



CHAPTER 1

ORIENTATION AND STATEMENT OF THE PROBLEM

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1.1 Introduction

The Healthy People 2000 Goals [U.S. Department of Health and Human Services, 1990], established the identification of infants with hearing impairment by one year of age as a priority. The World Health Organization [WHO] 1995 Resolutions urged member states to prepare national plans for the prevention of major causes of avoidable hearing loss, including **early identification** of hearing loss in babies, toddlers and children. These goals were set to ensure **early intervention** for infants and children with hearing loss.

Early intervention refers to the management of a hearing-handicapped child before primary school years, and especially before 3 years of age. In this context, early intervention includes both identification of hearing loss and the subsequent follow-up. Late intervention generally refers to intervention after spoken language is normally acquired, that is after 3 years of age [Bench, 1992].

Hearing loss essentially imposes a developmentally and educationally handicapping condition on the child who grows up in a hearing world. The goal of an effective intervention programme for such a child is to ensure optimal development of the child within the family. This goal can be accomplished in 4 ways:

- By early identification of an infant or child with hearing loss;

- By using amplification [hearing aids or cochlear implants] to reduce the primary effects of the hearing loss on development;
- By adapting the environment to meet the child's cognitive and linguistic needs;
- By educating, supporting and counselling the parents so they can provide a nurturing environment that promotes healthy social and emotional growth within the family. [Gatty, 1996].

Yoshinaga-Itano [1995] indicates that early identification of hearing loss, particularly at birth, not only minimises the deleterious effects on communication but can prevent delays in communication development from occurring. Research is proving that when optimal early intervention services are provided from the age of identification, the serious effects of sensori-neural hearing loss upon communication skills can be minimised.

The major goal of early intervention is to prevent the development of secondary problems in language, communication, cognition and social interaction. Early infancy is the most appropriate time for the child to acquire the foundations of language and communication, so that he/she can then follow the same naturally developing patterns of hearing children. Early intervention holds the promise of optimising a hearing-impaired child's language, speech, intellectual and psychosocial development and occupational/economic opportunity [Bess, 1993; Northern & Downs, 1993; Northern & Hayes, 1994; Scalon & Bamford 1990; Yoshinaga- Itano 1995].



Effective early diagnosis and management also includes involvement of the parent/caregiver at all stages of assessment and intervention as active participants [ASHA, 1991]. Increasingly, early intervention programmes have emphasised **home-based** treatment, and parent involvement. According to Downs [1994], early intervention yields the best potential language skills and produces optimal parent-child interaction that is requisite for ideal language development. Meadow-Orleans [1987] also states that early intervention programmes are likely to be successful if they have a strong emphasis on parent counselling and access to experienced staff. Bench [1992] concluded that parental attitudes, parental support and counselling, are probably more important for the success of early intervention than other variables.

Against this framework, the aim of this chapter is to indicate the need for, and the challenges presented by early intervention for children with hearing loss especially within the context of a developing country like Mauritius.

1.2 Background to Problem Statement: Early Identification

The early identification of hearing loss represents the first crucial step in an early intervention programme. The justification for early identification of hearing loss is typically drawn from four sources in the literature, namely, studies concerning sensory deprivation, critical periods, treatment efficacy and epidemiology [Kentworthy, 1987 in Alpiner and McCarthy p. 24]. The primary justification for early identification of hearing loss in infants relates to the

impact of a hearing loss on speech and language acquisition, cognitive development, academic achievement and psychosocial development [Bench, 1992]. Professionals working in paediatric audiology, speech-language pathology and early childhood special education endorse **early identification** as being critical to a child's communication skill development. Late identification of hearing loss results in late intervention with dire effects on the child's development. Children with hearing loss who are identified late have passed the critical periods of language and speech acquisition. These children typically exhibit delayed and disordered communication and are viewed to be poor verbal communicators.

The advantages of early identification of hearing loss among children have been demonstrated by carefully controlled studies by Yoshinaga-Itano [1995] amongst others. These studies indicate that children whose hearing loss was identified prior to 6 months, exhibited language development within the low normal range of development; however, children who were identified late remained 50% to 60% behind the language level of their normal hearing peer group.

To achieve the goal of early identification of hearing by 12 months of age, task forces were set up with a team of experts to recommend programmes for early identification of hearing loss among children. The National Institutes of Health [N.I.H.] U.S.A. Consensus 1993, The Joint Committee on Infant Hearing Position Statement [J.C.I.H] 1994, and European Consensus Development Conference on Neonatal Hearing Screening 1998, **recommended that the ideal solution would be to have a Universal Hearing Screening Programme at birthing places.**

This recommendation was based on the following facts:

- Childhood hearing impairments are a serious health problem affecting at least 1 baby in a thousand [Mauk *et al*, 1991];
- Intervention is considered to be most successful if commenced in the first few months of life [Yoshinaga-Itano, 1995];
- The high risk indicators of hearing loss can be used to identify up to 50% of children with hearing impairments [Mauk *et al*, 1991];
- Technology, such as otoacoustic emissions and automatic brain stem evoked response audiometry, is available to identify infants and children with hearing loss and finally;
- Effective programmes for intervention with young children with hearing loss have been developed in the USA and Europe.

It is concluded that the first step in an intervention programme should consist of a **hearing screening procedure** that can identify infants with hearing loss **early**, preferably at less than 3 months of age, in a rapid, reliable and accurate manner. According to Finitzo [1998 cited by Nemes p. 30]: “detection is pointless unless you can connect the infant to the needed services. Early identification of hearing loss must be followed by a timely and effective intervention programme”.

1.3 Problem Statement

To effect necessary changes in health care, countries must decide on the best approaches to adopt within the context of their specific characteristics and needs. This requires detailed and accurate information on needs, possibilities and consequences of recommended actions. Such information is often lacking, inadequate or unreliable, resulting in inappropriate policy choices [Varkevisser, Panthmananthan and Brownlee, 1991]. Clinical observations indicate that, in Mauritius, children with hearing loss are not identified early enough and that the follow-up is fragmented and inconsistent.

