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EDITORIAL: REHABILITATION OF THE DEAF AND HARD OF HEARING

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It is a pleasure to bring to you this Issue of *Community Ear and Hearing Health* on the theme of Rehabilitation of Deaf and Hard of Hearing People. The quest for the perfect rehabilitation programme seems to be one of the critical points in the area of hearing impairment. Today, even though there are many approaches to this question, there is some consensus:

1. People, especially children (but not only children), need to receive direct training, information and practice after receiving a hearing device. The

device itself will probably be of little value to children if an intensive, comprehensive and solid rehabilitation programme is not in place.

2. The sooner the better. We don't have time to spare! As soon as the person receives the device and has been cleared (as in the case of cochlear implants), rehabilitation should begin.

3. If the rehabilitation programme is for children, parents and/or other caregivers should be the first to be empowered, so that they



Mary Wairimu from Kambui School for the Deaf, Kenya

Photo: CBM/argum/Einberger

themselves can offer assistance to their child. Luterman goes as far as to say that there may be no gain in early identification of children with hearing losses or in bringing them to early rehabilitation, if good support is not offered to parents. Very often, because of lack of support, families will abandon programmes, retarding the development of their child's progress, because they themselves have not been cared for as they should after diagnosis.¹

4. The fourth aspect refers to language. Rehabilitation in terms of hearing impairment relates to language and communication. Programmes should aim to facilitate communication between family members and the deaf or hard of hearing person, whether that person is a child, beginning the language acquisition process, or a deafened adult who needs to re-organise the communication

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Asiel receiving a hearing aid at The Holy Land Institute for the Deaf (HLID) in Salt/Jordan

Photo: CBM/Heine

system around himself or herself.

There is a need for rehabilitation processes that aim to realise the full potential of the person, celebrate small progress, establish bridges and link deaf and hard of hearing people to the people they love and need.

In this Issue, you will find Professor Bevilacqua's article on Hearing (Re) Habilitation. This teaches that the basic principles of this process are early intervention; effective use of the electronic device; a structured, active family and specialised speech pathology therapy sessions, with an emphasis on the development of hearing skills and oral language. Furthermore, her paper recommends the integration of the child in a regular school, with the support of the speech pathologist and active parental participation.

Professor Mendes and Professor Novaes examine the complexity of early intervention, relating it to the fact that a secure background is necessary to reach desired goals in terms of social inclusion and communication modality - considering that different options will be suitable for different children. They also point out that in a country like Brazil, there are still limited choices, due to the issue of availability - depending on the geographic region of the country. (We only need to remember the Amazon region to realise that there are areas which lack the provision of care).

Patricia Castellanos, an audiologist from Guatemala, contributes by reflecting on the important role of parents of deaf and hard of hearing children - a role so important that the progress of a patient during intervention will greatly depend

on the quality and quantity of a parent's involvement in the process. In a country where there is no funding for hearing aids and cochlear implants, the author identifies a series of strengths and limitations.

Rosane Vargas, Professor at a University in south Brazil, discusses the possibility of uniting different paradigms,* suggesting that education of deaf children may include rehabilitation and sign language. In her

approach, she also strongly recommends the involvement of parents and stresses that they need to be welcomed and supported in the programmes offered to deaf and hard of hearing children. Mrs. Vargas comes from a background of considerable experience in deaf education, having been a teacher and principal of a school for the deaf for over 28 years.

Wendy McCracken, Senior Lecturer in Deaf Education, Manchester, UK, addresses the challenges of providing early years support for deaf children within a family centred framework - the role of parents and teachers of the deaf in family settings.

After 32 years of working in the area of deafness, I am still not sure about many things. What does it mean to be a person with a hearing loss? I can think of a close friend, profoundly deaf, a young, talented Brazilian architect and brilliant pianist - or of another young deaf woman who has just finished her doctoral dissertation in Brazil. It could also mean one of the many young deaf children that struggle in schools, caught between the many approaches to language, without mastering any one of them. It can also mean a young girl in a remote village in Guatemala, in Brazil, Tanzania or India - with no access to education, rehabilitation, or a hearing aid. What does it mean to be deaf? What does it mean when you are an elderly person, longing to share your stories, anxiously waiting for your family to share their news - but, because of a hearing loss, feeling completely sepa-

rated and isolated, with no access to hearing aids or a support programme? There are many extraordinary texts written by deaf people. Two classics are by Leo Jacobs, 'A Deaf Adult Speaks Out'² and Emmanuelle Laborit's, 'O Vó da Gaivota'.³ To fully understand, you have to be deaf, or hearing impaired.

This Issue hopes to contribute to the rehabilitation of deaf and hard of hearing people, offering choices and different views. It would be wonderful if one could live a long life that would enable us to collect all the wonderful experiences, so that hearing, deaf and hearing impaired people, together, could offer relevant and quality educational and rehabilitation programmes.

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Recommended websites:

1. <http://www.deafnessatbirth.org.uk/>
2. <http://www.oraldeafed.org/>
3. <http://clerccenter.gallaudet.edu/InfoToGo/index.html>



Jennfier Mukenye at Kambui School for the Deaf, Kenya

Photo: CBM/argum/Einberger

*Paradigm: A thought pattern, relating to the vision one has about deafness

HEARING (RE)HABILITATION

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Hearing habilitation and rehabilitation is the area of knowledge which drives the therapeutic process of hearing function alterations. Hearing disability prevents and/or hinders the acquisition of oral language in children with pre-lingual hearing impairment, and causes communication difficulties in children, adults and the elderly with post-lingual hearing loss. This speciality emerged some decades ago along with audiology, but expanded after World War II.¹ It became better known with the appearance of professionals with a doctorate degree in the field.

After the diagnosis of hearing impairment and hearing aid (HA) selection and fitting, the hearing function must be developed or recovered, depending on the time of appearance of the disorder. In the case of acquired hearing loss, a rehabilitation process must be carried out, with the aim of repairing lost function. In the case of congenital hearing loss, habilitation is needed, to initiate the development of this function. It is worth noting that, both in the habilitation



Children in auditory/oral language stimulation activities

Photo: Marta Maria Resegue and Joseli Soares Brazorotto, CPA USP Bauru

and rehabilitation of hearing function, the intervention is procedural, and requires a group of common procedures, beginning with the diagnosis of hearing loss, progressing to hearing aid selection and fitting, then extending to auri-oral speech pathology therapy, with family counselling and guidance.

