purpose and background of the society for Sound Hearing was outlined.** The presentation also detailed the efforts made by WHO in assessing the prevalence of hearing loss in various countries of the world. It outlined the guidelines developed by WHO regarding Prevention of Hearing loss and listed out the action pointers in relation to various stakeholders.

### **General Guidelines:**

- **A national Policy should be formulated/reformulated in all countries, all relevant stakeholders on board**
- **A National Committee to be constituted by the govt. at MOH**
- **WHO to develop template for development of national policy and programs**

### **National Committee:**

- Such a committee to be located at the MOH
- A focal person from MOH to be appointed as the Secretary
- The list of possible members is also stated.

### **Recommendations for Action Pointers:**

#### **WHO:**

- The network of WHO Collaborating Centers should be expanded
- WHO to provide guidelines to governments for development of PDHI programs
- Distribution of all information, publications, research highlights should cover all countries (through WR)
- Involve hearing impaired people in all aspects of planning
- Make recommendation to UN for commemorative International Year for Better Hearing
- Provide additional support

**National Governments:**

- Formulate and implement The National Deafness Prevention Program
- Appoint a separate directorate and focal person to coordinate the program
- Formulate a National Working Committee for Better Hearing ( or PDH), to develop a national time bound plan and annual meetings to be held with all stakeholders
- Set up training institutions for relevant medical and paramedical personnel
- Allocate finances and other resources
- Enact or enforce existing laws ( incl. noise pollution)
- Support research
- Support and promote a National Better Hearing Day
- Respect the human rights of the deaf and hearing impaired

**Non-Governmental Organisations:**

- All NGO's and INGO's should work within clear policy and guidelines formulated by the government
- Extend their work into PDH
- Establish networking within NGO/INGO and governments
- Organize and involve all to develop a major international campaign, coordinate with WHO to meet time bound goals
- Coopreate and network with countries or cluster of countries
- Develop communication media for information exchange ( newsletter, website, internet mail link)
- Coordinate NGO level meetings

**Professional Societies & Professionals:**

- There should be a focal person for PDHI in professional societies
- The societies should be technical advisors to the government in PDH
- PDH to be included in meetings, congresses and other activities
- Encourage publications on PDH in professional journals

- Encourage members and international societies for awareness and implementation of the recommendations
- Networking for cooperation towards Better Hearing

#### **Disabled person's Organisations:**

- Collaborate at all levels to express the needs
- Strengthen and network with hearing impaired organizations at national, regional and international levels
- Interact more with all the agencies involved in Better Hearing

### ***III STRATEGIES FOR INDIA: A DRAFT: Dr. Suneela Garg***

#### **a. Inclusive growth**

While evolving any strategy for prevention and control of hearing impairment focus should be on inclusive growth. The term inclusive consists of 5 key features.

- 1) Quality of life
- 2) Twin track approach (empowerment and mainstreaming PWDs)
- 3) Persons with disability as central
- 4) Comprehensive accessibility
- 5) Human rights

#### **b. Role of education sector**

The prevention and control of hearing disability is a multi sectoral approach in which education sector has an important role: GOI has started focussing on including children with disabilities into mainstream school and in this regard a historic Right to Education Act is passed. One of the major initiatives from the Government of India to promote "integrated education" is the program of Integrated Education of Disabled Children (IEDC). Under this programme states were provided 50% assistance to run program and children with disabilities were provided with financial assistance to attend school. However due to various bottle necks program does not have desired outcomes and it was revised in 1992.