Common wisdom has long held that the optimal welfare of the hearing impaired is served by the identification of the loss as early as possible and by immediate application of therapeutic intervention [Downs, 1994]. The economic data presented by Downs [1994] shows that by applying present technology for early identification and habilitation of affected infants, the cost of deafness to society can be reduced. Screening for hearing loss at birth and early intervention have the potential of considerably reducing a large part of the financial burden of hearing disability and significantly improving the quality of life of those affected. This is especially relevant in developing countries where there are not only financial constraints but also a lack of human resources and technology to provide services to the hearing impaired population [WHO, 1997].

There is currently a paucity of accurate, standardised, population-based data on the prevalence and causes of deafness and hearing-impairment, especially in developing countries [WHO, 1999]. Davidson, Hyde and Alberti [1989] compared a number of studies

and found that in general 1 to 2 /1000 children in developed countries have bilateral severe hearing loss. They also stated that the incidence in developing countries is almost twice as high as in developed countries. The reason was attributed to infections that are not controlled. This is a serious public health problem and requires National or Public Health Services for prevention. Moreover the prevalence, epidemiology, identification and intervention process for children with hearing impairments in developing countries, is not well documented to date [WHO, 1995].

The aural rehabilitation process involves two phases [Bess and Humes, 1995] namely, identification of the hearing loss and subsequent intervention. Early identification may be achieved by universal newborn hearing screening [N.I.H. Consensus, 1993]. However, in most developing countries, no hearing screening for any infant, not even those at risk for hearing loss, takes place [WHO, 1995]. High-risk indicators can detect at least 50% of the children with hearing impairments. If audiologists can accomplish early identification and intervention in the high-risk population, they can influence community policy makers to develop priorities for early identification and intervention [JCIH, 1994].

In developing countries the resources such as technology for screening, is lacking. There is no policy regarding referral and identification of children with high-risk indicators for hearing loss [WHO, 1995]. Under these circumstances, the identification of children with hearing loss is difficult. Often, the only manner in which children with hearing loss can be identified is through parental concern. Studies by Hitchings and Haggard [1983] indicate that professionals consider parents' suspicions of hearing loss to be invalid or do not regard their suspicions as indicators for

referral. Professionals need to value parents' opinions and must refer the children for hearing assessment when parents express concern regarding their child's hearing.

According to Bess and Humes [1995] **early identification** of hearing loss must be followed-up with a comprehensive service including:

- Auditory evaluation;
- Recommendation and fitting of hearing aids and
- Habilitation for the child and the child's family.

The aim of aural rehabilitation is to restore hearing function by providing amplification. In developing countries, achieving this aim is hampered by various factors. Most parents cannot afford to purchase hearing aids. If they have to depend on social aid there is likely to be delay in provision of the hearing aids and the child may not necessarily receive the most appropriate hearing aids. Furthermore, provision of hearing aids alone is insufficient to ensure that the child will have the opportunity to use his/her residual hearing. Aspects such as hearing aids' maintenance, training of parents in the functioning of the hearing aids and the handling thereof and training parents to communicate with their child, need to be implemented to ensure maximum benefits.

Follow-up of children with hearing loss also implies family support and appropriate development of communication [Laughton, 1994] which requires a team approach. The question can be asked that if there are limited number of personnel to provide early intervention services, as is the case in developing countries, then how and what are the services the child with hearing impairment

and the family receive? It is clear that the services required will be limited, inconsistent and fragmented.

Besides the habilitation issues for hearing-impaired children, an important issue is education and the question as to what educational services these children will benefit from arises. In developing countries, there is a lack of cohesive and articulated sense of direction in areas related to the education of deaf children. Issues pertaining to educating children with severe hearing loss should include the normal school curriculum and specifically teaching communication skills in which these children with hearing loss are lacking [Penn and Reagan, 1991]. Special schools with trained teachers are an option that is not readily available for children with severe hearing loss in developing countries. Another option is for these children to be placed in the regular neighbourhood school. However, whether the child with a hearing loss will be integrated successfully in the ordinary school is questionable as inclusion necessitates professional support that is often not available. It is a well-known fact that developing countries are often multilingual. This fact further complicates the educational issue and gives rise to language issues such as which language will be utilised for communication and for academic teaching [Clark, 1997].

The above discussion regarding the constraints to **early intervention** in developing countries can be summarised as follows:

- Lack of data regarding prevalence and epidemiology of hearing loss;

- Lack of human resources in the hearing care field such as Audiologists;
- Lack of technology;
- Inconsistent and fragmented follow-up hearing programmes;
- Lack of hearing aids and effective back-up service for hearing aids;
- No specific policies regarding education service;
- The many languages spoken among the hearing persons [WHO, 1995].

These constraints are common to Mauritius, which is a small developing country in the Indian Ocean. In spite of these constraints, Mauritius has inherent characteristics that predispose it favourably to be able to implement early intervention. The island spans an area of 1,865 square kilometres. In 1997, the total population was estimated at 1,112,636, comprising 556,428 males and 556,208 females. The crude birth rate was 17.4 with a total fertility rate of 2.12 [Health Statistics Annual, 1997]. The size of the island has positive implications for early intervention as children with hearing loss can access the available services readily and the limited population makes intervention goals achievable.

As Mauritius is a welfare state, the education and health services are free. Primary education is compulsory from the ages of 5 to 12 years and the literacy rate in the island is 83.2 %. Most inhabitants are employed [Health Statistics Annual, 1997] which implies that the parents of children with hearing loss have the potential to participate in the intervention process. The infrastructure for Primary Health Care is well organised. Public



awareness in paediatric care is very high, as health centres are centred in every district to promote health care and education. The immunisation system includes B.C.G, measles, M.M.R. D.P.T poliomyelitis and Hepatitis B. Immunisation coverage for 1997 was 87.1% [Health Statistics Annual, 1997]. This is important from the point of view of preventable causes of hearing loss.

