



IDENTIFICATION AND FOLLOW-UP OF CHILDREN WITH HEARING LOSS IN MAURITIUS

BY

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SUMMARY

TITLE: IDENTIFICATION AND FOLLOW-UP OF CHILDREN WITH
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Early identification of hearing loss followed by a timely and effective intervention programme for children with hearing impairment is necessary to minimise the negative effects of hearing loss on the development of cognition, psychosocial and verbal communication skills. Such early intervention programmes need to be multidisciplinary, technologically sound and take cognisance of the context in which the child and family function.

The main aim of this study is to obtain accurate and reliable baseline information regarding current status of the intervention process for children with hearing loss in Mauritius, a developing country. An exploratory, descriptive qualitative research design is selected to achieve this aim. Questionnaire-based interviews were carried out to obtain information from 37 hearing impaired children's parents regarding the median ages of suspicion of hearing loss, diagnosis and placement of hearing aids. The referral

process, diagnosis and the management of these children is described.

The findings indicate that children in the study were identified late [median age 24 months] and that the management process is fragmented. The strengths in the current identification and follow-up process namely, parental involvement and established public service structure are highlighted. The weaknesses in the current system are identified, for example, time lapses in identification process, provision of hearing aids and lack of co-ordinated services.

The theoretical and empirical research carried out forms the basis of recommendations that have practical implications for an early intervention programme for children with hearing loss in Mauritius.

Key words: Pre-lingual hearing loss; Prevention; Screening; Age of suspicion of hearing loss; Early intervention; Age of diagnosis of hearing loss; Management of hearing loss; Mainstreaming; Communication skills.



OPSOMMING

Vroeë identifiekasie van gehoorverlies gevolg deur 'n tydige en effektiewe intervensieprogram by kinders met 'n gehoorverlies is noodsaaklik om die negatiewe invloed van gehoorverlies op kognitiewe ontwikkeling, psigososiale en verbale kommunikasievaardighede so gering as moontlik te maak. Sodanige vroeë intervensieprogramme moet multidissiplinêr en tegnologies weldeurdag wees en moet die konteks waarbinne die kind en sy gesin funksioneer in aanmerking neem.

Die hoofdoel van hierdie studie is om akkurate en betroubare basislyninligting in te samel oor die huidige status van die intervensieproses by kinders met 'n gehoorverlies in Mauritius, wat 'n ontwikkelende land is. Om hierdie doelstelling te bereik is 'n Onderzoekende, beskrywende kwalitatiewe navorsingsontwerp is gekies. Onderhoude gebaseer op vraelyste is uitgevoer om inligting te verkry van die ouers van 37 kinders met gehoorverlies. Die inligting het sentreer rondom die gemiddelde ouderdomme waarop gehoorverlies vermoed is, diagnose en passing van gehoorapparate. Die verwysingsproses, diagnose en behartiging ten opsigte van hierdie kinders word beskryf.

Die bevindinge dui aan dat die kinders wat by die studie betrek was, laat geïdentifiseer is (gemiddelde ouderdom 24 maande) en dat die behartigingsproses gefragmenteerd is. Die sterk punte in die huidige identifiekasie- en opvolgproses word uitgelig en die swak punte word geïdentifiseer. Die teoretiese en empiriese navorsing wat uitgevoer is vorm die basis vir aanbevelings wat praktiese



implikasies het vir 'n program van vroeë intervensie by kinders met 'n gehoorverlies in Mauritius.

Sleutelwoorde: Prelinguale gehoorverlies; voorkoming sifting ouderdom waarop gehoorverlies vermoed word; vroeë intervensie; ouderdom waarop gehoorverlies gediagnoseer word; behartiging van gehoorverlies; hoofstroming; kommunikasievaardighede.

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CHAPTER 1

ORIENTATION AND STATEMENT OF THE PROBLEM

CHAPTER 1 ORIENTATION AND STATEMENT OF THE PROBLEM

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.