The fitting of electronic devices provides the hearing impaired person with access to the speech signal, at audible levels, demonstrating a significant gain in hearing performance. Furthermore, it enables the development of individual potential for the construction of oral language at levels and pace quite close to those of a normal hearing child, introducing new acoustic information in the child's every day context. This is an essential element for oral language acquisition and monitoring of his/her own speech. This further urged speech pathologists to introduce a new therapeutic model to suit hearing skills.

The new therapeutic profile presents language situations in a model which allows the child to perceive concepts in structured situations and transpose them for use in everyday expressive language. Using this model, we intend to report what we have proposed in the area of hearing habilitation for hearing impaired children.

First, however, it is necessary to put the hearing habilitation and rehabilitation in the context of the Brazilian scene. Although this knowledge area emerged some decades ago, in our country it has been developed by a group of speech pathologists since the 1970s. It was in 2004, with the determination of the Ministry of Health's Hearing Health Policies, that auri-oral speech pathology therapy was included in the Public Health System. (We refer here to policies number 2073 GMMS, 587 SAS/MS and 589 SAS/MS available at <http://portal.saude.gov.br/saude>)

Attending to this governmental resolution, professionals committed to the area of need have presented proposals in all



Children in auditory/oral language stimulation activities

Photo: Marta Maria Resegue and Joseli Soares Brazorotto, CPA USP Bauru

levels of services in hearing habilitation. Our programme offers services to children with disabling hearing impairments ranging from 40 dB up to 120 dB, in their early years, from birth to the age of seven. They attend the institution four times a week, part-time, where they are seen by a multi-professional team, and in the other period they attend a mainstream school. In the first months, we consider the area of oral language development through hearing, by means of auri-oral speech pathology therapy. Children whose oral language development is not sufficient for communication, those who cannot benefit from amplification, or those whose parents choose sign language, are referred to an educational programme that has bilingualism as its method, a programme within the same institution, but at another site and time. In this study, we will present the programme carried out with children who benefit from the use of hearing aids and auri-oral speech pathology therapy.

Considering hearing as the main route to acquiring oral language, the principles of this therapy include:

- Early intervention
- Effective use of the electronic device
- A structured, active family, open to the therapeutic process
- Specialised speech pathology therapy sessions, with an emphasis on the development of hearing skills and oral language.

Furthermore, it recommends the integration of the child in a regular school

Hearing (Re)Habilitation

with support of the speech pathologist and active parental participation.

In the therapeutic process, some tests are carried out for the beginning of auri-oral speech pathology therapy, including:

- Free field audiometry with amplification
- Speech recognition threshold (SRT)
- Speech detection threshold (SDT), with amplification
- Questionnaires - *Infant Toddler: Meaningful Auditory Integration Scale (IT-MAIS)*² and *Meaningful Use of Speech Scales (MUSS)*³ and, also,
- Ling's 6 sounds test (/a/, /i/, /u/, /s/, /ch/, /m/) for evaluation of detection, discrimination and recognition skills.

Other speech perception tasks, according to the age of the child, must be carried out as well. From these results, we establish the hearing and language category of each child, and start the work, monitoring his/her development. The Tables below present the synthesis of hearing categories proposed by Geers⁴ and the language categories proposed by Bevilacqua et al.⁵

The children in this programme are attended by a multi-professional team, assisted by a speech pathologist and audiologist. Each member of the team performs in groups of 3 or 4 children, a programme proposed by the assistants that is similar to that proposed by SKI-HI Institute, (<http://www.skihi.org/>) or the curriculum of Clarke School for the Deaf (<http://www.clarkeschool.org/>) aiming at developing communication, language and hearing skills. Role-play and dramatisations of daily activities are widely explored, besides music, poetry,

jokes, tales, among other educational games and incentives to encourage reading and writing from the age of five years. In addition, these children are given two weekly sessions of auri-oral speech pathology therapy, so that their specific difficulties can be worked out. These therapies may be individual or in groups, depending on the child's need.

When children are able to continue developing oral language in a natural and relaxed manner, the therapies focus only on the improvement of speech production and broadening of language, alongside hearing aid monitoring. Nevertheless, when the child does not accomplish such skills, we utilise more didactic and formal strategies for language development.⁶

In the case of children who do not present any development in a 3-4 month period, all proposals are revised, starting with the following initial questions:

- Is the hearing aid appropriate for the child?
- Is the auri-oral speech pathology therapy proposal appropriate?
- Are there serious external factors which are negatively influencing the therapy?
- Has the professional been able to interact correctly with this child and his/her family?

Guiding Principles of Auri-Oral Speech Pathology Therapy

A hearing aid listening check must be carried out daily at the beginning of every session, as well as the child's response to the Ling's 6 sounds test,⁷ which verifies sounds reception across the speech frequency range. In case the child does not perform as expected, the hearing aid and earmould are sent for a complete technical evaluation.

Table 1: Language Categories

1 – Does not speak.
2 – Emission of isolated words.
3 – Emission of simple phrases.
4 – Emission of complex phrases.
5 – Fluency.

Therapeutic activities promote the construction of oral language, prioritising the hearing function and the determination of therapeutic goals which will allow the generalisation of other skills. Orientation and counselling are also provided during the role-play of some daily situations, in a demonstration house.

The whole habilitation process is interspersed with cognitive aspects which aid in the development of hearing functions and acquisition of oral language, such as attention, memory and hearing processing, which refer to the skills of hearing sequencing, hearing comprehension and temporal and spectral resolution. These skills favour the recognition of simple acoustic contrasts and segmental and supra-segmental traces, which are prerequisites for better speech intelligibility and understanding of complex linguistic structures.

The development of the hearing function allows the child to discover the rules of the language within his/her daily experiences (morphosyntactic structures), while acquiring oral language in situations that encourage a richer vocabulary and more natural spontaneous expression.

Speech pathologists must be facilitating agents, as are the parents, who focus on changing the child's reality, by helping him/her to improve hearing and communication performance, thus enriching the therapeutic process.