However, the following hampers rendering professional services in hearing care: The Ear Nose and Throat [E.N.T] hospital has a centralised service with E.N.T specialists providing out-patient clinics on a session basis in the 5 Regional hospitals. There are only two Speech Therapy Units in the public sector and one of these also provides the Audiology service. There is one private Hearing Care Centre. Due to the fact that only two Audiologists and Speech Therapists are employed in the public sector, trained personnel for hearing care is scarce [Health Statistics Annual, 1997]. The technology available for hearing evaluation in the public sector is basic. Auditory Behaviour Observations, Sound Field testing, Pure Tone Audiometry and Immitance tests are available for confirming hearing loss. Follow-up programmes are limited to a diagnostic and re/habilitative service that is centralised and there are only two special schools, which cater for hearing impaired children as from 3 years of age.

Limitation in the number of professionals involved in hearing care and technological deficiencies are common to all developing countries [WHO, 1995]. Furthermore, professionals also have to deliver services to other communication disordered individuals [Health Statistics Annual, 1997]. This is a practical constraint to early identification and follow-up of children with hearing loss in most developing countries, and particularly in Mauritius.

Against this framework, it is the aim of this study to answer the problem as formulated in the following question: **What is the current situation pertaining to early identification and the subsequent follow-up for children with hearing loss in Mauritius?**

In order to provide an answer to this question a study is planned that is outlined in the figure 1.1 below.

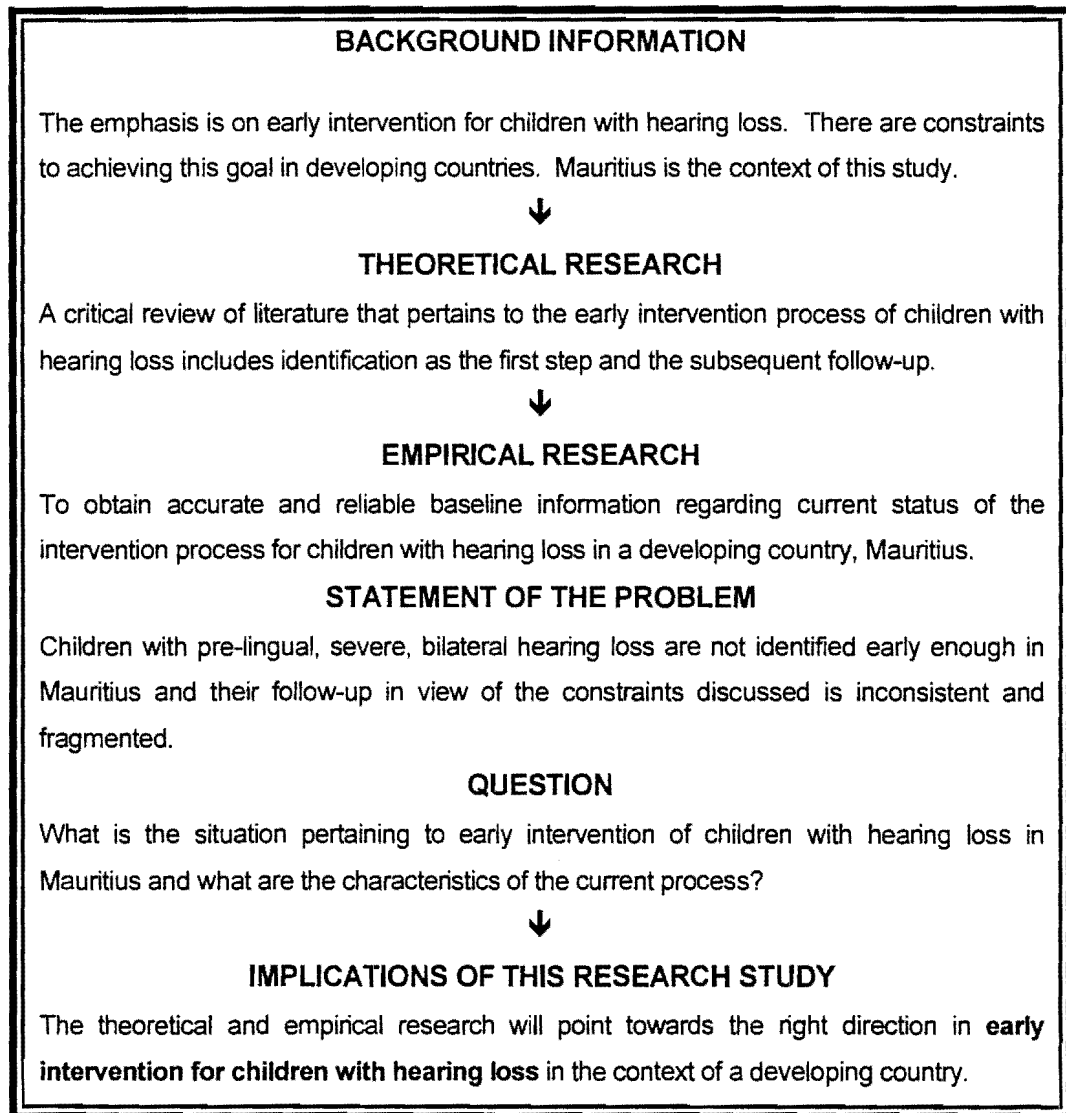


FIGURE 1.1 Central Components of this Study

1.4 Solution to the Problem

The identification and follow-up of children with hearing loss in Mauritius forms the context of this study. Sound research and documentation of its results must be implemented to support decisions regarding the implementation of **early intervention** for children with hearing loss. Research pertaining to developing countries is limited and no baseline information regarding the identification and intervention of children with hearing loss could be traced in the literature.