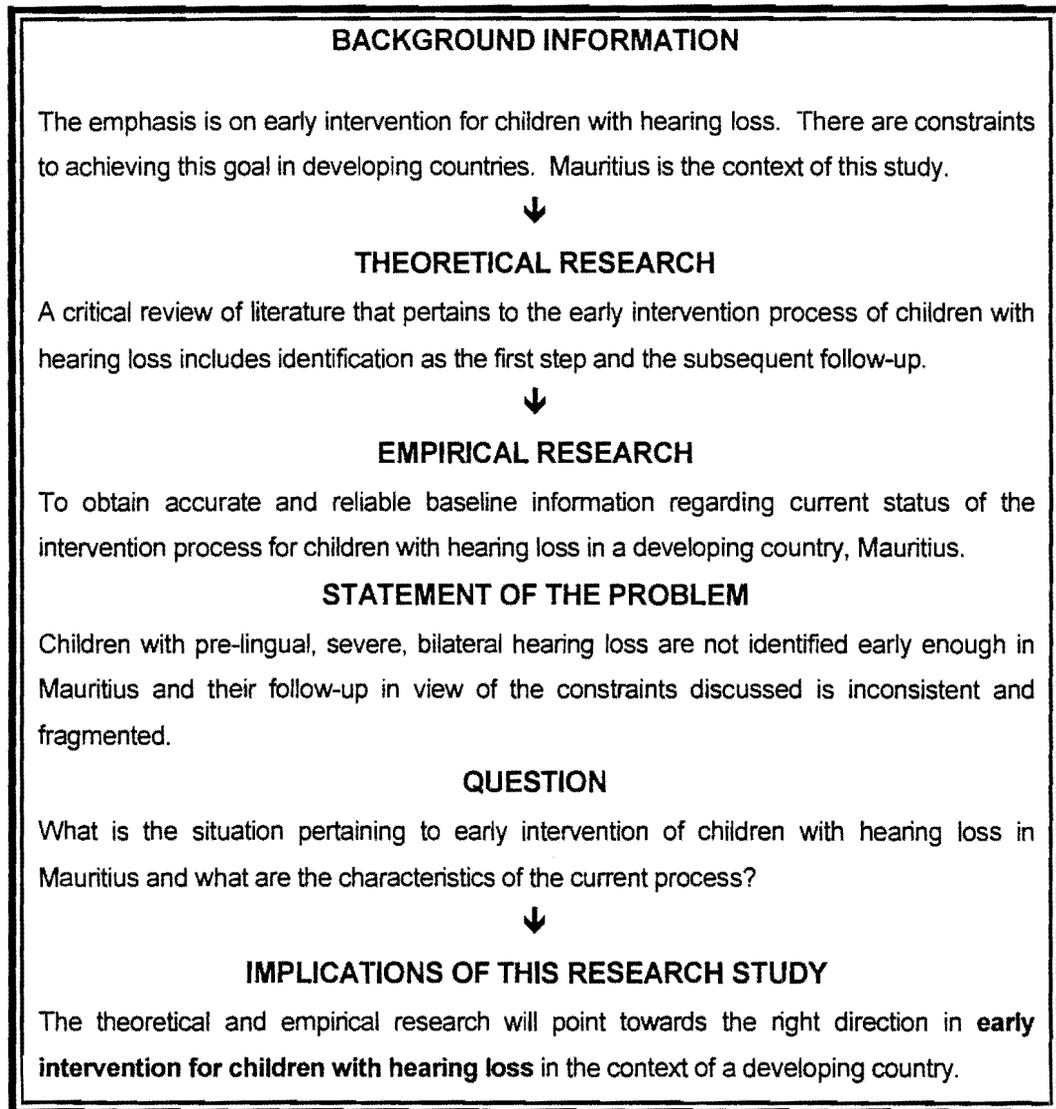


FIGURE 1.1 Central Components of this Study

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

CHAPTER 2 EARLY INTERVENTION FOR CHILDREN WITH HEARING LOSS

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.



CHAPTER 3

RESEARCH METHODOLOGY

CHAPTER 3 RESEARCH METHODOLOGY

3.1 Introduction

There are many constraints to early intervention for children with hearing loss in developing countries. Moreover, literature pertaining to prevalence, epidemiology and intervention of children with hearing loss in developing countries is limited. This lack of scientific knowledge has made it difficult for developing countries to plan and implement national programmes for early intervention of children with hearing loss.

From the theoretical background [Chapters 1 and 2], it appears that in developing countries the priority for children with hearing loss is to plan and implement early intervention programmes. To propose and implement an effective early intervention programme, it is first necessary to describe the current status of identification and follow-up of children with hearing loss. The most important parameters that describe early intervention for children with hearing loss are the age of identification of hearing loss, age of placement of hearing aids and the subsequent medical, therapeutic and educational follow-up [Carney 1996].

The theme of this study is early intervention for children with hearing loss and the context is a small developing country, Mauritius. The appropriate research question posed is **“How are children with hearing loss identified and what is the subsequent follow-up?”** In order to provide an answer to this question empirical research was undertaken. The aim of this chapter is to describe the research methodology employed to answer the aforementioned research question.