Parents are the first models for the development of oral communication, and the role of speech pathologists is to help them to provide productive and positive experiences in the construction of language through hearing. They must be capable of understanding the impact of hearing impairment, transforming the family routine, by developing suitable skills in the use and guidance of techniques that aid the development of language, speech and communicative

Table 2: Hearing Categories

0 – No detection of speech sounds.
1 – Detection of speech sounds.
2 – Perception pattern (standard).
3 – Initiating the identification of words.
4 – Identification of words through vowel recognition.
5 – Identification of words through consonant recognition.
6 – Recognition of words in open set.

situations at home. The speech pathologist should guide them to:

1. Interpret the meaning of the child's first expressions.
2. Take notes, videotape and discuss his/her progress.
3. Interpret objectives, short and long term.
4. Develop confidence in relations with the child.
5. Inform their decisions.
6. Encourage hopes and courage to change their 'listening.'
7. Take always the child's interests and benefits into account.

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Intervention for Hearing Impaired Children, Brazil

INTERVENTION FOR HEARING IMPAIRED CHILDREN IN HEARING HEALTH PROGRAMMES IN BRAZIL

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In September, 2004, a Brazil Government resolution by the Ministry of Health established the National Policy of Hearing Health Attention.¹ This introduced guidelines for procedures and evaluation for promotion; prevention and identification of hearing disorders; diagnosis; hearing aid dispensing, and intervention for hearing impaired subjects of all ages.

The resolution aims to:

1. Offer comprehensive attention to the client, starting with identification programmes, diagnosis, provision of hearing aids and therapy.

2. Offer follow-up for unlimited time, as needed.
3. Establish referral networks within the public system.
4. Implement continuing education for professionals within the Health System.

There has been a great effort to implement more comprehensive programmes - to guarantee that the personnel and infrastructure exist to fulfill the needs of a child or adult diagnosed with a hearing impairment. For adults, this intervention is more closely related to adjustment to amplification and communication strategies in different environments, over a set time period. For children, however, the intervention process is much more complex. First of all, the hearing aids are adapted to provide auditory stimulation aiming at oral language development. Therefore, it is just the starting point of a rehabilitation process that will last for many years.

We firmly believe that an intervention programme should be in place before an identification programme for hearing disorders is implemented, as rehabilitation will be the main route for the flow of children diagnosed as hearing impaired. However, technology and short term results have attracted professionals and investments into diagnostic and hear-



Deaf child during language stimulating activities using a story book. Centro Audição na Criança - DERDIC/PUC São Paulo, SP, Brazil

Photo: Beatriz Novaes

ing aid dispensing services, rather than implementing rehabilitation services.

The following require investment in personnel and are a long term commitment:

1. A multi-professional team for rehabilitation.
2. Support services for families.
3. School placement and support for mainstreaming programmes or special education.



Phonoaudiologist, Bia Mendes, counselling a mother on the use of a hearing aid during therapy. Centro Audição na Criança - DERDIC/PUC São Paulo, SP, Brazil

Photo: Beatriz Novaes

Early intervention for hearing impaired children is complex because theoretical background in different fields of knowledge is necessary to reach desired goals, in terms of social inclusion and communication. Different options will be suitable for different children. At this point in time in Brazil, we still have limited choices as availability depends on the geographic region of the country.

The National Hearing Health Policy has focused special attention in differential diagnosis and the establishment of oral rehabilitation programmes, within a Hearing Health Programme. The use of residual hearing through hearing aids, precluding sensory deprivation, is a necessary but not sufficient condition for a child to be eligible for oral intervention. Factors like family involvement, availability of a therapist and multiple disorders are just some of the factors that determine the prognosis of a child's oral language development.

There are many issues involving language development in children and we do not intend to address all of them in this paper. The biggest challenge is to create the proper language environment that will facilitate oral language acquisition in children wearing hearing aids or cochlear implants. When compared to hearing children, those who are hearing impaired can have a significant decrease in the

number of opportunities for uptake of oral language. Increasing the number of opportunities is the goal of the therapeutic process and parental orientation. There are specific techniques to achieve this, in a world where the majority of people have normal hearing.

Traditionally, different professionals are responsible for diagnosis, hearing aid fitting and early language intervention. In our experience, the integration of these services is the only way to guarantee that precise hearing thresholds and hearing aid prescription are validated through a child's auditory and language behaviour. Performance that reflects maximum capacity is the desired goal - to achieve language development compatible to the child's potential.²

Parental expectations are adjusted within this process. If the clinician, or parents, under or over estimate the child's capacity, hearing aids may be badly adjusted, compromising their efficiency in promoting oral language development. Protocols to follow up auditory and language development can be useful in communication between professionals and parents, promoting adjustments in the child's intervention plan.

Partnership with parents is a key aspect of an early intervention process. They are the primary caregivers and, therefore,

their involvement is a deciding factor in the child's success.³ In Brazil, low income families make up the majority of the population and, therefore, the child's hearing impairment is one of the many difficulties families have to face. This population has very low social and educational expectations and is frequently satisfied with any programme where they can find a placement. Poor communication between mothers and clinicians can be due to differences in their social, economic and educational backgrounds. To be successful, professional training has to include the needs, concerns and cultural values of parents - to actually practice parental involvement and not just preach it.

In developed countries, parent-centred programmes provide extensive education and guidance for parents. Most of them, however, depend heavily upon written materials, assuming the parents have the competency to understand it. The writing and reading abilities of low income parents in Brazil, as well as the different cultural characteristics of parents and clinicians, suggest the need for specific procedures to overcome these factors. While the content of the instruction remains the same, the strategies to be used with low income parents have to be different.

Preparation of professionals for work in the early intervention of hearing impaired children is a controversial issue. The skills required in parent centred rehabilitation are difficult to find. Therefore, the course work for undergraduate and graduate programmes has been modified in the last ten years - to adapt to Brazilian public health policies, integrating knowledge within a concept of a more interdisciplinary approach.