Marge [1991] emphasised the importance of preventing hearing loss in the asymptotic population [such as immunizing all girls against rubella at pre-puberty ages]. WHO experts [1995] have also recommended prevention of hearing loss in developing countries for avoidable hearing loss through appropriate vaccination programmes. The public health department has an important role in population-based services particularly in any national screening programme and in the implementation of legislation regarding the hearing impaired population [Penn and Abbot, 1997]. The demographics, socio-economic, technological and human resources available are context specific and therefore, the policies must also be relevant to the local context.

For the child with a hearing loss, Bamford and McSporrán [1993] describe identification, diagnosis and habilitation as recursive processes that are not entirely separable. To be successful, habilitation has to permeate all stages, from the suspicion of hearing loss to development of communication. What happens, what information is available, what contingent decisions are made, and how and to what extent are parents involved will affect

realisation of the child's full potential. This emphasises the importance of viewing the problem from the parents' perspective.

To achieve the objective of early intervention in a developing country, namely Mauritius, the research study will consist of two parts as illustrated in figure 1.1:

- Firstly, to critically review the literature and the current methods for early identification of hearing loss and the subsequent follow-up and
- Secondly, based on the theoretical background, to carry out an empirical research study to describe the current identification and follow-up process of children with hearing loss in Mauritius.

The outcome of this study will be to propose an **early intervention programme** for a developing country based on sound theoretical underpinnings and objective research findings.

1.5 Description of Important Terms

1.5.1 Hearing loss in this context refers to severe bilateral sensorineural hearing loss. **Severe** implies loss greater than 70 dB for frequency .5KHz 1KHz and 2Khz. [Katz, 1978].

1.5.2 Hearing Impairment refers to the condition that results from the impairment of the sense of hearing to such an extent that it interferes with communication and affects the social, emotional, educational and vocational aspects of the life of an individual. [DEAFSA, 1996].

1.5.3 Early Intervention can be described as including both assessment and treatment provided to families and their children below 3 years, who demonstrate or are at risk of demonstrating either a disability or delay involving communication, language, speech or prerequisite oral-motor behaviour [ASHA, 1989 p.32].

Early refers to an infant's development from birth until three years. **Intervention** refers to programme implementation designed to maintain or enhance the child's development in a specific area of competence, particularly when the child is at risk of developmental delays or disabilities [ASHA 1989 p.32].

1.5.4 Screening is designed to separate persons from an asymptotic population who have an auditory disorder from those who do not in a simple, safe, rapid, and cost effective manner. Screening programmes are intended to be preventive measures that focus on early identification and subsequent intervention [Bess and Humes, 1995 p.199].

1.5.5 Assessment is an in-depth examination of auditory function utilising behavioural, electrophysiologic, and acoustic immittance measures to determine the degree, configuration type and symmetry of any auditory impairment or to determine that the child does not have hearing impairment that could impede normal communication development. Assessment facilitates medical referral/treatment, aural rehabilitation, and education plan [ASHA, 1991 p. 39].

1.5.6 Prevention means the inhibition of development of any disease or disorder. To hinder or block is primary prevention; to impede or interrupt is secondary prevention [Gerber 1990 p.293]. Three levels of prevention are distinguished:

Primary prevention aims to prevent the occurrence of the disease or injury in a population; for example, health promotion and preventive measures such as vaccination, genetic counselling and nutrition [WHO 1991 p.8].

Secondary prevention refers to early identification for purposes of early intervention [Gerber 1991 p. 298]; for example, programmes to detect hearing loss as early as possible through screening programmes and identification of at risk groups.

Tertiary prevention aims to minimise the hearing disability and its sequel, through habilitation/rehabilitation; for example, application of corrective measures such as hearing aids, special education and rehabilitation [WHO 1991 p.8].

1.6 Outline of Chapters

This subsection provides a brief overview of the contents of the chapters.

Chapter 1 Introduction: The introductory chapter provides the background against which this study was developed. The challenges in early intervention for children with hearing loss and the constraints faced by developing countries are introduced. Theoretical and empirical research is proposed as a solution to the problem.

Chapter 2 Early intervention for children with hearing loss: Present research regarding the current models of service delivery for early intervention of children with hearing loss is critically reviewed. Early identification methods are discussed. The WHO recommendations for developing countries are reviewed. This

chapter provides the theoretical underpinning for the empirical research.

Chapter 3 Research Methodology: Chapter 3 provides the methodology for achieving the aims of the study by describing the research design; the research criteria for sample selection; material and apparatus; research procedures for data collection and finally, data analysis and statistical procedures are described.

Chapter 4 Results and Discussion: This chapter presents the results of the study. Both quantitative and qualitative analyses of the results are provided. The research results are discussed and interpreted.

Chapter 5 Conclusions and Recommendations: In the last chapter, the results are integrated, an overview of this study is provided, and an early intervention programme for the children with hearing loss is proposed. A critical evaluation of the study is included. The chapter opens doors to future research and closes with a summary.

1.7 Conclusion

Socio-economic factors and health structure indicate that Mauritius, a small developing country, is ready to take on the challenge of Healthy People 2000 that is 'identification of hearing loss by 12 months of age'. However, according to ASHA [1989 p.82], identification programmes should be instituted only when all components are available to provide appropriate follow-up services to the infant and his/her family. The systems of intervention and follow-up must be in place before any screening

or identification process is implemented. This implies the importance of planning and co-ordination of early intervention programmes based on the needs and services available in the Mauritian context.

The context of the study is very important, as service availability and accessibility are **prime** considerations. The early intervention models from developed countries, though in the foreground, cannot be directly applied to any developing country. A variety of challenges exist in developing countries for example, financial constraints, limited human resources, [audiologists, speech-language pathologists, and other professionals involved in identification and follow-up of hearing impaired children], limited technology and lack of policies regarding children with hearing loss.

It may appear that identification and follow-up goals for Mauritius should be manageable as the population is limited and the geographical area is small but clinical observations indicate that children are identified late [later than the 12 months] and their follow-up is inconsistent and fragmented. It is a priority to document the current status of identification and follow-up process of children with hearing loss in Mauritius.