3.2 Aims of the Study

The main aim of this empirical research is to **describe the current identification and follow-up process for children with severe hearing loss in Mauritius**. The current early intervention models tend towards parent-professional partnership [Laughton, 1994] therefore, **parents' perspective** regarding current intervention process will be studied. In order to achieve the main aim, the following sub-aims are formulated:

- Determining the high-risk indicators for hearing loss that are present among the children with hearing loss
- Determining the age of identification and describing the identification process
- Describing the diagnostic process in terms of age and acceptance by parents
- Describing the management process followed with the children after diagnosis of hearing loss
- Determining whether relationships exist between certain aspects of the biographical data and the results obtained.

3.3 Research Design

A qualitative research design [Leedy, 1997] was selected to describe, explain and interpret the emerging patterns of identification and follow-up of children with hearing loss. The type of research design chosen depends on:

- The nature of the problem
- The knowledge already available
- The resources available for the study

[Varkevisser *et al* 1991].

The problem in the current study concerns a homogeneous group of hearing-impaired children with severe pre-lingual hearing loss, in Mauritius. There is a dearth of information regarding how these children are identified and what their follow-up is. Therefore, an **exploratory, descriptive, qualitative research design** was selected. An exploratory study is a small-scale study, which is carried out when little is known about the problem. A descriptive study involves the systematic collection and presentation of data to provide a clear picture of a particular situation. In descriptive studies the information is collected from a sample and the findings are often used to make conclusions about the population [Varkevisser *et al*, 1991].

According to Leedy [1997] the purpose of a **qualitative research design** is to describe, explain, explore, interpret and then to develop theory. The qualitative research process is holistic and "emergent" with the specific focus, design, interview instruments and interpretations developing and changing along the way. The method selected for the data collection was a **survey research design** that involves describing the characteristics of a group by means of instruments such as interview schedules and questionnaires. Survey research ultimately aims to solve problems through interpretation of data that has been gathered [Leedy, 1997]. The data collected in the current study will be analysed, interpreted and inferences will be made based on the findings.

3.4 Research Sampling Procedure

Carney [1996] points out that children with hearing loss form a heterogeneous group and it is important to define the subgroup under consideration. To answer specific questions a homogeneous sub-population must be selected. The characteristics that need to be considered when choosing samples of participants include:

- degree of hearing loss;
- presence of other handicapping conditions;
- socio-economic status;
- native language of the family;
- location of dwelling [urban or rural];
- hearing status of the parents of the child [hearing or deaf];
- general population factors.

These variables must be accounted for when carrying out empirical research for children with hearing loss [Carney, 1996].

Before proceeding with data collection, a subject selection criterion was formulated. The following provides the underlying motivation for the selection criteria and how the research selection procedure was activated.

3.4.1 Consent from Authorities

Permission was requested from the Ministry of Health and Quality of Life, to use the Audiology and Speech Therapy Unit Records for sample selection [see appendix A].

3.4.2 Selection Criteria

The following criteria for the selection of subjects were formulated.

♦ **Children who are under 10 years of age**

Children less than 10 years were selected for this study. Generally early intervention refers to programmes for infants and toddlers particularly in pre-school years [Bench, 1992]. However, in this study the upper age [10 years] became a factor because if the cut off point were limited to less than 5 years, then those children who are identified late in Mauritius would be passed over and subsequently, the analysis of data would give a false picture of the age of identification of hearing loss.

♦ **Children identified with hearing loss within the period, January 1996 to December 1998 [Sample Frame]**

The sample frame for this study was a period of three years spanning from January 1996 to December 1998. Records before January 1996 were not considered, as that would imply relying on parental memory of events, which might be blurred. The aim of this study was to describe not only the identification but also the follow-up process, therefore records after December 1998 were not included. Another reason for the stipulation of the time period was to try to ensure that the parents had overcome their initial shock and emotions regarding the diagnosis of a hearing loss in their children and were able to participate in the study in a meaningful manner.

♦ **Children with severe bilateral sensori-neural hearing loss**

[Greater than 70 dB in frequency .5KHz 1KHz and 2KHz in both ears, Katz 1978]. This criterion was set to ensure that the children selected were a homogeneous group with pre-lingual severe bilateral hearing loss. Research by Kile [1993] has shown that severe hearing loss and age of identification are inversely proportional. Therefore this type of hearing loss should be detected early and the subsequent follow-up should be timely to avoid the negative consequences of late identification and intervention.

Children with conductive hearing loss were not included, as this type of hearing loss is amenable to medical treatment. The identification and management needs of children with unilateral, mild and moderate hearing loss are different from those of children with severe sensorineural hearing loss [Bench, 1992], therefore, they were not included in the sample. The selected sample was a homogenous group of children regarding the degree and type of hearing loss. This enabled the control of the variable inherent in different types and degrees of hearing loss.