Considering the diversity of hearing impaired children, multiple factors contribute to the decision making process, leading to the choice of the best educational option. This process is done in partnership with the parents and is the focus of the first stages of the intervention process. Degree of hearing loss; age; hearing aids and cochlear implants; age of intervention; expectations and availability of the families; socio-economic and cultural issues; cognitive and emotional development; availability of services in the community, malformations and multiple disorders are some of the many factors that make each child and each

decision process unique. Partnership with parents in the first years of life plays a major role in this process.⁴

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Parents Involvement, Auditory Habilitation/Rehabilitation

PARENTS INVOLVEMENT IN THE AUDITORY HABILITATION/ REHABILITATION PROCESS IN HEARING AID AND/OR COCHLEAR IMPLANT USERS

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In order to observe fully the results in the auditory and language performance of hearing aid and/or cochlear implant users, it is necessary to acknowledge all the factors that affect the habilitation/rehabilitation process. Amongst these factors, the one that stands out is the influence that parents have over the process. It is so important, that the progress a patient makes during intervention will greatly depend on the quality and quantity of parental involvement in the process.

Experience gained in Guatemala in relation to this process, provides useful

suggestions for the implementation of habilitation/rehabilitation programmes in other countries with similar conditions. In order to provide the reader with the proper perspective on this subject, we have identified a series of strengths and limitations. These apply to countries where audiological services are not available to the whole population and in countries where deaf children and their families do not have the expected support from the State, in regard to funding for hearing aids and cochlear implants.

As far as our strengths go, we consider the following key elements:

1. Few, but very well accomplished professionals in the field.
2. Good links existing with other professionals in Latin America, allowing networking.
3. Outreach which has been possible through training parents and other professionals.

In regard to limitations, we have identified:

1. Restriction of resources.
2. Services are centralised in Guatemala City.
3. High rates of illiteracy.
4. Lack of (or very few) indirect services for clients and the community, in terms of consultation and advocacy.

Despite these challenges, we have now been able to provide community services



*Girl from Antigua, Guatemala. BTE hearing aids
Photo: Patricia Castellanos de Muñoz*

in education - offering free parent training courses, on-going training for other professionals and partnership with other key contacts in the field.

In order to ensure that parental involvement in the habilitation/rehabilitation process has a significant influence over auditory and language performance, we now emphasise the following essential aspects:

1. It is essential to complete a thorough study of each patient's medical file - to evaluate all the factors that determine good progress.
2. The use of guidelines for observation may allow fuller access to



*Girl from Quetzaltenango, Guatemala. BTE hearing aids
Photo: Patricia Castellanos de Muñoz*



Hard of hearing siblings from San Juan Sacatepequez, Guatemala

Photo: Patricia Castellanos de Muñoz



Otoacoustic emissions screening programme, Guatemala

Photo: Patricia Castellanos de Muñoz

the patient's whole environment. Observations should take place in natural and structured settings and should not only involve the patient but his or her social and emotional environment.

3. It is vital to determine the auditory, language and behavioural goals to be set and monitored by both therapists and parents, in order to have a detailed recording of the progress made in all areas. Other observers can participate as well.
4. The use of specific instruments that allow the recollection of data, will also aid the proper analysis of the auditory and language performance in patients.
5. It is imperative to have a clear idea of the services that are available in the city or country, as there are so few specialised and trained professionals in audiology and therapy. This makes the achievement of goals harder.

Suggested Reading

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Education of Deaf Children

EDUCATION OF DEAF CHILDREN: A CHOICE OF PARADIGMS*

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Significant changes in thought (philosophy) concerning the education of deaf children have occurred over the decades. The way in which deaf people are perceived has been affected by the historical events that mark each century of humanity.

These philosophies have been discussed and brought together inside two great schools of thought.^{1,2} These philosophies are the clinical paradigm* (or rehabilitation) and the cultural paradigm (or socio-anthropological). According to Paul and Quigley,¹ the clinical view sees

the deaf person from the point of view of his/her auditory deficit, believing that the social, cognitive, communicative and linguistic abilities of deaf people depend on the capability of oral language acquisition. In fact, this model describes deaf children from a hearing child model.¹ The socio-anthropological paradigm sees the deaf person as a member of a linguistic minority that has sign language as its centre. This language has the same status as an oral language and it makes it possible for deaf people to achieve all levels of thought, with the same psycho-socio-linguistic possibilities as hearing people.

Clarifying this concept, Paul and Quigley¹ explain that theoreticians who defend the cultural view, 'see deafness as a natural condition, not as something bad or a disability that needs to be 'cured' or prevented. It is argued that many deaf people do

not want to be equal to those who listen'.

These differences in the way we understand deafness may have a positive or negative impact on the deaf child. We know that many couples desire to become parents and that the expectations projected on this child are very profound.³

'We dream about our children and we put on them all the perfection, all the



Citizenship centre for deaf young people, CEPES, Brazil

Photo: Rosane Vargas

*Paradigm: A thought pattern, relating to the vision one has about deafness

greatness of a human being. In our fantasies, the desired son is the most handsome, the most perfect, the most intelligent, the successful professional that we wanted to be, and we want to give to this child all the things that we wanted for us and did not get. In fact, we see in this child the prolongation of ourselves, the person that could be our ideal selves!'.³

In the case of deaf children of deaf parents, in many cases, acceptance may be easier because parents already know and understand what deafness means. These parents tend to introduce a communicative system early, through the use of sign language, in order to facilitate language acquisition.

Once the aetiology of the deafness is discovered, and the degree of deafness is established, usually a school with one of the two paradigms is offered to parents. In the 'clinical' school, education would probably include the following:

1. Use of hearing aids.
2. Auditor training.
3. Speech reading (training of visual perception).

However, it should be pointed out that in order to have a reasonable level of success in this process, it is necessary to offer an early and strong intervention programme. Even so, many deaf people do not achieve a good level of oral language or good comprehension and generalisation of language.

In the 'cultural' school, we do not compare the deaf child to a hearing child; there is no standard of normality. People will use sign language freely, because this is the spatial-visual language that offers the possibility of communication, and also the function of forming thought. The function of language is not only communication itself, it also serves to develop the child's cognition, therefore, the whole cognition begins to be determined by language, influenced by culture.⁴

Parents, in this paradigm, need to learn sign language. Later, their child will go to a school with other deaf children to acquire knowledge through systematic learning. That is part of the school's task.

These polarised visions may lead people who work with deaf children, and parents,

to make extreme decisions, approaching this situation with an either/or answer - in other words, choosing to use either oral language or sign language.