Following recommendations were made

- **Increase the number of normal as well as special schools for HI**
- **Expand the scope of special schools**
- **Curriculum changes and evolving methodology for teaching disabled.**
- **Teachers as primary screening agents**

c. Livelihood and social empowerment: To bring PWDs into mainstream it is absolutely essential to increase means of their livelihood and to make them feel socially empowered. Following can be done in this regard

- Provide vocational and social rehabilitation training to people with hearing disabilities
- Advocate for a more sympathetic policy environment and greater protection for rights of people living with hearing disabilities
- Increase access to information and creating additional jobs for the disabled e.g. modernization of equipments and on the job training for deaf
- Increased public awareness of concerns and needs of people with disabilities

d. Role of apex institutes

All India Institute of Speech & Hearing (AIISH), Mysore & Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH) are two apex institutes. Currently these institutes are involved in

- Development of manpower by undertaking or sponsoring the training of trainees and teachers, employment officers, psychologists, vocational counsellors etc.
- Conduct, sponsor, coordinate and subsidize research into all aspects of the education and rehabilitation of the hearing handicapped.
- Develop model services for rehabilitation of the hearing handicapped.
- Serve as an apex information and documentation centre in the area of hearing handicapped .

There is a need to enhance the capacity of these institutes and to bring up more institutes.

e. Role of industrial sector

Currently proportion of hearing impaired in industrial sector is 10.7% (ICMR). Since most of people working in this sector are illiterate and ignorant about the ill effects of the noise a lot needs to be done. Currently following is being done in this sector:-

- The ICMR promotes occupational and environmental health research,
- Pioneering work of The National Institute of Occupational Health, Ahmedabad, in the area of industrial noise.
- In India the international standard for safety from noise exposure is recognised and noise-induced hearing loss has also been incorporated into the Indian Factories Act (1996 amendment) as a notifiable and compensatable disease

#### f. Role of NGOs

A lot of NGOs are working in this field and some have done exceptionally well. A few characteristics of NGOs make them an excellent way of reaching to masses:-

- NGOs has good rapport in the community
- Primary prevention: increasing awareness among common person
- Secondary prevention: identifying the persons with HI by surveys, sponsoring the children for surgeries like cochlear implant
- Development of curriculum and accreditation of schools run by NGOs
- International NGOs can provide technical support to government programmes

#### g. Role of medical professionals

- Sensitizing the medical professionals to ototoxic drugs
- Screening high risk deliveries to diagnose HI at the earliest stage
- Strengthening immunization services
- Catching under-nutrition at the early stage through the used of WHO growth chart
- Apex institutions like AIISH and AYJNIHH to support smaller institutions in capacity building to have more speech therapists and audiologists
- Linkages with institutes for HI

- Institution based HI register which can later be integrated into a national register – utilizing the unique ID system to develop policy specific for them.

#### ***IV Barriers and Challenges to Ear and Hearing care in the community: Dr. Shelly Khanna Chadha***

Barrier is defined as something that impedes or obstructs, and challenge is a call to engage in a fight or contest. Several kinds of barrier are identified in the way of successfully fighting with the problem of hearing impairment and deafness:-

- 1) Inadequate resources (Trained health care professionals & Health care infrastructure
- 2) Socio-economic (Social, Educational, Economic, Knowledge, Traditional practices)
  - a) Economic factors
    - 41% of Indian population lives below poverty line, as per International standards (<\$1.25 per day)
    - As per Indian standards (<Rs 12 per day), 27.5% are below the poverty line.
    - It has been recorded that poorer households have lower health care seeking behaviour.
    - Paradoxically, the main reason is lack of time.
  - b) Educational level
    - Parental educational level, especially mother's education is in direct relation to the care seeking behavior in the community.
  - c) Traditions
    - Quacks and traditional healers are more accessible and more entrusted than doctors in certain parts of the community.
  - d) Lack of awareness
    - Very poor overall awareness of ear diseases in the community.
    - Unhealthy practices are common.
    - Misguided beliefs are rampant.

- OTC drugs also contribute to improper therapy and unsuitable treatment.
- 3) Mismatch between demand and supply of trained manpower.
- 4) Inadequacies in infrastructure (Cupboard audiometers, Shelves microscopes, Expensive equipment, Poor distribution of resources, Grass root level infrastructure).

#### **V. Inclusion of Children with Hearing Impairment: A Rights**

**Issue: Dr. MNG Mani:** There are millions of children with disability all over the world. The irony of the situation is that developing and economically weak countries have more burden of disability and economically developed nations have less burden of disability. Current situation:-

- 90% of these children are present in developing countries
- Less than 10% of these do not have access to any type of education.
- In India over 3 million CWDs enrolled in general schools but it constitutes only 66% of the population among children with disabilities, deaf children in schools constitutes less than 15%

It was envisioned in Bilwako Millennium Framework to "*Create a Rights Based, Barrier-Free and Inclusive Society*". International declarations aim at providing equal access to education for all children and youth with disabilities by 2015.