♦ **Children with pre-lingual hearing loss.**

To be included in the present study a pre-lingual hearing loss was a criterion as the aim was to determine the age of identification in children with homogeneous hearing loss. Pre-lingual hearing loss is defined as hearing loss that is present in a child before language and speech develop [Bench, 1992]. To develop verbal language children must be exposed to speech in their first 2 years of life [Bench, 1992 p.23] hence, children who are pre-lingually hearing

impaired do not develop verbal experience over the language-critical years unless their hearing loss is identified early and intervened with early use of amplification.

◆ **Children with no other disability besides hearing loss**

Children with multiple handicaps were not included in this study as their identification process and follow-up needs are different from children with only a hearing loss [Bench, 1992].

The sample selected must be as representative of the total population as possible [Leedy, 1997]; therefore, the following characteristics of the children namely gender, family background, and socio-economic status and educational background of parents were not considered as delimiting factors.

3.4.3 Subject Selection Procedure

The following procedure was followed for the selection of the subjects.

Study of Hospital Records

In Mauritius, the Ear Nose and Throat [E.N.T.] hospital and the Audiology and Speech Therapy services are centralised. The hospital records can therefore be considered to be a national database. The Audiology and Speech Therapy Unit provides a service to all referred cases with communication disorders. A **new case register** is maintained in the Audiology and Speech Therapy Unit where records of all referred cases for communication disorders are kept. These referred cases include children and adults referred from the public and private sector. In this new

case register, the following information is routinely noted when a patient is first referred:

- Case Number
- Date of registration
- Name
- Address and Telephone number
- Date of Birth
- Referral Source
- Diagnosis.

The new case register in the Audiology and Speech Therapy Unit included children with varying degrees and type of hearing loss. From the sample frame January 1996 to December 1998 a total of 65 children were selected in the first “sample list” with reference to the selection criteria.

Study of Medical Records

The records of the children were studied and on the basis of the following information some were excluded:

- 10 children with bilateral moderate hearing loss
- 5 children with multiple handicaps were eliminated, as they did not meet the selection criteria.
- Further study of the remaining 50 medical records revealed that two children had a post-lingual hearing loss. These two were also eliminated from the sample.



- The final sample list therefore included **48 children** meeting the selection criteria. **Voluntary participation and consent from the parents**, who will now onwards be referred to as **respondents** was sought before commencing the study.

3.4.4 Research Sample

The research sample determined by the selection criteria and procedure finally included 48 children as shown in figure 3.1