1.8 Summary

The introductory chapter provides an overview of the main theme of the study namely **early intervention of children with hearing loss**. The process involved in early intervention, early identification and timely follow-up of children with hearing loss is described. The rationale for this study is provided and the context



of the study, the small developing island of Mauritius, is described. Important terms are described in this chapter. The outlay of the 5 chapters of the study is described to orient the reader to the study.



CHAPTER 2

EARLY INTERVENTION FOR CHILDREN WITH HEARING LOSS

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2.1 Introduction

The main aim of this study is to describe the current status of intervention for children with hearing loss in a developing country, Mauritius. To achieve this aim, a literature review is carried out that can form the **THEORETICAL** basis for the empirical research to follow.

Mauk *et al* [1996] stated that the possibility of early identification, diagnosis and habilitation of children with hearing impairments is within reach:

- If we have appropriate understanding of the magnitude and consequences of hearing loss in children
- If we are able to learn from professionals' efforts in the early identification of hearing loss
- If we are able to evaluate and use emerging technologies appropriate to screen for hearing loss during the neonatal period
- If we are willing to develop collaborative uses of resources already in place.

This statement by Mauk *et al* [1996] provides a framework for the ensuing discussion.

Professionals in developed countries have carried out extensive research on the subject of identification and management of children with hearing loss and their findings are well documented. A literature review of the current early intervention programmes in

the developed countries will serve as a theoretical background to this complex problem.

Early intervention may be described as the provision of educational, therapeutic, preventive and supportive services for young children with disabilities and their families. Early infancy is the most effective time for a child to begin learning the foundation of language and communication, cognition and social interaction. Because of the enormous learning potential of infants [the critical period of learning being 0 to 3 years], **early intervention programmes** are critical for pre-lingual children with significant hearing impairment [Bailey, 1992, p.385].

Yoshinaga-Itano, [1998] states that children who are identified early and receive intervention prior to six months of age have significantly better receptive language, expressive language, personal social skills, receptive vocabulary, expressive vocabulary and speech production. These benefits also encompass the parents. According to her, parents of early-identified children report significantly less stress than parents of later-identified children. On the other hand, late-identified children have developmental language quotients, which remain 50% to 60% late for their chronological age throughout their early childhood period.

From the foregoing it is clear that to initiate early intervention and to minimise the negative consequences of hearing loss, all children with hearing loss must be identified as soon after birth as possible [Downs, 1994]. Early intervention is therefore a worthwhile goal.

2.2 Early Identification of Hearing Loss

Appuzzo and Yoshinaga-Itano [1995] reported the **benefits of early intervention** in a study based on 69 children with hearing loss participating in an early intervention programme. They divided the subjects into 4 groups **according to the age of identification**. Groups were reasonably similar with respect to age at the time of testing, degree of hearing loss and level of general development. The outcome data of the intervention was based on the parent report using the Minnesota Child Development Inventory. 14 of the children identified earliest [by 2 months of age] were functioning almost at the same grade level as normal hearing children while those identified latest [25 + months] were functioning at the lowest levels. This implies that for effective intervention and management **early identification** is the crucial first step.

The Healthy People 2000 document [1990] suggested reducing the average age at which children with significant hearing impairments are identified to no more than 12 months and recommended the use of high-risk indicators for hearing loss to target screening of new-borns. Based on the fact that technological developments have produced screening methods that are rapid, reliable, sensitive and easily administered, the National Institutes of Health [N.I.H.] Consensus Statement [1993] recommended Universal Neonatal Hearing Screening [U.N.H.S].

Table 2.1 highlights the most salient parts of empirical research findings and changes over time pertaining to early identification of hearing loss among children in USA. Two relevant studies from UK are cited in table 2.2. The tables are followed by a critical discussion of the research findings.



Table 2.1 Studies in USA pertaining to Identification of Hearing Loss among Children

*Key: H.L.=hearing loss H.A.=hearing aids E.I.=early intervention mths= months

AIM	AUTHOR /DATE	METHODOLOGY	RESULTS
To determine age of Identification of H.L. and provide baseline information	Moore et al 1991	Parents of 46 children with H.L. were interviewed by telephone in Oregon	Age of Suspicion of H.L: 22 mths Age of Identification of H.L.: 30.6 mths Age of placement of H.A : 38.7 mths
High risk birth screening and age of Identification of H.L.	Mauk et al 1991	Parents of 70 children between 6 and 9 years were interviewed in Utah	50% children had known high risk indicators Age of Suspicion of H.L: 9.9 mths Age of Identification of H.L.: 12.8 mths Age of Placement of H.A : 17.1 mths
To determine Age of Identification of H.L. as a function of severity of H.L.	Kile 1993	A survey over 25 years of 244 files of children with H.L.	Age of Identification of H.L. is inversely proportional to degree of H.L. Age of Identification of severe H.L. 20 mths Age of Identification of profound H.L. 16 mths
Early Identification and provision of E.I. services	Strong et al 1994	2768 children's survey in 10 states for severe H.L.	Age of Identification of H.L 18 mths Start of E.I. services 24 mths
To determine the ages of Suspicion, Identification and Intervention for Children with H.L.	Harrison and Roush 1996	National study by mail survey of 331 parents of children with H.L. from infancy to 5 years	Children with no high-risk indicators for H.L. [median ages] Age of Suspicion of H.L: 8 mths Age of Identification of H.L.: 13 mths Age of Placement of H.A : 16 mths Start of intervention: 16 mths Children with known high-risk indicators for H.L. Age of Suspicion of H.L: 7 mths Age of Identification of H.L.: 12 mths Age of Placement of H.A : 15 mths Start of Intervention: 16 mths

The salient features of two studies pertaining to ages of identification and referral process in UK are presented in table 2.2

Table 2.2 Studies in UK pertaining to Identification of Hearing Loss among Children

AIM	AUTHOR/ DATE	METHODOLOGY	RESULTS
Age of identification and referral process of children with H.L.	Davis and Wood 1992 cited by Bamford and McSporrin in 1995	Birth cohorts 1983-1986 of all children with severe H.L.	Median age of referral for hearing assessment 10 mths Identification of H.L. 12 mths Placement of H.A: 16 mths
To examine the effectiveness of Health Visitor Hearing Screening	O'Hare et al 1998	Records of all children with severe H.L from a 5 years cohort 1989-1994 in Lothian UK were studied. Number of subjects : 40	Age of Identification of H.L was 19 +/- 5 mths If high-risk neonatal hearing screening were available potentially 67.5% children could have been identified by 6 mths of age.

