

***'EXPERT COMMITTEE MEETING FOR DEVELOPMENT
OF GUIDELINES REGARDING INFANT HEARING
SCREENING IN INDIA'***

HELD AT

***MAULANA AZAD MEDICAL COLLEGE,
NEW DELHI***

ON

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LIST OF PARTICIPANTS

An expert committee meeting was held on the 18th of January 2009 at the Maulana Azad Medical College, New Delhi. The meeting was attended by the following experts:

1. Dr. Arun K. Agarwal, Director-Professor of ENT, Delhi
2. Dr. Achal Gulati, Professor of ENT, Delhi
3. Dr. A.S. Bais, Director-Professor of ENT, Delhi
4. Dr. Sunila Garg, Professor of Community Medicine, Delhi
5. Dr. M.M. Singh, Professor of Community Medicine, Delhi
6. Dr. J.C. Passey, Professor of ENT, Delhi
7. Dr. T.S. Sidhu, ENT Specialist, Delhi
8. Dr. J.K. Sahni, Professor of ENT, Delhi
9. Dr. Shelly Khanna Chadha, Professor of ENT, Delhi
10. Dr. G.K. Sethi, Professor of Paediatrics, Delhi
11. Dr. Monica Juneja, Professor of Paediatrics, Delhi
12. Mr. Biswajeet, Audiologist, Delhi
13. Dr. Neelima Gupta, Professor of ENT, Delhi
14. Dr. Vikas Malhotra, Professor of ENT, Delhi
15. Dr. Arjun Dass, Professor of ENT, Chandigarh
16. Dr. Asha Yathiraj, Audiologist, Mysore
17. Mr. R. Rangasayee, Audiologist, Mumbai
18. Mr. V. U. Nandur, Professor of Audiology, Hyderabad
19. Dr. Mary Kurien, Professor of ENT, CMC Vellore
20. Dr. Karan Sharma, Professor of ENT, Amritsar
21. Dr. Naresh Panda, Professor of ENT, Chandigarh
22. Dr. Bulantrisna Djelantik, President of the Society for Sound Hearing, Indonesia
23. Dr. Suchitra Prasansuk, Ex-President of Hearing International Thailand
24. Dr. Rakesh Shrivastav, Professor of ENT, Nepal
25. Dr. Madan Upadhyay, Ex-Director, Disease & Injury Prevention, WHO SEARO & Vice-President, Society for Sound Hearing, Nepal
26. Dr. Vinay Hans, CMO, DGHS, MOHFW, Delhi
27. Ms Alok Guha, WHO SEARO, Delhi

OBJECTIVES

The Objectives of the meeting were:

1. To discuss the existing programme for neonatal & infant hearing screening in India & rest of the world
2. To establish the most effective strategy for detection of deafness in Infants at the community level and the hospital level.
3. To prepare a plan for implementation of Infant hearing screening under the National Programme for Prevention Control of Deafness in India.

The main criteria that were set for the guidelines to be developed are:

1. It must be community based
2. Must be practically implementable
3. Should seek to identify all infants with moderate to profound hearing loss by the age of six months.
4. The modalities must be built on evidence based and sound technological principles.
5. Services must be integrated with the existing health care delivery system.
6. It should be cost-effective
7. It should include formal as well as non-formal modes of testing.
8. Diagnosis must be accompanied / followed by suitable treatment and habilitation.

PROCEEDINGS OF THE MEETING

SESSION I: BACKGROUND

Back ground presentations were made by experts

1. PREVALENCE AND AETIOLOGY OF HEARING LOSS AND DEAFNESS:

Prevalence:

The current epidemiology of Hearing loss and deafness in the world, the South East Asia region (of WHO) and India was presented (annexure 1). As per estimates, there are 255 million Hearing Impaired persons in the world. Of these, two thirds live in developing countries. 50% of this hearing loss is preventable. India has the largest number of hearing impaired in the region and houses the largest Deaf (Bilateral profoundly hearing impaired) population in the region. The detailed break up presented is as given below:

NUMBER OF HEARING IMPAIRED & DEAF IN THE COUNTRIES OF THE SOUTH EAST ASIA REGION

COUNTRY	POPULATION	BABIES BORN DEAF ANNUALLY*
Bangladesh	130,000,000	2,600
Bhutan	600,000	18
DPR Korea	22,260,000	668
India	1,009,000,000	30,270
Indonesia	210,000,000	6,300
Maldives	300,000	9
Myanmar	52,000,000	1,560
Nepal	23,000,000	690
Sri Lanka	19,000,000	570
Thailand	65,000,000	1,950
TOTAL	1,531,160,000	45,935

(*: Estimated babies born deaf annually in South East Asia countries, based on an estimated incidence of 0.2% of all babies born, with an estimation of a birth rate of 1.5%)

PERCENTAGE OF POPULATION SUFFERING WITH PROFOUND HEARING LOSS IN COUNTRIES OF THE REGION

COUNTRY	INDONESIA	INDIA	MYANMAR	SRILANKA
81+ Db	0.27	0.30	0.18	0.70

Aetiology of Hearing loss and Deafness:

The various causes that can lead to Hearing loss and deafness were listed. The important causes in terms of Prevalence within this region and the country were considered:

<u>Country</u>	<u>Indonesia</u>	<u>India</u>	<u>Myanmar</u>	<u>Sri Lanka</u>
Causes (%):				
Ear wax	15.9	13.2	9.0	2.9
Chronic supp. otitis media	5.2	3.6	6.0	2.0
Serous otitis media	3.0	0.3	2.1	2.1
Dry perforation of tympanic m.	0.5	2.6	1.8	0.5
Bilateral genetic (cong. deafness)	0.2	0.1	0.5	0.2
Non-infectious (mostly aging)	10.3	4.1	5.0	9.2
Other causes + unknown	26.6	3.2	24.0	7.6

Though Congenital deafness forms only a small part of the entire aetiological spectrum of Hearing loss, the fact is that this form of hearing loss has the most severe and debilitating effects on the life and development of the child who is affected as well her family. Undetected and untreated, this child will fail to develop suitable language and communication skills. It is therefore essential that this hearing loss must be identified at the earliest possible stage in life and rehabilitated in order to ensure suitable personal,

educational, social and economic growth of the child. This child is the focus of this Infant Hearing screening programme.

Causes of Congenital hearing loss include:

- Prenatal factors:
 - Genetic causes
 - Prenatal Maternal Infections including the TORCH infections
 - Use of Ototoxic drugs in pregnancy
- Natal causes:
 - Birth Asphyxia
 - Low birth weight
- Postnatal causes:
 - Hyperbilirubinemia
 - Meningitis

2. **The Joint Committee recommendations** were presented by Dr. A.K. Agarwal (annexure 2)

A brief summary of the recommendations of the Joint Committee on Infant Hearing were given.

It was stressed that in its recommendations (2000), the Joint Committee on Infant Hearing Screening has given weightage to the fact that parent/caregiver concern is an important criteria for considering the child for diagnostic tests for assessment of the hearing status.

3. **Screening for Hearing loss:** Identification and Diagnosis was presented by Dr. Asha Yathiraj, on behalf of Dr. Vijalakshmi Basavraj, Director, AIISH, Mysore. Various modalities available today for effective identification of Hearing loss were discussed.(Annexure 3) These include:

- **Screening tests:**
 - Subjective tests:

Questionnaire based screening with a proforma that takes into account the high risk factors,

- developmental milestones in relation to hearing and speech as well as caregiver concern. Two types of questionnaires developed by AIISH, Mysore were presented. These include:
 - Questionnaire for Medical Professionals
 - Questionnaire for non-medical health care providers
 - Behavioural observation
 - Objective tests:
 - Oto-acoustic emissions
 - Automated ABR screening
 - Diagnostic tests:
 - Auditory Brainstem response testing
 - Auditory steady State response testing
4. The importance of Early detection and Diagnosis of deafness was discussed and reiterated. It was stated that ideally all children with deafness should be identified by the age of 2 months, in order to ensure that they are initiated on the path of habilitation by the age of 6 months. Neonatal Hearing screening is an ideal approach in this regard. However, in the context of the ground realities of India and the fact that, at present, the average age of detection of Congenital deafness in children is close to three years, it was felt that the upper limit of age for ensuring diagnosis of deafness may need to be re-established.