RESEARCH SAMPLE CHARACTERISTICS

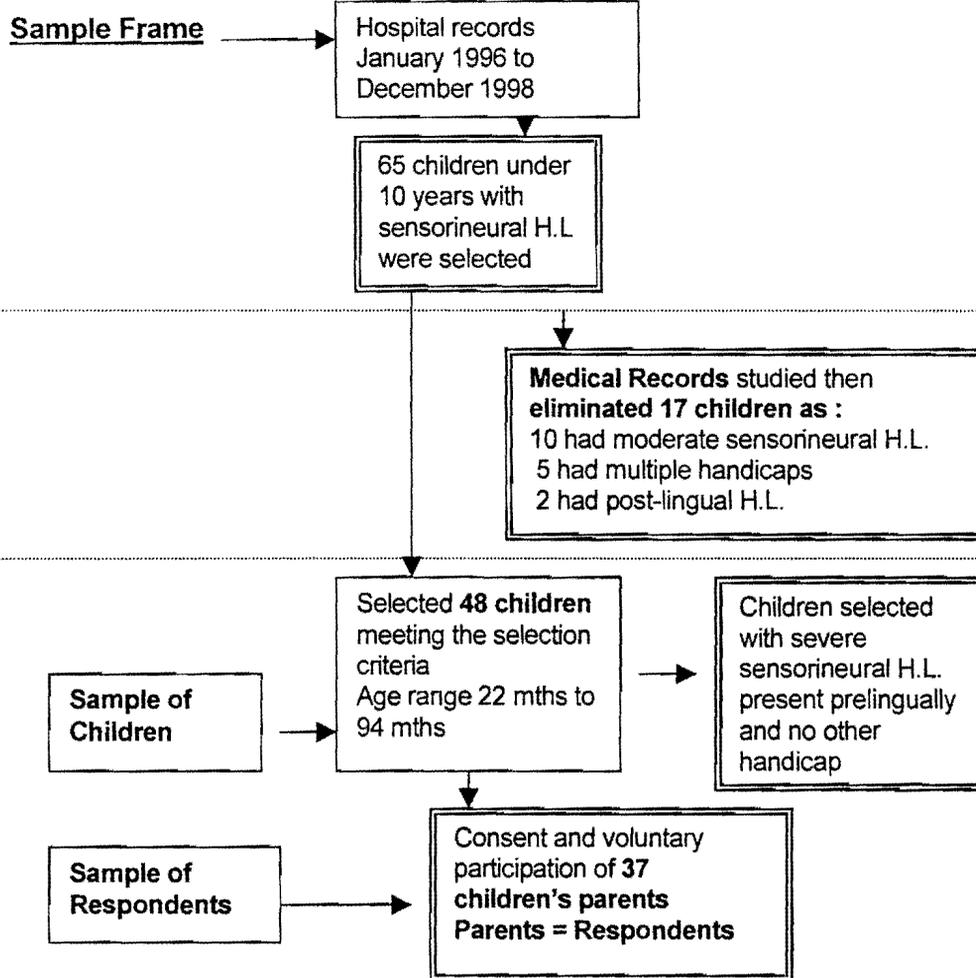


Figure 3.1 Research Sample

3.4.5 Description of the Subjects

In this section the subjects involved in the study will be described in terms of the following groups:

- A. Children selected in the sample
- B. Respondents
- C. Interviewer and the rater.

A. The children selected for this study

In all 37 children were selected for the study. All of them met the selection criteria as set out in 3.4.2. Table 3.1 provides a summary of the children's background characteristics.

Table 3.1 Background of the children

Region/ Gender	Urban N.	Rural N.	Total N.	%
Male	13	11	24	64.9
Female	4	9	13	35.1
Total	17	20	37	100
%	45.9	54.1	100	

Table 3.2 Number of children in the family and position of the child with hearing loss

Number of children in the family

Rank	1	2	3	4	5	Total
1 st	8	5				13
2 nd		18				18
3 rd			2	1		3
4 th				2		
5 th					1	
Total	8	23	2	3	1	37

B. Description of the Respondents

The characteristics of the respondents are summarised in tables 3.3, 3.4 and 3.5.

Table 3.3 Respondents

Respondent	N.	%
Both Parents	17	46.0
Mother	16	43.2
Father	2	5.4
Other	2	5.4
Total	37	100

Table 3.4 Educational background of the parents

Parent/ Level	Mother	Father	N.	%
Primary	18	15	33	44.6
Secondary	17	21	38	51.4
Tertiary	2	1	3	4.1
Total	37	37	74	100

Table 3.5 Income of the parents

Monthly Income in Rupees	N.	%
Upto 5000	23	62.2
5000-10000	10	27.0
10000-20000	2	5.4
20000 and over	2	5.4
Total	37	100

These tables indicate that the majority of the respondents in the sample were represented by both parents, 46%, followed by mothers 43%. This indicates that the families were motivated and involved in the study. Only one respondent was the grandmother of twins selected in the sample as both parents were hearing impaired.

The educational background indicated that the majority of the parents had at least primary education. From the income ranges it was clear that a large majority belonged to the low-middle income group. The respondents were representative of the population of Mauritius.

C. Description of the Interviewer and Rater

The research methodology involved questionnaire-based interviews. The characteristics of the interviewer and the rater are described.

Interviewer: As the interviewer was both the audiologist and speech therapist with whom the respondents followed therapy for their child with hearing loss, she had good rapport with the respondents. The interviewer, also being the researcher, took specific care not to let any subjective bias distort the data. Though, Leedy [1997, p.28] states “..data in descriptive survey research are particularly susceptible to distortion through the introduction of bias into the research design”; in this study to safeguard data from the influence of bias, the questionnaire was filled out by an independent rater based on the audio-cassette recordings of the interviews conducted.

Rater [also referred to as the research assistant]: The rater was a Nursing Officer. The research assistant has experience in working with persons with hearing impairments, hence she was expected to understand the subject for example: hearing aid placement, medical follow-up and habilitation. The research assistant listened to every tape recording and independently filled out the questionnaire. These survey forms filled out by an independent listener were used for data analysis.

3.5 Material and Apparatus

The following material and apparatus was used to carry out the survey research:

- hospital and medical records for subject selection and verification of the information;
- questionnaire on which the interview of the parents was based;
- audiocassette recordings of the interviews.

Table 3.6 depicts the material and apparatus used.

Table 3.6 Material and Apparatus

Material	Use of Material
Hospital and Medical Records	For subject selection and to verify information provided by the respondents
Questionnaire	To obtain information from respondents regarding current status of identification and follow-up for children with hearing loss in Mauritius.
Apparatus	Use of Apparatus
Tape Recorder [National] with external Sony Microphone	To record the interviews. This was used to check reliability of the questionnaire-based interview. The external microphone was used for high fidelity recordings.
Audiocassettes 60 minutes each	Each respondent's interview was audio tape recorded

The material and apparatus will be discussed in the following sections.