That is why we prefer an attempt to combine these paradigms, in spite of the fact that, theoretically, they may be considered incompatible.¹ Deaf children take a long time to acquire oral language. Even with intensive rehabilitation programmes, they often do not acquire enough understanding of this language. In a bilingual situation, we have to consider that the acquisition of sign language should be a natural one, and that 90% of deaf babies are born in to hearing families,⁵ where parents use an oral language. With all this in mind, we could choose to rethink the project of education of this child with a hearing loss, proposing the following:

- To welcome and support parents when deafness is discovered in their child
- To give parents and children an opportunity to interact socially with deaf adults who are integrated in society, so that parents may make positive choices for their children, based on these models
- To give information about the education and rehabilitation of deaf people
- To propose a plan to (re) establish communication between hearing parents and deaf children
- To give priority to the learning of sign language as soon as possible, because this language will be a used as a support for their thinking
- To adapt the child to a hearing aid and offer visual and auditory hearing stimulation (depending on each child's individual needs)
- To enable professionals who work with deaf babies to know and use sign language.

It seems to us that we should see each child as unique, with his/her unique characteristics, in his/her socio - cultural



Deaf young people at citizenship centre, CEPES, Brazil

Photo: Rosane Vargas

context. We should not forget that language is a symbolic system of human groups and that it represents a step in cognitive capacity. It is language that gives us the concepts, the ways to organise what is real, the mediation between the subject and the object of knowledge. It is through language that higher mental functions are socially formed and culturally transmitted. It is important to highlight again that language is not just a way of communication, but also a way to organise thought.

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CHALLENGES IN PROVIDING FAMILY CENTRED EARLY YEARS SUPPORT FOR DEAF CHILDREN AND THEIR FAMILIES

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In the UK, there is a long tradition of providing support and guidance to families who have a deaf child. The concept of what 'early' means, within the UK context, has changed significantly. Prior to the introduction of the Newborn Hearing Screening Programme (NHSP), the average age of identification of permanent childhood deafness in the UK was 2 years 7 months (Davis et al, 1997).¹ This presented very considerable challenges to professionals who were placed in the position of 'rescuing' deaf children who had already fallen behind other children in the same age group. The gap between typically developing children, who by this age had established the building blocks of language, developed skills in using syntax* using a well established lexicon** and late identified deaf children, was very large. Such gaps were seldom overcome despite the best efforts of families and professionals. The original work of the Colorado group led by Yoshinago-Itano (1998 a,b,c, 2001)^{2,3,4,5} have demonstrated that for very early identified deaf children, who are identified before six months of age, and receive sensitive support within the home, are able to achieve language levels and social skills within the normal range, albeit within the low average scores. This is independent of the mode of communication used and of the degree of deafness. There is no definition of what 'sensitive' support consists of and this raises major challenges for services in respect of their development. The introduction of NHSP in England was preceded by the development of an on-line copyright free website. This was specifically developed to provide up-to-date information for the professional on working with very early identified deaf children

* *Syntax: Rules of grammar in forming phrases and sentences*

** *Lexicon: A list of words with their meanings*

(www.deafnessatbirth.org.uk). In addition, postgraduate training was developed in this area, recognising that the introduction of NHSP has implications far beyond the screen itself, which need to be addressed if services are to be available for families who have deaf children (McCracken et al, 2005).⁶ Currently, a national study of the outcomes of NHSP in England (www.positivesupport.co.uk) is exploring this as one of the aspects of this study.

Teachers of the Deaf

Within the UK context, Teachers of the Deaf (ToD) have traditionally been the main family support worker with pre-school deaf children, visiting parents at home and at mother and toddler groups. The framework of delivery has, however, undergone significant changes in the last five years. There has been a strong move away from the expert model where ToD visits focused on working with the child, using a range of toys provided by the education service. It was common practice that the ToD modelled patterns of interaction that were focused on promoting positive interaction and fostered the development of communication skills. This expert model placed the ToD in a position of power and the parent in the role of a recipient of practice. Both parties knew what their role was and where the power lay. This model has been challenged. It presents parents with an expert model that potentially de-skills families and places them in the position of being recipients of services rather than partners. Within an expert model of delivery, communication games demonstrated by a ToD may be seen as something the family have to do, even when it would not normally be part of their family life. ToDs are now encouraged to use the family setting, with all the possibilities this brings, to actively support development rather than imposing toys and activities which may not reflect the family's lifestyle.

Parents and the Deaf Child

Whilst professionals who have experience of deafness are keenly aware of the potential benefits of very early intervention, parents may well feel shocked and at a loss as to what to do. Professionals then

reassure parents that they should talk as usual, play and interact with their child as usual and with perseverance, communication skills will grow and develop. When identification was delayed, parents usually had concerns and were, in many cases, relieved to find out that their child simply could not hear. NHSP means that concerns may be raised within hours of birth, if the screen results in a referral, despite careful explanations that referral only means the response was unclear and this can be for a range of reasons. Emotionally labile parents with a new baby may not be able to take in anything other than their baby is being referred for a further check of their hearing status. While audiology services, health care managers and ToDs may welcome very early audiological assessment and fitting of amplification, for parents this can be a difficult and challenging time (McCracken et al, in press).⁷ Unlike the parents of late identified children, very early identified children are unlikely to show any obvious signs of being deaf. Parents do not usually focus on communication skills in the first months of life, rather they enjoy their baby, naturally using eye gaze, smiling, chatting to their child about daily activities. During the early months, parents naturally respond as if their child can understand, they fill in what would be the child's response (Karmiloff-Smith, 1994; Jusczyk, 2000).^{8,9} This 'dance' between mother and child has all the key aspects of communication that ToDs want to establish - synchrony, contingency and turn-taking. Yet the very identification of permanent deafness may fracture this natural relationship, setting up new expectations, raising concerns and challenging basic patterns of early interaction.