It was again re-emphasized that inclusion is not an option but a compulsion and it should co-exist with special school system.

There are some concerns in educating children with hearing impairment like

- Communication
- Visual cues in learning
- Use of signs / gestures
- Illustrations in materials
- Sensitizing the teachers



**VI. Role of ENT professionals in Primary ear and hearing care: Dr. A.K.Agarwal**

ENT doctors have to play a important role in this concept. It is they who face the consequences of the absence of such primary care, on a daily basis. They have to play several roles like:-

- a) Advocacy: Have the contacts and power to:
  - Lobby with the government
  - Lobby with the industry
  - Sensitize and motivate other professionals
  - Motivate the formation of Disabled persons network/self-help groups
- b) Training
  - Training of trainers at all levels
- c) Screening
  - They have to be ready to offer their services for community based activities such as screening camps.
  - All screening camps must be based on the concept of 'No Screening without Service'.
- d) Treatment
  - In view of the high load of ear diseases such as discharging ear (5%) in the community,
  - They have to be ready to deal with the greater load for medical and surgical treatment, wherever awareness and screening is strengthened.
- e) Awareness creation
  - Awareness creation has to take place at all levels, with all health care providers being a part of this.
  - However, as health professionals, we have a special place in the society and in the minds of our patients.
  - We must use this advantage to spread the message of primary ear & hearing care in the community.

**A National Programme for Prevention & Control of Deafness in India is now running for the last 5 years. A brief detail of this programme is as below:**

The National Programme for Prevention and Control of Deafness (NPPCD) was launched on a pilot basis from August 2006. It was implemented in 25 districts over 10 states, ie Andhra Pradesh, Assam, Gujarat, Karnataka, Manipur, Sikkim, Tamil Nadu, Uttranchal, Uttar Pradesh, New Delhi and 1 union territory of Chandigarh.

In 2008, this project has taken the shape of a full fledged National Programme and is to be gradually expanded to include 200 districts by the end of the 11<sup>th</sup> Five year plan. The programme is based on **the Healthy Ear District concept** and the District Hospital is the focus of the Programme.

For the purpose of implementing this project, the existing health infrastructure is to be utilized and upgraded.

The **State Medical College** would be the Centre of Excellence which will support the programme.

The **District Hospital** are being the nodal point for the actual implementation of the programme. The government and private doctors as well as Audiologists are involved. The District hospital is being strengthened with the provision of equipment to enable diagnostic as well as therapeutic and rehabilitative procedures to be carried out here. The doctors at the **Primary Health Center and Community Health Centres** are trained to reorient them to ear problems and are being provided with the basic diagnostic equipment, to enable them to diagnose, treat and refer the patients with hearing and ear diseases.

The function of the Health Care workers at the various levels (including MPW, AWW) within the health care delivery system has been defined and each person is being trained to perform that specific function.

## **VII Role of IEC in combating hearing impairment and IEC development under sound hearing: Dr. G.K. Ingle**

IEC is defined as, "a package of planned interventions which combine informational, educational and motivational processes".

It can be considered as the backbone of any intervention and success of any program also depends on its IEC component. Formation of strategy consists of

- Planning
- Implementing
- Monitoring and evaluating a strategy

IEC has a definite role to play in hearing impairment. It can help overcome hurdles like Ignorance of symptoms, misbelieves and stigma attached to deafness. Till now, no active intervention has been done to increase awareness and stimulate demand for prevention and management of hearing impairment. Development of IEC material has been done under aegis of society of sound hearing. All the material has been made by consultative efforts of various specialists and extensively field tested, modified and again reviewed. The development of material has been done keeping in mind factors like (Comprehension, Attractiveness, Acceptance, Involvement, and Inducement to Action).