SESSION II: SHARING EXPERIENCES

Experts from various parts of the country put forward their experiences with various forms of screening (Annexure 4-7). These include:

- Hospital based neonatal screening
- Hospital based Infant screening
- Experiences with various diagnostic modalities
- Community based screening through:
 - Oto-acoustic emissions testing
 - Questionnaire based assessment for hearing loss
 - Auditory Brainstem response testing
 - Behavioural screening

Various aspects of Infant hearing screening in India were debated and discussed.

SESSION III: POSSIBLE MODALITIES FOR COMMUNITY BASED INFANT HEARING SCREENING IN INDIA.

An option of models for Infant Hearing Screening was presented to the expert committee and were discussed (Annexure 8).

In order to develop a screening programme which is:

- Community based
- Practical
- Effective
- Technologically sound

The following points must be kept in mind:

- 1) Majority of the data pertaining to hearing screening in children emanates from the developed countries. As the population profile, economic, social and cultural trends in these countries are very different from those within India, there is a strong need for us to develop our own database.

- 2) Sporadic data is available with respect to Neonatal Hearing screening from various parts of our country. Data presented at the meeting

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- 3) revealed that most investigators have followed the recommended guidelines with a step-wise process of Hearing assessment.

All reported good success rates with the combined protocol of Initial screening with OAE. If the child fails the test, it is repeated once. If the test is failed a second time, the child is then subjected to 'Auditory Brainstem response' testing.

Both universal and high risk register based modalities of screening have been practised. It was the opinion of the group that where possible, Universal screening programmes should be followed at the institutional level. The house voiced the concerns that, in view of:

- a) The fact that most tertiary level centres have a large number of deliveries occurring there,
- b) There is poor availability of human resources at these centres,

A High-risk register screening may be a more practical approach to follow at the beginning.

- 4) There have been few, sporadic efforts at assessing the efficacy of a community based infant hearing screening programme in India. The majority of the data pertaining to hearing screening in Infants focussed on:

- a) Institution based screening
- b) Neonatal screening

In the context of India, which has a large rural population and where over 50% of the births take place at the domiciliary level, we have to think beyond the institutional level.

Only those small percentages of children, who are born at the level of the tertiary centres, are likely to undergo hearing screening at birth. Hence, it is important that the concept of Neonatal hearing screening be extended in the context of our country; to include other infants with a view to identify as many hearing impaired children as early as possible.

While Neonatal Hearing screening can be implemented at the institutional level, a community based programme for identification of hearing impairment is the need of the day.

With the launch of the National Programme for Prevention and Control of Deafness, ear & hearing care services are being brought to the doorstep of the consumers. In order to ensure that the maximum number of persons within the community is able to benefit from the programme, screening services too have to be made available at the grassroot level.

5) India has a well developed health care delivery system. The main levels of service provision include:

i) Grassroot/Community/Village level: Anganwadi workers are the grassroot level health care workers providing honorary health services to the community. They help in care of children upto the age of 5 years.

ii) Subcentre level: Multipurpose workers, male & female are present at the Subcentre. One subcentre caters to a population of approximately 5000. This is the centre where children are brought for immunization.

iii) Primary level: Primary Health Centre is the first point of contact between the community and professional medical care. One PHC caters to a population of 30,000 persons.

One out of every four PHCs is upgraded to a Community Health Centre and caters to a population of 1,20,000. Four specialists are available at this centre including:

- Physician
- Surgeon
- Obstetrician
- Paediatrician

As institutional deliveries take place here, this is an important centre. However, it must be noted that NO ENT doctor, Audiologist or Audiological technician are posted at this level.

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- iv) Secondary level: The District hospital catering to a population of 10,00,000 is the first level where ENT doctor and Audiological resources are accessible to the community.
 - v) Tertiary level: Medical Colleges and other centres provide specialised care.
- 6) It is a fact that with a variety of National programmes being run in the country and the grassroot level workers being involved in most of them, these workers are an overburdened lot.
- 7) It must also be kept in mind that an Anganwadi worker is an honorary worker and not a regular paid employee. ASHA (Accredited Social Health Assistant) now being employed under the National Rural Health Mission, is a voluntary worker and her work is mostly incentive based. These factors would need to be kept in mind and addressed.
- 8) About 55% of the children of India are covered by the Universal Immunization Programme. The first vaccine being given at the time of birth, the child is usually brought to the Subcentre for immunization at the age of 6 weeks for the next immunization.