In table 2.1 and table 2.2 salient features of studies from USA and UK regarding early identification of hearing loss among children have been highlighted. Despite the aim of the various studies being different, the parameters described were similar that is determining the ages of identification of hearing loss, amplification and start of intervention.

The methodology applied for the studies had some flaws that affected effective data collection. Telephone interviews, mail surveys and files were used in some of the studies to obtain information. For example, in the Harrison and Roush study [1996], of the 1500 survey forms sent out, only 401 were returned and data from 331 could be analysed. Interviews are known to have a high response rate [Neutens and Rubinson 1997]; however, they are expensive to conduct. The final number of subjects was rather small in all the studies described. Despite the above shortcomings major positive outcomes of the studies need to be highlighted.

Mauk *et al* [1991] have shown that high-risk indicators can identify hearing loss earlier among children and have recommended more extensive use of high-risk registries in conjunction with more widespread education of parents and primary care providers regarding early behavioural indicators of hearing loss.

Harrison and Roush [1996] reported that when known high-risk indicators were present, hearing loss could be identified at least a month earlier. The median age of 12 months in their study is still late compared to the target set by Universal Neonatal Hearing Screening of identifying children with hearing loss in the neonatal clinic but the principle is probably sound.

Bamford and McSporrán [1995] pointed out that **early** should mean **as early as possible after birth**, at least for the more severe hearing losses. The U.K. and European studies demonstrate that Health Visitors Screening methods are widely employed in identification of hearing loss. Once a child can sit independently around 6 months of age, has a good head turning control, it is

possible to obtain reliable information about hearing levels from distraction techniques in behavioural tests. The health visitors were found to be the highest referral source for hearing evaluation. This was due to the fact that they undertake the routine hearing screening in the community [McCormick *et al* 1984]. A prerequisite for this method is that the country has an established health system that includes Health Visitor Screening for developmental sequences. The negative fact about using health visitors is that the children are usually identified only after 6 months. O'Hare, Green and Grigor [1998] concluded that there is a greater scope for early identification of hearing loss by introduction of the high-risk neonatal screening rather than improving health visitor screen. Their study revealed that health visitor screen method has poor coverage and that the number of false negatives referred for hearing evaluation is very high.

The current early identification of hearing loss implies a hearing screening process among infants and young children. Auditory deprivation during the first two years of life will have a lifelong impact upon the level of auditory language achieved [Hasenstab 1987]. For this reason, early identification of hearing loss as close to birth as possible is absolutely imperative. Depending on the context and health system in a country and depending on the financial, technological and human resources available any identification plan for children with hearing loss will have to plan an efficient **hearing screening programme** to ensure early identification and subsequent follow-up.

2.3 Follow-up of Children Identified with Hearing Loss

Bess and Paradise [1994 p.332] observed that “it is improper to screen for a disorder without certainty that facilities for suitable follow-up care for those who fail the test are both available and accessible”. They were concerned about the lack of professionals available for the follow-up services and the financial means of the family. Davis [1993 in McCormick p.6] suggests that screening programmes also need to have good and thorough audiological and educational service as a back up.

It can be concluded that early identification of children with hearing loss must be followed by a comprehensive plan of medical, therapeutic and educational management [Diefendorf *et al* 1990]. Gabbard *et al* of Marion Downs Centre for Infant hearing [1998] have described the follow-up after identification with an appropriate term ‘TRANSITION.’ Once the infant is detected with a hearing loss by any screening / identification method, preferably as early as possible, the transition for the hearing assessment is important. Studies have reported that even with good screening processes in place many infants and children are lost for follow-up to diagnostic procedures. A good example of this is the Utah high risk screen indicator identification programme which was discontinued due to the fact that only 50% of parents of children with risk indicators making appointments for follow-up and 50% of these not keeping their appointments [Mahoney and Eichwald 1987] for diagnostic procedures.

Diagnosis involves determining the type and degree of hearing loss and should include medical clearance from the otologist for audiological assessments. ASHA [1989] provides guidelines for

auditory testing of infants less than 36 months and cautioned that the use of any one test alone is to be discouraged. Corroboration of results from a given test should be sought using information gained from the case history, parents' comments, behaviour observation audiometry and of course electrophysiological tests.

Vesterager and Parving [1995] found that, once diagnosed, only about half the children in their study were fitted with hearing aids within the shortest possible interval [8 to 10 days]. Efforts towards early identification will have limited effect upon the development of the hearing impaired child if for a number of reasons there is additional delay in placement of hearing aids, or if the parent does not follow the recommendations for the use of the hearing aids. In 1996, "Amplification for Children with Hearing Loss", Paediatric Working Group, stressed the need for objective timely strategy for amplification for infants and children with hearing loss. The group recommended the provision of appropriate, reliable and undistorted amplification as a four-stage process involving assessment, selection, verification and validation. In order to ensure that the hearing aids will be used successfully a hearing aid orientation programme for the parents, teachers and other caregivers was also recommended. For young children, the need for follow-up at least once every 3 months during the first two years of using amplification was stressed. Facilities for repairs, servicing of hearing aids are equally important, otherwise the infants and children are left with long periods without hearing aids [Clark 1997].