Family Centred Framework

Teachers of the Deaf and other Early Support workers in the UK are working within a family centred framework, where parents of children are seen as experts in their own child. This places professionals in a role where they work together with families (joint working), respecting the family's expertise and using this as a basis for service provision. This has been strongly endorsed by recent government initiatives. A

number of significant government guidance documents were issued, including Every Child Matters (www.ecm.gov.uk), Together from the Start and Deafness Early Intervention for deaf children (birth - 3rd birthday) and their families. Early Support is the central government mechanism that seeks to achieve better co-ordinated, family-focused services for young disabled children and their families across England, which is developing as part of the re-structuring of services in response to Every Child Matters. It facilitates change in partnership with families who use services and the many agencies that provide services for young children (www.earlysupport.org.uk). This programme has focused on ensuring that early identification of disability is met with a range of resources to support families. It is a pan-disability initiative rather than being deaf specific. Early Support provides a range of materials that aim to provide a practical framework within which a range of government initiatives can be facilitated and delivered. Materials range from the Service Audit tool, aimed at positively supporting joint working, to information for parents about specific disabilities. It also provides information about the range of services they may meet, a family file to avoid duplication of information, and the Monitoring Protocol to allow parents and professionals to look at a child's developing skills. Most recently, guidance on achieving Informed Choice for parents, and on working towards providing it by services, has been developed as part of the Government's Early Support package (www.earlysupport.org.uk).

org.uk). Training consortiums are available to provide training to a range of professionals and parents. Parents can, thus, have access to a broad and balanced programme of resources and information, ToDs provide support but the expert position is modified. ToDs seek to empower parents, promote positive parenting and independence. ToDs are still experts but have to develop a range of interpersonal skills that allow expertise to be carefully grafted onto family skills rather than undermine them. Partnership is seen as crucial but it must be an equal partnership, where parents have control and develop their expertise, rather than a transplant model where the ToD models behaviour and the parent follows. The move to family centred approaches and growth of the internet both challenge what are frequently viewed as the traditional skills of a ToD. As understanding of early communication continues to grow, technological options rapidly develop the knowledge and skills base required by ToDs and other early support workers, making ongoing professional development a key factor in ensuring services are well placed to support families.

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Recommended Websites

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2. <http://www.positivesupport.co.uk/>
3. <http://www.everychildmatters.gov.uk/>
4. <http://www.deafnessatbirth.org.uk/>





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WORLD-WIDE HEARING CARE FOR DEVELOPING COUNTRIES

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A New Partnership

WWHearing — *World-Wide Hearing Care for Developing Countries* is a new global partnership to promote better hearing through provision of affordable and appropriate hearing aids and services. It gives priority to developing countries and underserved communities, where the needs are greatest. Its founding organisations include Non-Governmental Organisations, users of hearing aids, interested governments, manufacturers – commercial and not-for-profit, professionals, donors, experts, academic centres and international bodies.

Effects of Hearing Loss on People

Deafness and hearing impairment have profound effects on people at all ages. Helen Keller, who was blind and deaf, said 'deafness is a much worse misfortune' and 'blindness separates us from things, but deafness separates us from people'.

In particular, deafness and hearing impairment:

- Damage the development of speech, language and mental skills in children, especially when starting in early infancy
- Slow progress in school
- Cause difficulties in obtaining, keeping and performing an occupation
- Produce social isolation and stigmatisation at all ages and in both sexes
- Are both a cause and consequence of poverty and a huge economic burden on individuals and society.

These difficulties are much worse in developing countries where there are very few services or trained staff and little awareness to help deal with them.

Providing appropriate and affordable hearing aids and services on a massive world-wide scale is likely to be the most effective and cost-effective way to make the biggest reduction to the impacts of this disability.

Size of the Problem

In 2005, 278 million people in the world had moderate or worse bilateral hearing impairment (WHO estimate). Two thirds of these live in developing countries and 68 million are children. The vast majority would benefit from hearing aids. This means that 35 million hearing aids could be needed annually in developing countries, together with services and staff to fit them. Unfortunately, only about one million are actually available there. Even in developed countries, only one third of the hearing aids required are fitted.

Call to Action

The World Health Organization produced the *WHO Guidelines for Hearing Aids and Services for Developing Countries*, which are the foundation for WWHearing's work. At the launch of the guidelines, WHO called on the private sector to provide affordable hearing aids in the developing world. It was proposed that the only way to address the problem was to encourage the setting up of public / private partnerships between national governments of developing countries and hearing aid manufacturers. But neither body could do this by themselves, so that in 2003 the key stakeholders listed in the first paragraph came together at WHO, Geneva and established *WWHearing*.

The main tasks of *WWHearing* are to:

- Gather information on provision / need in developing countries
- Encourage provision of appropriate, affordable hearing aids and services on a massive scale
- Stimulate public-private partnerships in countries
- Promote projects for fitting, follow-up, repair, training.

What is WWHearing Doing Now?

In July 2006, *WWHearing* registered as a charitable association in Switzerland, and

in October signed a Project Collaboration Agreement with WHO so that the two organisations can work together more closely on these tasks (please see <http://www.who.int/pbd/deafness/activities/WWHearing/en/index.html> for more information).

The major initiatives of *WWHearing* at present are:

- Supporting a pilot study in Tamil Nadu State, India to evaluate a hearing aid service delivery model for poor villagers using community health workers to find those in need and fit and follow-up their hearing aids (Partner: Christian Medical College, Vellore, India).
- Supporting a pilot study to measure outcomes and cost-effectiveness of training teachers of deaf children to fit and follow-up hearing aids for poor hearing-impaired children in Guangxi Province and Beijing city, in China. (Partner: China Rehabilitation Research Center for Deaf Children).

It is planned that lessons learnt from these pilot studies will lead to much larger projects in many more locations:

- Calling for proposals from implementing agencies for provision of hearing aids in major developing countries. So far, proposals from Brazil, Ethiopia, Indonesia and Philippines have been approved for support.
- Seconding a suitable person to WHO to take responsibility for the whole Programme for Deafness and Hearing Impairment (including responsibility for WHO's involvement with *WWHearing*).

Over the next five years and beyond, as these projects are shown to be successful, funding and partners will be sought to implement progressively full-scale projects in targeted developing countries with the largest needs - and where the opportunities for effective interventions are greatest. □

A Practical Guide to Quality Interaction with Children Who Have a Hearing Loss

Clark, Morag

Plural Publishing, San Diego, 2007.