3.5.1 Medical Records

Hospital records were used to select the sample initially and to verify parental information. They were used also as background information and when required, used to assist parents recalling of ages and dates since exact dates of registration, evaluation of hearing and hearing aids placement on the children were recorded in the medical records of the subjects. Parents remained the primary source of information throughout the interview.

3.5.2 The Questionnaire

The survey research design involved compiling a questionnaire which, was used as a basis for the interviews to seek relevant information.

A. The primary **aim** of the questionnaire was to determine from the parents' perspective the identification and follow-up process of their children with hearing loss. They were believed to be the primary source of information as they are with the child throughout the pre-diagnostic, peri-diagnostic and post-diagnostic period.

The questionnaire is provided in Appendix B.

B Format of the questionnaire: It mainly included closed questions. Neutens and Rubinson [1997] suggest that closed questions are easy to answer, code, score and reduce subjective bias during the interview. They require the respondent to choose an answer from amongst a list provided. But as the aim was to describe the intervention process from the parents' perspective, it was necessary to add open questions so that they could provide information that they considered relevant and important. The questionnaire had 10 main sections and subsections to probe information relevant to describing the intervention provided to their child with hearing loss.

C. The language of the questionnaire was English. Although the Mauritian dialect is Creole, it does not have a written script; thus, the questionnaire was prepared in English. However, the questions were asked in Creole in the same manner to all the participants in the study to ensure reliability and facilitate easy communication with the respondents. The responses were noted on the questionnaire in English.

D. Contents of the Questionnaire : The questionnaire consists of 10 sections which are discussed as per the main headings.

Section 1: Identification of children and Section 2: Identification of parents, and their subsections describe the identity and biographical information of the children and the respondents. These variables influence the problem indirectly [Cone & Foster, 1993] and the child with a hearing loss has to be viewed in the context of his/ her family background. This information will provide a realistic base for the planning of family-centred programmes.

Section 3: Family history of hearing loss and Section 4: Perinatal /Medical history of the children and the subsections were concerned with the high-risk indicators and whether an indication of the cause of hearing loss could be obtained from the parents. The high-risk indicators for hearing loss as listed in JCIH [1994] were used as a checklist in the questionnaire. [Refer to appendix C]. This information provided an indication of parental awareness regarding the possible cause of their child's hearing loss. This list could indicate, for preventive measures of hearing loss, the most common causes of hearing loss in the sample. This information could also be useful in early identification of hearing loss by identifying children who need to be screened for hearing loss.

Section 5 probed information regarding the **identification of hearing loss**. The age of suspicion of hearing loss by the parents indicates the approximate age at which they were concerned about their child's hearing. This indicates how aware the parents were regarding auditory behaviour. The referral process the parents

took before being referred to the Audiology and Speech Therapy Unit for hearing assessment will indicate:

- the persons whom the parents first contacted and
- the persons who referred these children for hearing evaluations.

This information can be utilised when planning programmes for public and professional awareness of hearing loss. The lapse of time from the suspicion of a hearing loss by the parents to the confirmation of the hearing loss is a good indicator of how well the services are co-ordinated and how effective they are.

Section 6 covered information pertaining to the **diagnosis of the hearing loss**. It was important to determine whether there were any delays in the diagnosis of the hearing loss after the child had been referred to the Audiology and Speech Therapy Unit for hearing assessment. Parental acceptance of the diagnosis of hearing loss was explored indirectly by asking the parents whether they had sought a second opinion. This information may indicate whether parents were not convinced about the diagnosis of the hearing loss and subsequently sought a second opinion.

Section 7 probed information regarding the core of habilitation for children with hearing loss that is **placement of hearing aids**. Information was sought regarding who provided the hearing aids. The time lapse from the time of the hearing assessment to the placement of hearing aids was determined. These questions indicated whether follow-up after the diagnosis of hearing loss was prompt or whether the parents had to wait for long periods for the child to be fitted with hearing aids. An additional question pertaining to the acceptance of the hearing aids by the child

indicated whether the hearing aids were effectively utilised for communication development.

Section 8 was formulated to obtain information regarding the **follow-up** of children with severe hearing loss and to determine the type of information that was given to the parents. It is considered important that a team for follow-up sees these children, and the E.N.T. specialist forms an integral part of that team [Diefendorf *et al*, 1990]. Information regarding the medical follow-up and habilitation for communication in the Audiology and Speech Therapy Unit was probed. It has been documented that once infants and young children are fitted with hearing aids they must be seen at least once every 3 months for a period of two years [Paediatric Working Group, 1996]. These follow-up sessions for the checking of hearing aids, monitoring of hearing levels of the child and providing support to the parents, indicate the efficiency of service provided to the child and the parents during intervention. A question was also included regarding the means of communication used by the child.