Finally it was concluded that

- Changing behaviour is not an easy or quick task,
- IEC interventions cost money to implement and to sustain over time,
- Change within five per cent of a designated population represents good progress

## **VIII. Role of apex institutes towards capacity building for prevention, early diagnosis, management and rehabilitation: Dr. Vijaylakshmi Basavraj**

All India Institute of Speech and Hearing (AIISH), MYSORE is an apex institute dedicated towards providing training in field of disabilities. It is helping in bringing up trained manpower. Some special features of the institutes are summarized below:-

- Centre of excellence in the area of deafness
- A science and technology institute
- Centre of advanced research
- Provide clinical services
- It has eleven departments (speech language science, electronics, audiology, ENT, special education etc.)
- Run several kind of Diplomas, Bachelor courses, Master programs, Doctoral Programs and Post Graduate programs
- Institute provides out reach services like
  - Newborn hearing screening in hospitals
  - School screening
  - Industrial screening

The role these institutes can play in prevention and control of hearing disability was emphasized.

### **IX Community Based Rehabilitation - a strategy for Inclusive Development: Ms Silvana Mehra, Ms Lisa Johnson**

CBR is a comprehensive, rights-based strategy for inclusive development and poverty reduction. This strategy evolved after Alma Ata "Health for All" Declaration of 1978 in recognition that the majority of people with disabilities had no access to service and over the time it has evolved into a comprehensive strategy.

Key components of CBR today are

- Social Inclusion
- Active Participation
- Sustainable community based solutions
- Empowerment of persons with disabilities
- Promotion of Self advocacy
- Working to create a barrier free environment

The CBR is a matrix of interlinked and interdependent activities.

- Each components is as important as each other, they are inter-related and not sequential
- Important to see Matrix not only as a planning tool, but from the point of view of persons with disabilities (How can we assist in increasing information, choice and ease of access?)

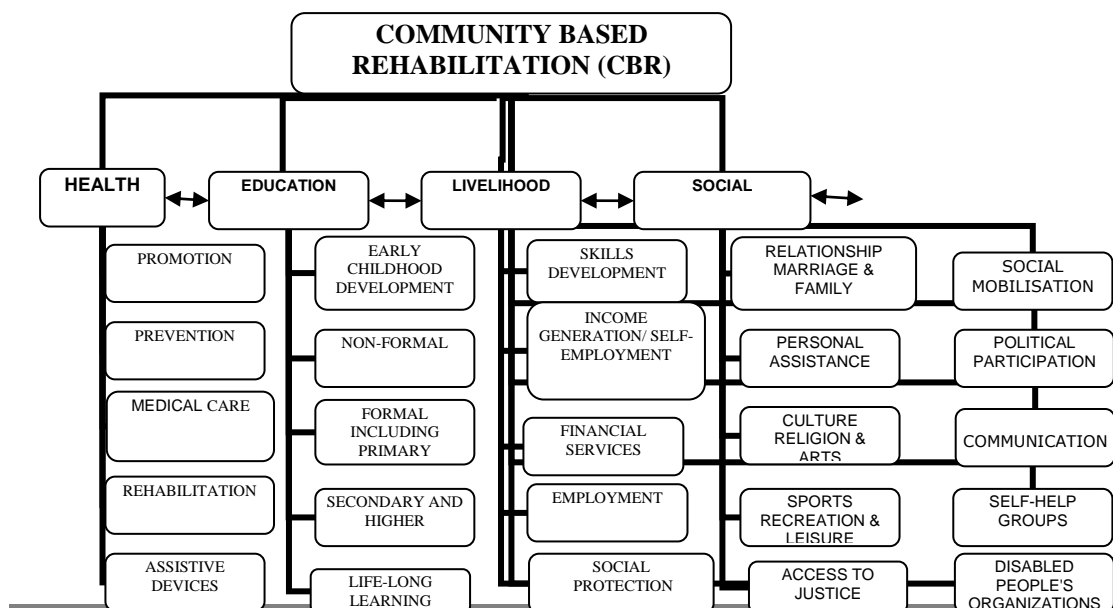
- There is a need to strengthen the social and empowerment elements, these have often been neglected in the past
- No one organization can do it all, nor should they (depends on capacity, mandate, resources, local priorities)
- CBR does call on us however, to broaden the range of stakeholders (including PWDs, their families and DPOs) with whom we engage, to form linkages & work collaboratively
- UNCRPD provides both a clear philosophical framework along with a practical “road-map” for where we need to go – CBR can be a powerful tool for taking us there