ISBN-13: 978-1-59756-112-9;

ISBN-10: 1-59756-112-6

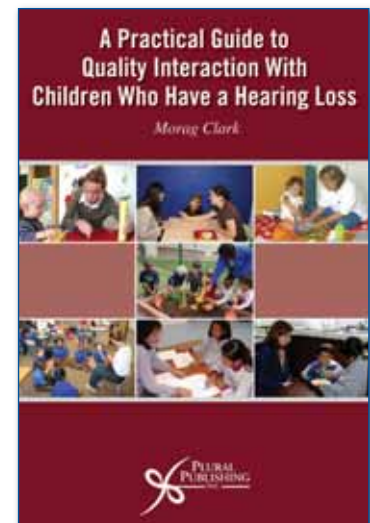
147 pages

This book is a valuable resource to all that are committed to the development of oral language in children who have a hearing loss. The Guide offers examples and suggestions for optimal habilitation and focuses on the Natural Auditory Oral approach: the maximum use of the child's residual hearing, starting from the earliest possible age; fitting of appropriate hearing aids or cochlear implants; a natural, normal language based environment; a firm conviction on the part of parents and professionals that the child has an innate capacity to develop fluent

spoken language and a sign-free environment. The author centres this work on parents and family members, who are considered to be the key elements in creating a language - learning environment. This Guide is an important contribution to the field of deafness, based on the author's vast international experience. Dr. James W. Hall III, in his Foreword to the book states that 'The future has never been brighter for infants and young children with hearing loss' (p.viii), and the book aims to address these possibilities from the point of view of quality oral habilitation. The seven chapters discuss hearing as a basis of development of spoken language, daily living as the foundation for language, parent guidance, international experience, educational placement and offer an

overview of developments from Mid-20th century onward.

Beatriz Raymann



Helping Children Who Are Deaf

Niemann S, Greenstein D, David, D

The Hesperian Foundation

Berkeley, 2004

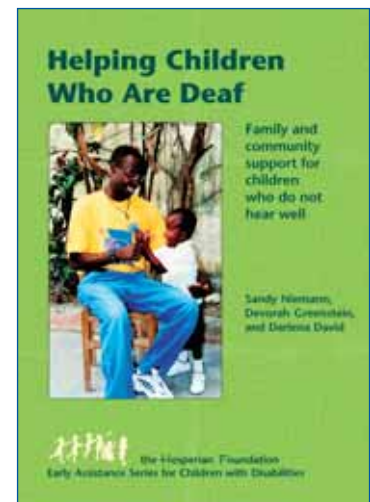
ISBN: 0-942364-44-9

245 pages

This excellent book was written for parents, and other caregivers of young children who have a hearing loss. The approach is that a child with a hearing impairment is the responsibility not only of his / her parents, but of the entire community - to welcome and accept this child once it learns how to do this. The book offers information, explanations, and ideas to help parents and the community to care for the whole child.

Basic principles are explained in a way that makes it easy to adapt to the different situations. The activities were developed by families with deaf and hard-of-hearing children, deaf adults, community-based development workers, health workers, educators and other experts from over 17 countries. The major themes are about language acquisition and development, hearing assessment, communication, listening and social skills, supporting parents, educating a deaf child, preventing child sexual abuse and preventing deafness.

Beatriz Raymann



Counseling Persons with Communication Disorders and their Families

Luterman D M

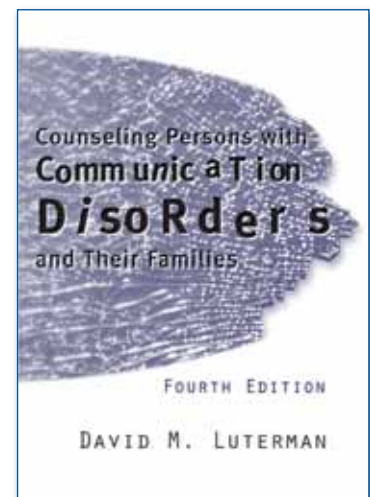
4th Ed. Pro-Ed, Inc. Austin, 2001

ISBN 9780890798768

There are very few books written in regard to counseling, with a direct focus on audiology and communication disorders. This book centres its topics on counseling, not only for parents of children with this type of disorder, but also offers advice for families of adults who later develop this condition. Much of the information presented is illustrated with real life experiences and daily living situations, which makes it very easy reading.

Also, it describes models in counseling that can be adopted by an audiologist or speech-language pathologist, after analysing the pros and cons of each one. A lot of the data presented has been collected from a wide variety of studies that have been performed. The book offers a series of useful techniques for patient management during the grieving and coping process, and for the management of families (parents, grandparents, spouse, etc.). This book is a must for everyone working in the field of communication disorders.

Patricia Castellanos de Muñoz



Progress towards early detection services for infants with hearing loss in developing countries

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Background: Early detection of infants with permanent hearing loss through infant hearing screening is recognised and routinely offered as a vital component of early childhood care in developed countries. This article investigates the initiatives and progress towards early detection of infants with hearing loss in developing countries against the backdrop of the dearth of epidemiological data from this region.

Methods: A cross-sectional, descriptive study based on responses to a structured questionnaire eliciting information on the nature and scope of early hearing detection services; strategies for financing services; parental and professional attitudes towards screening; and the performance of screening programmes. Responses were complemented with relevant data from the internet and PubMed/Medline.

Results: Pilot projects using objective screening tests are on-going in a growing number of countries. Screening services are provided at public/private hospitals and/or community health centres and at no charge only in a few countries. Attitudes amongst parents and health care workers are typically positive

towards such programmes. Screening efficiency, as measured by referral rate at discharge, was generally found to be lower than desired but several programmes achieved other international benchmarks. Coverage is generally above 90% but poor follow-up rates remain a challenge in some countries. The mean age of diagnosis is usually less than six months, even for community based programmes.

Conclusion: Lack of adequate resources by many governments may limit rapid nationwide introduction of services for early hearing detection and intervention, but may not deter such services altogether. Parents may be required to pay for services in some settings in line with the existing practice where healthcare services are predominantly financed by out-of-pocket spending rather than public funding. However, governments and their international development partners need to complement current voluntary initiatives through systematic scaling-up of public awareness and requisite manpower development towards sustainable service capacities at all levels of healthcare delivery.