GUIDELINES FOR INFANT HEARING SCREENING IN

INDIA

With the consideration of the factors stated in the previous section, as well as the Prevalence and Aetiology of Hearing loss and deafness; the technology of screening and diagnosis of hearing loss and the importance of early identification, the following guidelines have been agreed upon for implementation under the National programme for Prevention and Control of Deafness in India.

- 1) It is essential to identify infants suffering with Hearing Impairment at the earliest possible time in life to ensure better opportunities: medical, rehabilitative, educational, social and economic.
- 2) It must be our effort to identify all infants suffering with any degree of hearing loss, either unilateral or bilateral, as this may impede the proper psychological, social and educational development of the child. However, the primary focus of the programme is essentially on those children who have severe to profound hearing loss in both ears. This is due to the fact that an impairment of this degree would not be compatible with the development of language and communication skills in the child. Further, this degree of hearing loss would be easier to identify than the lower degrees, in the community. In order to ensure that the first category is not missed out in an effort to identify the lower and less debilitating forms of hearing loss, the focus of the screening programme must be on the child with moderately-severe to profound hearing loss in both ears. However, this does not imply the exclusion of those children who suffer with lower degrees of hearing loss from the programme. As and when a child with a lower degree or with unilateral hearing loss is detected, he/she must be guided for suitable access to diagnostic, therapeutic and rehabilitative services available.
- 3) **Age:** In view of the deleterious effect of bilateral hearing loss, it must be the mandate of the screening programme to diagnose all such infants by the age of 6 months, in order to allow them to derive maximum benefit from the therapeutic and rehabilitation services.

- 4) The **format for the Community based Infant hearing screening** has to be bi-pronged:
- a) **Formal screening:** within the health care delivery system from the grassroot level to the Secondary/tertiary level.
 - b) **Non-formal screening:** Carried out by the members of the community as well as the health care providers that they come in contact with.

5) Who will undertake this screening?

- a) **Formal Screening:** Within the health care delivery system of our country, it was considered that the **Multi-purpose worker** will be the most suitable person to undertake the task and report on it. She will undertake the formal screening. The Multi-purpose worker will screen the child coming to her. In case of any suspicion of hearing loss, she will need to refer the child for hearing assessment to the Audiologist/ENT doctor at the district hospital level.
- b) **Non-formal screening:** Besides the periodic contact with the Health care worker, there are many persons who spend time with a young infant and are therefore more likely to pick up signs indicating a potential loss of the hearing ability. These include:
 - i) **Parents/primary care givers of the child**
 - ii) **Close family**
 - iii) **Anganwadi workers**
 - iv) **Doctors** who may be called upon to treat the child in case of any childhood illness.

All these persons ought to be able to look for signs indicating that the child may possibly be hearing impaired. They must guide the child/parents into the formal screening system. In order to make them aware of the normal developmental process of hearing and speech and to sensitise them to the signs which may indicate loss or absence of hearing, they will undergo trainings/awareness campaigns through the National programme for Prevention and Control of Deafness.

6) Where will the screening take place?

The screening will need to take place at all levels. In order to identify all infants with hearing loss at the earliest, the screening will need to follow two strategies:

- a) **Community based screening:** at the level of
 - i) **Formal screening:**

This will be through the Multi-purpose worker at the **Subcentre**, the trained Medical Officer at the Primary Health Centre, the ENT doctor and audiologist at the District hospital.
 - ii) **Non-formal screening** at the **domiciliary and Anganwadi** level
- b) **Institutional Screening:** Institution based screening will have two roles:
 - i) Universal Hearing screening of all infants who are born at the centre (**District hospitals, Referral centres, Medical colleges**) or admitted to the institute after birth.
 - ii) Providing facilities for audiological diagnosis of infants suspected to have hearing loss and referred from various other centres.