Purpose of the CBR guidelines:-

- Provide practical guidance on how to initiate a CBR programme or to strengthen an existing one
- Provide a framework for working across sectors as a basis for scaling up CBR efforts & achieving greater comprehensiveness
- Promote CBR as strategy for inclusive development, disability mainstreaming and poverty reduction
- To encourage the participation and empowerment of people with disabilities in development / decision making processes
- To contribute to the implementation of the UNCRPD.

Target audience:

- CBR managers, NGOs, Ministries, Policy makers, primary health care & education programmes, organisations of people with disabilities



## ***X. Role of Rehabilitation Council of India: Dr. J.P. Singh***

The Rehabilitation Council was set up as a society under the Societies Registration Act in the year 1983 and was subsequently converted into a statutory body, by an Act of Parliament in 1992 giving statutory powers to enforce uniform standardization and regulation of all training policies and programmes in the field of rehabilitation and special education all over the country.

Objectives of the RCI

- To regulate the training policies and programmes.
- To bring about standardization of training courses.
- To regulate these standards in all training institutions uniformly throughout the country.
- To recognize institutions/organizations/universities running master's degree/ bachelor's degree/ P.G.Diploma/ Diploma/ Certificate courses.
- To promote research in Rehabilitation and Special Education
- To maintain a Central Rehabilitation Register for registration of professionals/personnel.

RCI is the regulatory body which lays down criteria for running different courses, institutions willing to run courses have to get clearance from RCI. To update the knowledge and skills of the professionals, a number of short-term / refresher courses / orientation programmes / Seminars / Workshops are supported / organized by the Council.

RCI implemented the National Programme for Prevention & Control of Deafness launched by the Ministry of Health & Family Welfare, Govt. of India.

The Council launched Post Graduate Diploma in Disability Management (PGDDM) course for Medical Practitioners. This course is being offered in distance mode through Indira Gandhi National Open University (IGNOU). The Ministry of Health & Family Welfare Govt. of India agreed to recommend this course for training of Medical Officers

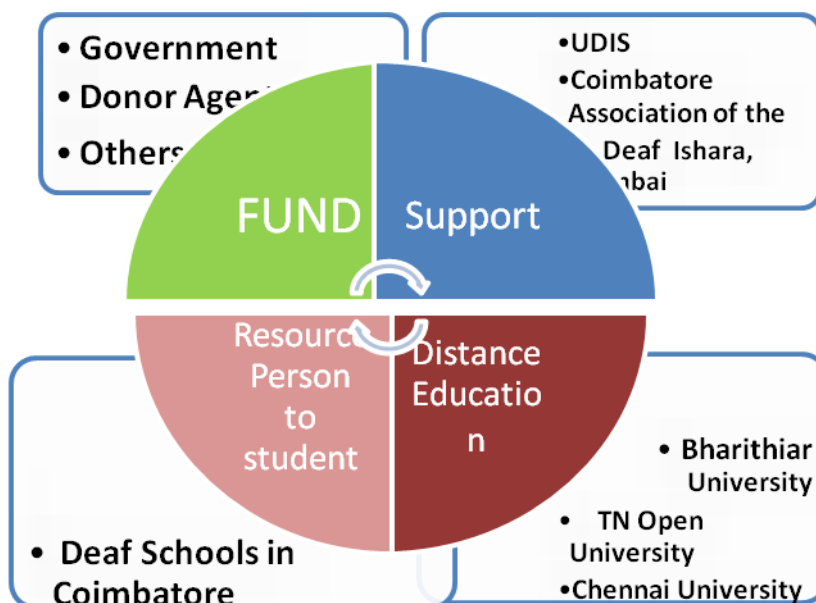
## **XI. Role of DPOs: Mr. Murali, Deaf Leaders**