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Universal newborn hearing screening in Singapore: the need, implementation and challenges

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With about 1 in 1000 born with severe to profound hearing loss and about 5 in 1000 with lesser degrees of loss, congenital deafness is the commonest major birth defect. It is the recommended standard that hearing loss in newborns be detected by 3 months of age and intervention implemented by 6 months of age. Delayed detection and intervention may affect speech, language and psychosocial development, resulting in poor academic achievements. Universal newborn hearing screening (UNHS) is the only effective

way of detecting all babies with hearing loss, within the recommended time frame. A survey in Singapore revealed that traditional childhood hearing screening programmes resulted in late detection (mean age, 20.8 months; range, 0 to 86 months) and late intervention (mean age, 42.4 months; range, 1 to 120 months). Increasingly, UNHS is becoming standard medical care in developed countries. In Singapore, UNHS has been implemented in all hospitals with obstetric services. Although a screening rate of more than 99% has been achieved in public hospitals, private hospitals have a screening rate of only about 77%. Parents' awareness and acceptance of early detection is still lacking, and this

needs to be addressed by appropriate public education. Support from obstetricians and paediatricians will significantly contribute towards this objective. Effective programme management is essential; this includes the use of data management systems, the maintenance of a team of experienced screeners, and efficient coordination between screening and diagnostic services. Early detection of childhood deafness, together with early and effective intervention, maximises the chances of successful integration into mainstream education and society.

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Aetiology of deafness among children at the Buguruni School for the Deaf in Dar es Salaam, Tanzania

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To identify the causes of deafness, 354 pupils attending the Buguruni School for the Deaf in Dar es Salaam, Tanzania, were studied. Of these children 205 were boys and 149 were girls, a sex ratio of 1.4:1. The onset of deafness was congenital in

36 (10.2%) and acquired in 318 (89.8%). Among the children with acquired deafness, the cause was unknown in 77 (24.2%); meningitis in 76 (23.9%); ototoxicity in 66 (20.8%); mumps in 53 (16.7%); febrile convulsions in five (1.5%), otitis media in 28 (8.8%) and measles in 13 (4.1%). Among the children with congenital deafness, only ten (27.8%) were identified before the age of 2 years. The findings indicate that most (75.8%) of the causes of acquired deaf-

ness are preventable through immunization, early diagnosis and proper treatment of ear infections and avoidance of prescription of ototoxic drugs. This emphasizes the need for programmes aimed at improving the health services at primary levels of health care which will in turn prevent deafness.

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Practical screening priorities for hearing impairment among children in developing countries

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Routine screening for hearing impairment in childhood is now widespread in industrial countries, although there is considerable controversy over the most efficient techniques and procedures. In most developing countries, however, routine screening programmes for hearing impairment do not currently exist.

The problems involved in implementing screening programmes in developing and industrial countries are very different, and in selecting screening procedures for a particular population the following factors have to be taken into consideration: the environmental test conditions; the availability of resources for equipment and the training of testers; the local attitudes towards disability; the level of hearing impairment that may cause handicaps; and the major types of pathology causing hearing impairment. We suggest that in developing countries children should be screened at school

entry using a simple field audiometer and that the external ear be inspected for the presence of a discharge. There is an urgent need to develop reliable and simple screening procedures for infants and young children; where possible, all children should be screened for severe or significant hearing impairment before the age of 2 years. No screening should, however, be implemented until appropriate follow-up services are available.

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Language ability after early detection of permanent childhood hearing impairment

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Background: Children with bilateral permanent hearing impairment often have impaired language and speech abilities. However, the effects of universal newborn screening for permanent bilateral childhood hearing impairment and the effects of confirmation of hearing impairment by nine months of age on subsequent verbal abilities are uncertain.

Methods: We studied 120 children with bilateral permanent hearing impairment identified from a large birth cohort in

southern England, at a mean of 7.9 years of age. Of the 120 children, 61 were born during periods with universal newborn screening and 57 had hearing impairment that was confirmed by nine months of age. The primary outcomes were language as compared with nonverbal ability and speech expressed as z scores (the number of standard deviations by which the score differed from the mean score among 63 age-matched children with normal hearing), adjusted for the severity of the hearing impairment and for maternal education.

Results: Confirmation of hearing impairment by nine months of age was associated with higher adjusted mean z scores for language as compared with nonverbal ability (adjusted mean difference for receptive language, 0.82; 95 percent confidence interval, 0.31 to 1.33; and adjusted mean difference for expressive language,

0.70; 95 percent confidence interval, 0.13 to 1.26). Birth during periods with universal newborn screening was also associated with higher adjusted z scores for receptive language as compared with nonverbal ability (adjusted mean difference, 0.60; 95 percent confidence interval, 0.07 to 1.13), although the z scores for expressive language as compared with nonverbal ability were not significantly higher. Speech scores did not differ significantly between those who were exposed to newborn screening or early confirmation and those who were not.

Conclusions: Early detection of childhood hearing impairment was associated with higher scores for language but not for speech in mid childhood. Copyright 2006 Massachusetts Medical Society.

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Early hearing detection at immunization clinics in developing countries**Olusanya BO, Okolo AA***Institute of Child Health and
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Early hearing detection has become a standard of neonatal care in most parts of the developed world. A growing number of developing countries are also currently exploring practical and culturally appropriate options for early hearing detection. Recent findings from ongoing infant hearing screening programs

in Nigeria and South Africa suggest that hearing screening programs are feasible if integrated into early childhood immunization programs in developing countries, especially where a significant number of births occur outside regular hospitals. A major challenge for a multi-stage screening protocol is how to minimize default rates for follow-up till diagnosis. However, this could be systematically addressed through improved parental education and appropriate support at various stages of the program.

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Teacher and pupils at the Holy Land Institute for the Deaf (HLID) in Salt/Jordan. The Institute is a rehabilitation centre for hearing impaired children and young people

Photo: CBM/Heine

COMMUNITY EAR AND HEARING HEALTH**Aim**

- To promote ear and hearing health in developing countries

Objectives

- To facilitate continuing education for all levels of health worker, particularly in developing countries
- To provide a forum for the exchange of ideas, experience and information in order to encourage improvements in the delivery of ear and hearing health care and rehabilitation.

Guidelines for Authors

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