The aim of **Section 9** was to seek information regarding the **educational system** that these children were following. It was particularly important to find out which educational choices were available for children with hearing loss. This information could also be useful in planning early intervention services.

Section 10 included open-ended questions. It was deemed important that parents have the opportunity to add pertinent information to the closed questions. Erwee [1996] states that open ended questions require the respondent to provide their own answers. The answers to the open questions can provide the

researcher with new insights, side comments and explanations, and therefore these were included in the questionnaire.

3.5.3 Apparatus

All interviews were recorded on tape from a desk model National Audiocassette Recorder that had a counter. An external Sony microphone to ensure high fidelity recordings and 60 minutes Sony cassettes were used to record each interview.

The purpose of these recordings was two-fold: Firstly, all information, particularly pertaining to the open questions could be replayed and secondly, an independent listener [the rater] could listen to all the recordings and complete the questionnaires independently for reliability of information noted by the interviewer.

3.6 Pilot Study

3.6.1 Aim: A pilot study was carried out on the questionnaire before being used. Leedy [1997 p.199] states, "The questions for the interview should be as carefully planned and as carefully worded as the items in the questionnaire. Furthermore, they should be pilot tested, to ensure that the questions are clear, precise and free from bias."

3.6.2 Material and Apparatus: depicted in table 3.6 were used in the pilot study to verify their reliability and validity for use in the final study.

3.6.3 Procedure: Respondents who met the selection criteria were not chosen to complete the pilot questionnaire as this would

diminish the small sample size. Two subjects however, met the selection criteria of the study except for:

- Degree of hearing loss [the subjects selected had moderate hearing loss which warranted use of hearing aids].
- Falling on the periphery of the defined time frame [January 1996 to December 1998] for selection.
- The questionnaire-based interview was carried out on one subject exactly as planned for the main study. After this the questionnaire was reworded and modified for the pilot test on the second subject.

3.6.4 Results: It was concluded that:

- The questionnaire format and content was clear;
- The interview time was approximately 30 minutes;
- The Audiology and Speech Therapy Unit was found to be a suitable place for the interviews as it was convenient for the parents who have been following therapy at this venue;
- The recording of the interview went smoothly and parents did not appear to be self conscious about the interview being recorded.

Following these two pilot tests it was decided that the data collection procedure for the research sample could proceed.

3.7 Data Collection Procedure

3.7.1 Consent from Parents

- Letters were posted requesting the parents of the 48 children selected, to attend a meeting at the Audiology and Speech Therapy Unit, E.N.T Hospital. This venue was selected, as the parents are familiar with the Unit where their children follow therapy. The letter also gave the parents an option of making another appointment if they could not attend the meeting. [See Appendix D, Parent Invitation]. Parents of 28 children attended this meeting.
- Meeting parents of the selected children. During the meeting the researcher addressed the parents in the local dialect, Creole. They were given a brief background of the purpose of the study and the nature of questions they would be asked. The parents were informed that their participation involved giving an interview of approximately 30 minutes during which they would answer the questions, as set out in the questionnaire. They were then assured of confidentiality. Copies of the questionnaire were circulated to the parents and the data collection procedure was explained to them. It was also explained that the information provided by them would be tape-recorded and the answers to the questionnaire would be used exclusively for the purpose of this study. The interview would be organised at a mutually convenient time in the Audiology and Speech Therapy Unit, which the parents are all familiar with. They would be informed of the results of the study and the researcher would reimburse their travelling expenses.

- **Signing Consent Forms:** At the end of this preliminary meeting, parents were advised to make an appointment for the interview if they agreed to participate in the study. They were also assured that there was no compulsion for them to participate. They were requested to sign the consent form if they agreed to participate in the study. [Refer to Appendix E: Consent form]. Parents of all 28 children agreed to participate and made appointments for the interviews.

Parents of the 20 children who did not attend the meeting were contacted later by telephone and letters were once again sent to them. 9 children's parents could not be contacted and 2 of the remaining 11 parents declined to participate in the study. Interviews were carried out with 37 respondents [28 attended the meeting, 9 of the 20 were reached and agreed to participate in the study].

3.7.2 Interviews

Interviews are invaluable research tools when the problem under scrutiny is one in which the respondents' own verbally expressed views are central features of the context being studied [Erwee, 1996]. Therefore for this study, questionnaire-based interviews were utilised for data collection based on the following rationale:

- The level of education was not a major factor.
- The sample size was small [N=37] so it was possible to ensure that the researcher personally interviews all the respondents. This was seen to enhance the consistency of data collection procedure.
- Use of the local Creole to enhance the respondents uninhibited verbal expression.