Mr. Murali outlined the potential role that a DPO can play in the overall strategy for prevention of hearing loss in the context of Community Based Rehabilitation. He showcased the example of Deaf Leaders, a DPO active in the Southern region of India and the kind of work which this organisation is undertaking with the motto: **Deaf Empowerment Activities For Literacy , Education, Accessible, Development, Employment, Rehabilitation & Sports.**

He outlined the activities:

- ✓ Job Placement
- ✓ Welfare Scheme
- ✓ News Website
- ✓ Vocational Training
- ✓ Sign Language Development
- ✓ Workshop
- ✓ Best Award
- ✓ Resource persons to students
- ✓ career
- ✓ Short Deaf Film
- ✓ Awareness

A model of how interagency cooperation can be undertaken was presented:



Finally in the end salient features of the seminar were highlighted:-

- 25000 children born with deafness in India.
- NSSO data 31% of the hearing impaired children ever join school and 2/3<sup>rd</sup> of them drop out before 3<sup>rd</sup> standard.
- Identify organizations that would come to support deafness (rotary)
- Indian Medical Association can contribute by having their journal carry messages related to Ear & Hearing care on the back and front pages.
- Sensitization: a miniscule of budget of polio that is required for hearing impairment
- Integrate hearing impairment with communication (speech disability)
- Involve WHO office in documentation process
- Of all the sectors of the Community Based Rehabilitation Approach, this expert group could address only two factors relating to: Health & education and make suggestions regarding integration with Livelihood sector and social sector.
- Take the questions to the people present today and look for answers / resource person
- Strategy paper should be for and on behalf of Government of India.



## *RECOMMENDATIONS REGARDING PREVENTION OF DEAFNESS AND HEARING IMPAIRMENT*

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- Ear Diseases and deafness in the country must take into account the newly launched Community Based Rehabilitation (CBR) matrix of the W.H.O. The focus of the strategy is to be on health, and education sector, which must be detailed in a comprehensive manner with inclusion of other sectors in a phased manner. Working committees should be made including representatives from concerned sectors.
- The Strategy focus of the strategy must be on the person/s with disability and representatives of Disabled persons' organisations must be a part of the strategy formulation.
- Of the CBR matrix, the main focus of the strategy has to be on the Health component. However, Education sector should be involved in a more comprehensive manner.
  - Health sector: The aspects addressed should include:
    - Health Promotion activities
    - Prevention of disease through awareness creation. It is important to understand that the focus here has to be on Primary ear & Hearing health and prevention of ear diseases such as Otitis media as well as congenital and acquired hearing loss.
    - Making treatment of ear diseases accessible to all sections of society and in all places, rural and urban within the community. For this purpose, a community based approach has to be followed and primary ear & Hearing care services must be available at the grassroot level.
    - Rehabilitation services for the hearing impaired have to be made more accessible to all levels of society. For this purpose, the Healthy Ear District model of

services, currently adopted by the National Programme is a suitable one.

- Assistive devices: Hearing aids are being provided at the District level through various vendors. However, consideration also has to be given to other devices including cochlear implantation.
- Education sector:
  - The number of special schools should be increased with modifications in the curriculum, based on inputs from experts.
  - There should be a greater focus of inclusion of the deaf child within the mainstream schools. Guidelines for this must be available, for schools to adopt. This should be followed by advocacy with HR ministry to make the implementation of such guidelines mandatory.
  - Teachers should be primary screening agents for ear & hearing disorders. As they are the ones who interact with children in school and can identify children with disability and refer them to suitable referral facilities.
- The strength and number of apex institutes providing education and training in audiological services (such as AIISH, Mysore, AYJNIHH, Mumbai) should be increased. This can help in bridging the gap between demand and supply and fulfilling the acute shortage of trained manpower. These institutes should also develop mechanisms to retain such manpower in our country and provide them with better employment opportunities. These institutes can also help in standardizing norms and accreditation for special schools which are mainly in private sector. They must also guide smaller institutes in capacity building.
- NGOs and private sector should help Ministry of Health by providing statistical data various aspects such as Ear problems,

hearing loss and noise hazards. Existing guidelines regarding Noise Induced Hearing loss should be widely circulated to heads of institutions and to private sector agencies for implementation of legislation and compensation relating to NIHL.