Besides the placement of hearing aids, another important TRANSITION is from attention to the auditory aspect to communication therapy. Kentworthy, [1987 in Alpiner and

McCarthy p. 19] states that larger issues than just how to identify children with hearing loss typically confront the clinician. All children regardless of their hearing sensitivity face the formidable task of learning language. From the standpoint of identification, the disease of interest is not simply hearing loss but the complex problem of hearing impairment and language and speech delay. As Gatty [1996, p.7] asks, "What is known to be true about the relative benefits of different approaches to language acquisition and education when children do not hear normally? Parents query whether their child will be able to learn to speak or will have to use sign language for communication. There is little empirical data on the efficacy of early intervention programmes to help parents choose an appropriate programme for their child. In addition, political and social factors can influence the choices made by the parents and professionals regarding education of young children". Gatty [1996] concludes that there is no single approach that is appropriate for all children. Variables such as cause and degree of hearing loss, family resources and values and the child's capacities in all developmental areas are some variables that will have to be considered when choosing an effective **communication intervention** programme.

The choice of means of communication will in the final instance be dictated by the educational options available to the child. The debates whether children with severe hearing loss must be in special class, mainstreamed or integrated with normal hearing children are ongoing. Clark [1997] states that in many countries practical issues such as availability and accessibility to appropriate schools dictate the choice of educational system.

2.4 Early Intervention Programmes

Rossetti [1996] discusses the current early intervention service delivery models namely:

- Centre-Based: Group activities to provide consultation and training for parents and intervention services for the child in a **centre** where professional staff and technology are available.
- Home-Based Programmes: Provide support to parents, information, advice and materials. The child also receives direct intervention within the **natural home environment**.
- Home-Centre combinations: These combine programmes that include **centre-based child programmes and home visiting components**.

A model programme for successful early intervention for children with hearing loss is the SKI HI Programme [Glover *et al* 1994]. It was initiated in 1979 in Utah, USA, with financial support from US Department of Education and to date has been implemented all over the USA. The major goals of the SKI HI model are to identify children with hearing impairments as early as possible and to provide a family-centred, home-based programme. Two interesting features of this programme that have relevance for developing countries are that though no hearing screening is directly carried out, the programme stresses public and professional awareness and secondly, there is a training component for the parents and service providers.

The characteristics of the SKI HI Programme are:

- Public awareness and referral for hearing evaluation

- Diagnosis and assessment of the hearing loss
- Direct therapy for the child, including provision of hearing aids and ear moulds and communication intervention
- Complete home-based family support programme for families with infants, toddlers and pre-schoolers ages birth to 5 years who are deaf or hard of hearing

The rationale of this programme is that the home setting is the most consistent and natural educational setting for young children. Parents play a central role in the habilitative process. Meaningful daily experiences that are ideal for communication and language development happen in the home.

Strong *et al* [1994] studied the efficacy of the SKI HI Programme, based on data sheets of 2,768 children with a mean hearing loss of 75 dB. They concluded that:

- On an average, children included in the SKI HI programme were identified by 18 months of age
- The median age of starting the programme was 23 months
- These children had higher rates of language development during intervention than prior to intervention and had greater language gains than is expected by maturation alone.
- Of the 1404 children included in the SKI HI programme from 1986 to 1989 the largest percentage of these children were functioning in mainstream/integrated classrooms.

The study by Strong *et al* [1994] lacked details regarding the lapse of time from identification of hearing loss to placement of hearing aids, whether the programme was consistent for the subject sample and whether they considered the perspective of the parents regarding the efficacy of the programme. In other words, some of the important issues regarding efficacy of the SKI HI programme have not yet been answered.

Nevertheless it still seems to answer some important questions regarding the problem of early intervention for children with hearing losses.

Carney [1996 p.187] has questioned, “**what is precisely meant by early intervention?**” Is it initial fitting with a hearing aid? One cannot equate habilitation with hearing aids fitting only. If the only intervention used is device oriented and no programme of treatment accompanies it for a period of time, then early intervention cannot be assumed to have begun. The habilitation process such as information to parents identification of resources available in the community are important components in the management process of infants with hearing impairments. Early intervention also includes the beginning of communication intervention. Family involvement issues are very important aspects of intervention. Does this begin at the time of identification of hearing loss or the time when they enrol in a programme? Carney [1996] summarises **early intervention** as an umbrella term inclusive of identification of hearing loss, placement of hearing aids followed by communication intervention and education with parent-professional partnership throughout the early intervention programme.

2.5 Focus on Early Intervention for Children with Hearing Loss in Developing Countries

All the relevant research studies have the consensus that early intervention is the only viable approach for children with hearing loss. The successful early intervention models for children with hearing loss stress that **early** is the key to a successful habilitation programme for children with hearing loss.

The World Health Organization [WHO] has been involved in prevention and management programmes for hearing impaired persons in developing countries. Under its auspices various symposia and meetings have been held to address the problem of hearing impairment. Among these are:

- The South East Asia Regional meeting in India [1991], to formulate guidelines for the management of programmes for prevention of deafness;
- The Regional office for the Western Pacific meeting in the Phillipines [1994] for prevention of hearing impairment and deafness;
- The prevention of hearing impairment in Africa held in Congo [1995];
- International Symposium on Deafness and Hearing impairment in developing countries held in Manchester, U.K. [1995];
- Future Programmes for Prevention of Deafness and Hearing Impairments in Geneva [1997].

These meetings organised by WHO in various regions and over time indicate the commitment of the WHO in prevention and management of persons with hearing loss globally.

Following is a brief review of the two of the most relevant 'symposia'. The recommendations are summarised in Table 2.3.