7) Methodology of Screening:

- a) **Community based:**
 - i) Formal screening at the subcentre level to be undertaken by the Multi-purpose worker:
 - **Questionnaire based assessment:** undertaken using a suitable, simply worded, pertinent questionnaire that is based on the High risk register and history regarding parental observation. It is suggested that the modality of working out a common fact sheet for all disabilities (under NRHM) can also be looked at in the future. Discussions with NRHM would need to be held in this regard.
 - **Behavioural assessment through Distraction testing.**

If a child has a positive factor on history, irrespective of the result of behavioural testing, the child ought to be subjected to hearing screening. Those who are without any positive factor on history, but have failed on behavioural testing, should be reassessed at the next

visit. If the baby's response still remains inadequate, she should be referred to the district hospital for further assessment.

Hence, all children who:

- i) have any positive risk factor, on the questionnaire based assessment,
- ii) have no risk factor but who fail the behavioural testing twice must be referred for further audio logical assessment.

In all referred cases the health care worker must provide suitable guidance to parents regarding:

- (1) Need to get the child's hearing tested.
- (2) The fact that getting the hearing tested is a painless and easy procedure.
- (3) Need to do so at the earliest possible.
- (4) Where and how the hearing tests can be done.
- (5) Need to follow the advice given by the doctor/s, audiologists.

b) Institution based: Screening at the District hospital and Medical Colleges will be done through:

- i) Ear examination by the ENT doctor
- ii) Assessment through Oto-acoustic emissions

Those failing the OAE test will then be subjected to an ABR examination. As the ABR test is not available at the District hospital, the child will be referred to a suitable centre nearby, such as a medical college for the test to be conducted by audiologists.

Due to the practical considerations in performing an ABR test, the child will need to take an appointment for conduct of this test.

A repeat OAE is advisable and recommended in all patients failing OAE testing once. However, in order to minimise the number of visits that a parent has to make and to optimize compliance, this criteria will need to be relaxed. All children having a risk factor or failing behavioural testing, who are referred from the community, and who

Fail behavioural testing at the District hospital, should be promptly referred for the ABR testing to the suitable nearby facility.

Those children who have been identified and tested at the District hospital only, through the Formal Institutional screening Programme (refer section 6b i)), should undergo second OAE testing before being referred for ABR.

RECOMMENDATIONS REGARDING INFANT

HEARING SCREENING:

There must be:

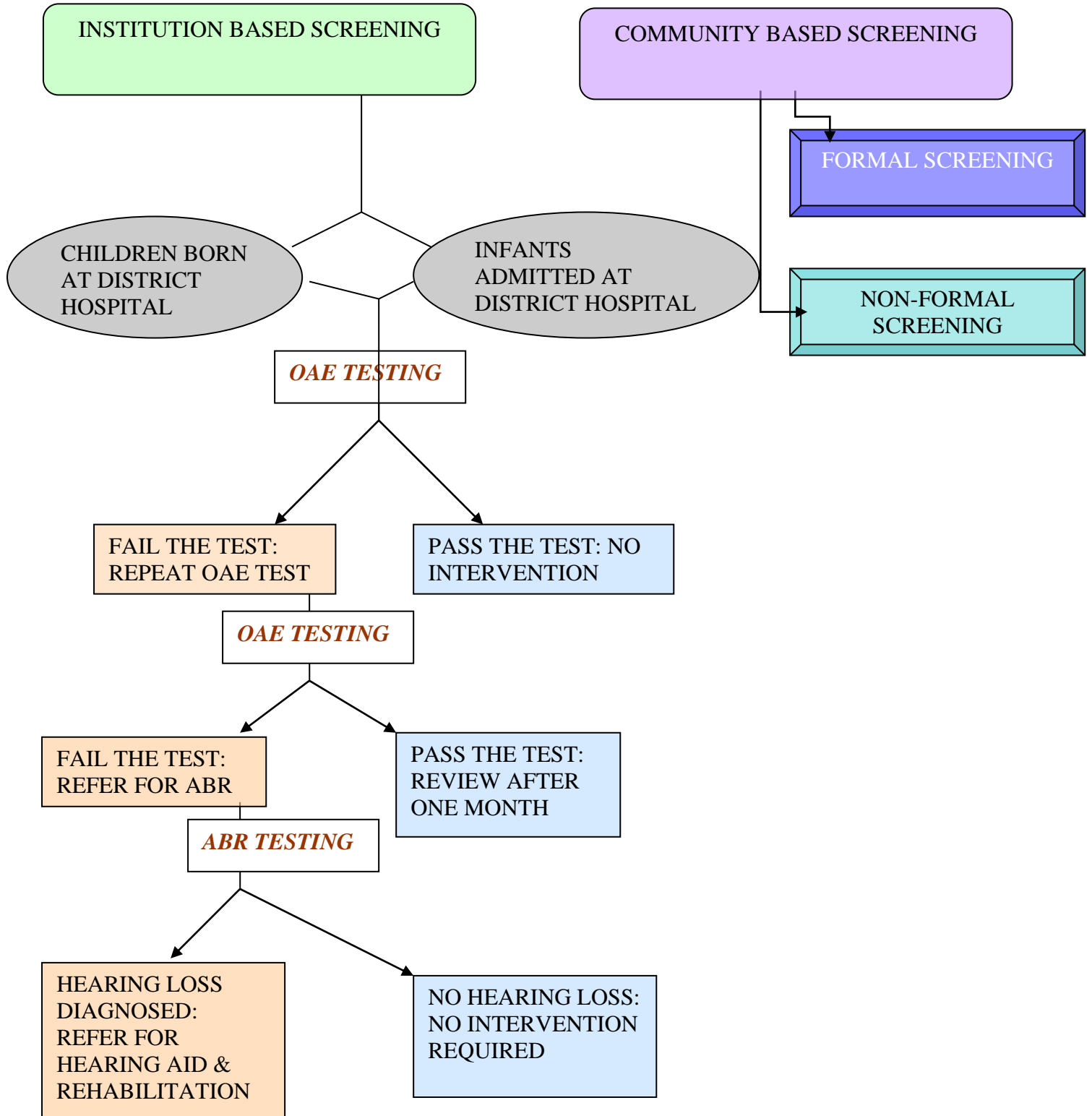
- Training of all levels of manpower are being carried out under the NPPCD including parents. Information and instructions regarding the importance of early detection of deafness must be a part of the training. The trainings must sensitize the personnel to the proper development landmarks with relation to hearing and speech and how to suspect and identify hearing loss in a child.
- A suitable questionnaire for screening of infants at the subcentre level must be developed and validated. The questionnaire must be simple, brief and comprehensive. Efforts need to be made to integrate these questions with a common disability index under the NRHM.
- It would be suitable if some special mark of identification can be put on the road to health or immunization card of those children who are suspected to have hearing loss. This flag or mark will help in easy identification of children requiring special attention in this regard during their subsequent visits.
- Multi-purpose workers, Anganwadi workers, ASHA and parents must be trained regarding the identification process, without overburdening them and within the constraints and confines of their abilities.
- All district hospitals must be provided with Otoacoustic emission screeners. Efforts should be made to also make the screener available at the CHC level.
- It is highly recommended that a fully equipped audiological diagnostic unit manned by a fully qualified Audiologists be developed at each District hospital. This should have an OAE, ABR machine and ASSR, if possible. This will obviate the need for referral to a tertiary institute for ABR and will hence reduce the number of patients who drop out due to difficulty in travelling long distances. It will help to make the complete diagnosis available under one roof, as it should be, in order to ensure smooth implementation of the screening programme.

However, till such a time as this is achieved, the screening programme would need to be carried out in a three tiered manner, as proposed.

- All medical colleges must have a suitably equipped audiology department that is in a position to carry out the audiological work-up of the child suspected to suffer with hearing impairment.
- Suitable guidance must be provided to the parents at all levels regarding the importance of testing, the methods and the importance of early identification.
- Suitable rehabilitative measures must be available at the District hospital level to ensure proper treatment of the child identified with hearing loss.
- Efforts must be made, in all cases, to integrate the hearing impaired child within the regular schooling system. Discussions must also be initiated with the 'Sarva Shiksha Abhiyan' in this regard.
- The Infant hearing screening programme can be successful only when the community realizes the importance of early identification of deafness and understands that deafness can be treated and such children can equal their peers in all spheres of life, if timely intervention is initiated. Hence, it is important that the programme must be accompanied by a suitable awareness campaign in this regard.

FLOW CHART

INFANT HEARING SCREENING



FLOW CHART: COMMUNITY BASED SCREENING