- Industrial sector has a very important role to play in the strategy and this must be detailed along the following lines:
  - Mandatory implementation of Hearing Conservation programme in all industrial houses should make Pure Tone Audiometry mandatory for all new employees, audiological assessment at least once a year, intensive public awareness campaigns via different media, maintenance of records.
  - The industrial sector also needs to be more sensitized towards the needs of the people with hearing impairment (PWHI) working in their agencies. Greater stress must also be laid on employment of persons with disabilities in all sectors.
  
- Medical professionals can play a much bigger role apart from providing medical care. Through the various associations and organisations functioning at national and subnational levels, they can help in raising awareness regarding Primary Ear & hearing health. They can also help in creating a demand for education by motivating parents to admit children in schools. screening of school children for hearing impairment is another activity that associations can undertake.
  
- There should be continued effort to develop more IEC material to disseminate message of prevention. This material must be accessible to all service providers and NGOs. The material must be available for translation, display and use.
  
- Constitution of a National Committee at the MOH with a focal person in the ministry serving as the secretary. The members of this committee should consist of all the relevant stakeholders.

The existing national committee within the Ministry of Health and Family Welfare should be expanded to include experts from other fields. The programme/committee should also develop linkages with other ministries/departments, such as Social welfare, education etc.

- The existing national policy regarding hearing impairment (prevention & control) should be reviewed by this committee with immediate focus on primary level at the underserved and unserved areas. A disease wise priority list would see middle ear diseases and congenital conditions at the top.
- The network of WHO collaborating centers should be expanded. WHO should provide guidelines to governments for development of PDHI programs. Distribution of all information, publications, research highlights should cover all countries (through WR). Make recommendation to UN for commemorative International Year for Better Hearing
- The national program is to be considerably expanded in the next five year plan. The following recommendations (for the national government) can help to improve the program:
  - a. Appoint a separate section and focal person to coordinate the program
  - b. Formulate a National Working Committee for Better Hearing ( or PDH), to develop a national time bound plan and annual meetings to be held with all stakeholders
  - c. Set up training institutions for relevant medical and paramedical personnel
  - d. Allocate finances and other resources
  - e. Enact or enforce existing laws ( incl. noise pollution)
  - f. Support research
  - g. Support and promote a National Better Hearing Day

- h. Promote and Respect the human rights of the deaf and hearing impaired. This must be achieved through greater advocacy regarding inclusion in all aspects especially educational inclusion, inclusion in livelihood and social inclusion.
  
- NGOs continue to be the interface between communities and the national programs. A uniform code for all the NGOs working the hearing impairment sector was recommended with the following highlights:
  - a. All NGO's and INGO's should work within clear policy and guidelines formulated by the government
  - b. Extend their work into PDHI
  - c. Establish networking within NGO/INGO and governments
  - d. Organize and involve all to develop a major international campaign, coordinate with WHO to meet time bound goals
  - e. Cooperate and network with countries or cluster of countries
  - f. Develop communication media for information exchange ( newsletter, website, internet mail link)
  - g. Coordinate NGO level meetings
  
- Professional societies should select a focal person for PDH & making use of the technical expertise, be able to serve as advisors to the MOH committee. PDH can be brought to the fore-front by encouraging research and publications in the professional journals and conferences etc.
  
- Disabled persons organizations would be at the core of every strategy that is to be formulated and should be involved at every stage of development of plans and implementation of programs.

## *FUTURE COURSE OF ACTION*

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1. To formulate subcommittees to work on the following details of the strategy:
  - a. Health promotion and Prevention
  - b. Medical and audiological services
  - c. Rehabilitation & assistive devices
  - d. Education
2. To prepare a detailed strategy and advocate its adoption by the Govt. Of India.

## PICTURES

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Presentation by Dr. Suneela Garg



Participants in the seminar