Table 2.3 Highlights of two symposia organised by WHO

NAME OF SYMPOSIUM	AIMS	OUTCOME AND RESULTS
Formulation of Guidelines for Management of Programmes for the Prevention of Deafness India 1991	<ul style="list-style-type: none"> • To review the existing status of hearing impairment • To prepare guidelines for Management of National Programmes 	<ol style="list-style-type: none"> 1. Priority is to identify prevalence and epidemiology of H.L. 2. High priority to programmes for children with severe pre-lingual hearing loss 3. Preventive measures such as Immunisation Programmes 4. Strengthening of otological services and referral system to specialised services
International Symposium on Deafness and Hearing Impairment in Developing Countries Manchester 1995	To discuss 5 themes <ul style="list-style-type: none"> • Epidemiology • Screening • Prevention • Human Resource Development • Community Development <p>With 4 cross cutting issues namely: research needs, health education, service provision and regional variations</p>	<ol style="list-style-type: none"> 1. Lack of data in developing countries therefore research is required 2. Necessity of Immunisation Programmes for prevention of deafness and hearing impairments 3. Constraints such as lack of human resources, technology and finances identified in developing countries 4. Proposal for an organising body at National Level to implement Hearing Screening and training of community health workers

The main constraints [Amin, 1995] identified in the various symposia for early identification of hearing loss in developing countries are financial, technological and manpower constraints and constraints on the **management side** for children with hearing loss resulting from:

- Non availability of hearing aids
- Lack of facilities and non availability of spare parts to repair hearing aids
- Non availability of modern equipment to provide language therapy and education to the pre-lingual and pre-school children
- Shortage of schools for special education
- Shortage of teachers for special education
- Non availability of speech therapists or any form of communication pathology
- Non availability of trainers for training the teachers for the deaf.

The implications of these constraints are that any proposal for early intervention programme must take into consideration the current status of identification and follow-up programme in the specific country. The availability of funds, technology and human resources will form the base of the intervention programme.

2.6 Conclusion

The basic and most immediate goal for all children with hearing loss must be early detection followed promptly by appropriate intervention. Besides the support of professionals, parents have an important role and should be active participants in the detection and intervention process [Diefendorf *et al* 1990].

Research has shown that screening children with high-risk indicators, will identify only 50% of the children with hearing loss and as 50% of the children with hearing loss do not exhibit any high-risk indicators universal hearing screening should be the goal. Where home-based behavioural screening is done [in UK], it demands an expensive infrastructure. Also it seems to be not as effective as Universal Hearing Screening Programmes. In order to substantially reduce the age of identification of children with hearing loss, Universal Neonatal Hearing Screening [UNHS] should be targeted [N.I.H. consensus, 1993]. Because of the unique accessibility of almost all infants in the new born nursery, the screening of all new born infants both high and low risk, for hearing impairment prior to hospital discharge was recommended.

It is equally important to have a back up system for diagnostic evaluation service [Bess 1993]. This is lacking in developing countries where there is either very limited or no technology for screening at birth. Moreover, a good audiology back up service where infants identified can be referred for follow-up is also lacking.

Dependable hearing aids with high fidelity sound and appropriate to the child's hearing loss must be fitted. The habilitation for development of language, speech and communication should be

initiated simultaneously with the fitting of hearing aids [Marlowe 1993]. In the developed countries hearing aids are easily available and the cost can be borne by the individuals as well as social aids and insurance reimbursement possibilities exist. Besides, hearing aids maintenance and services are available, so much so that, this aspect of management in developed countries is taken for granted. In developing countries this can be a major issue and can cause major constraints in the intervention process of children with severe hearing impairments as pointed out by the experts in the WHO/CBM workshop [1998].

Parent-professional partnerships and home-based intervention have proved to be very successful early intervention models particularly in the USA. For developing countries this would mean diminishing the direct therapy caseload for the professional in the centre-based model. It appears to be a suitable alternative in developing countries where there is scarcity of professionals and their time is divided with other variety of cases. However, initially training programmes for the parents will require more planning and time to build the parent networks. Community-based rehabilitation workers or community health workers could also be trained to identify and refer early infants and children where hearing loss is suspected. These human resources have to be identified in the local context.

From the literature review for various developing countries, it was noteworthy that the needs and recommendations for most developing countries in Asia, South Pacific and Africa were similar. As there is considerable ignorance of the true size of the problem together with a lack of awareness of the possibilities of prevention and uncertainties about the most appropriate methods of

rehabilitation, the priority identified by WHO experts for developing countries, was **promoting research** to assess the most appropriate intervention strategies. However, to plan these strategies so that all the children born with severe hearing loss receive the same care and standard of service [equity] it is very important to study from the parents' perspective the intervention process for children with hearing loss.

Empirical data pertaining to the current intervention process in a developing country will be researched in this study. The theoretical research indicates the following parameters to describe the intervention process:

- Identification process of hearing loss
- The age of the placement of hearing aids and
- The medical, therapeutic and educational follow-up.

With a strong theoretical background [as discussed in this Chapter] and empirical research data from a developing country, an early intervention programme for children with hearing loss on a national basis can be proposed.

2.7 Summary

To initiate early intervention and minimise the speech and language delays associated with it; all children with hearing loss must be identified as soon after birth as possible. Empirical research pertaining to how early identification goal is achieved and the age of identification of hearing loss in developed countries were reviewed critically.

Once the hearing loss is identified, hearing aids must be fitted as quickly as possible, preferably within a few weeks of the time the loss is identified. Therapy must begin right from the time of identification of hearing loss [Madell 1995 in Blackman p 11]. The empirical findings pertaining to age of fitting of hearing aids were reviewed. The follow-up subsection described the current views on communication and education for the children with severe hearing loss.

Literature pertaining to intervention programmes in developing countries is scarce, as not much research has been carried out. The objective of the WHO Programme for the Prevention of Deafness and Hearing Impairment [1991] is to eliminate avoidable hearing impairments through appropriate preventive and curative measures. The outcome of the regional meetings organised by the WHO has been a documentation of the constraints in developing countries. The constraints to early intervention programmes are similar for developing countries in Asia, Africa and the South Pacific.

The current trend in developed countries is to view **early intervention** for children with hearing loss as comprising early identification of hearing loss and professional-parent partnerships for the maximum development of the child's potential despite the hearing loss. Public awareness and well informed parents regarding hearing and speech development have proved very valuable in improving the efficacy of early intervention for infants and children with hearing loss. In developing countries, despite various constraints that were discussed, an **early intervention** programme must be visualised and targeted.