Interview by questionnaire would ensure a high response rate. [Neutens and Rubinson, 1997].

As mentioned previously, the questionnaire was in English but a Creole translation of the questions was prepared. The questions were asked in Creole and the parents answered in Creole. The interviewer took special care to ask the questions as they were worded in the Creole translation of the questionnaire. Completing the questionnaire in English did not pose any practical problem as the majority of questions were closed questions.

The average time for the interview was 30 minutes, which was short and so encouraged respondents to give reliable information throughout the interview. All 37 interviews were conducted within a time span of 3 weeks.

Response Rate Table 3.7 depicts the response rate.

Table 3.7 Response Rate

Respondent	N.	%
Participants	37	77
Non-contacts	9	18
Refusals	2	5

* Key: Respondents = parents Non-contacts= parents who could not be contacted Refusals= parents who did not wish to participate in the study

The response rate calculations were based on Neutens and Rubinson [1997 p.100] formulae for computing the Response Rate.

$$\text{Response Rate} = \frac{\text{Number of completions} \times 100}{\text{Number in the sample}}$$

$$\text{Non contact rate} = \frac{\text{Number of participants not contacted} \times 100}{\text{Total known eligible}}$$

$$\text{Refusal rate} = \frac{\text{Number of respondents refused} \times 100}{\text{Number of eligible respondents contacted}}$$

3.7.4 Reliability

To ensure that no researcher bias was present, the rater completed all the questionnaires based on the audiotape recordings. The researcher verified the details and used these questionnaires for data analysis.

3.8 Data analysis

Leedy [1997, p. 107] states that all research requires logical reasoning. Qualitative studies tend to use an inductive form of analysis whereby observations of particular cases may be generalised to a class of cases. Inductive reasoning emphasises the after-the-fact explanation and a theory emerges after careful observation of evidence [data]. In this research study the data is analysed qualitatively. However, numerical data pertaining to ages of suspicion, identification of hearing loss and placement of hearing aids is treated statistically. Data analysis is performed to interpret the data obtained within the framework of the aims of this study.

3.8.1 Quantitative Analysis

Quantitative analysis using medians were performed on the following variables:

- Age of suspicion of hearing loss
- Age of hearing evaluation i.e. age of confirmation of hearing loss
- Age of hearing aids placement on the child

After the analysis of data was completed the emerging pattern was described.

The median ages indicated the central distribution for identification and follow-up and frequency tables were used to describe how the individual scores are dispersed around the median.

Time intervals were calculated to identify any delays from one stage to another such as:

- Lapse of time from the suspicion of hearing loss to the confirmation of hearing loss
- Lapse of time from the recommendation of hearing aids to the placement of hearing aids on the child.

3.8.2 Qualitative Analysis

All the information obtained from the sample was analysed, interpreted and the findings were tabulated and discussed. The main aim of the study was to describe, explore and interpret the identification and follow-up of the children with hearing loss by utilising a qualitative descriptive survey research. Therefore descriptive statistics was used to summarise, condense and organise the data into more convenient and interpretable form [Maxwell and Satake, 1997].

High- risk indicators for hearing loss that were present in the family, maternal, or child's birth history were described in frequency tables.

The referral routes were described. The persons whom the parents contacted when they suspected hearing loss and the persons who referred the children to the Audiology and Speech Therapy Unit for

hearing evaluation were categorised. These were analysed and results were presented as frequency tables.

The following variables were described using frequency tables:

- Provision of hearing aids
- Medical follow-up
- Habilitation for communication development
- Educational service these children benefit from.

The responses to the open questions were also qualitatively described to complete the picture of this complex problem with many variables.

3.9 Conclusion

Research pertaining to intervention process for children with hearing loss in Mauritius is non-existent to date. According to Whitson [1995, in Hugo, 1998] researchers have the specific ethical responsibility to execute relevant and effective research. This means that research must be socially justifiable and relevant to the context. This empirical research was planned to obtain and interpret baseline information, which is necessary before planning any intervention programme. The various methodological steps presented above are facilitative in realising the aims of this study. The answers and information obtained will ensure that any early intervention programme that is proposed will be based on sound scientific findings.



3.10 Summary

This chapter presented the methodology followed in realising the aims of this study. The steps taken in carrying out the empirical research were explained in detail: The research design selected the sample selection criteria and the sampling techniques were described. The materials and apparatus used for data collection were also described. The theoretical basis for the choice of statistical methods employed and the manner in which the obtained data were analysed was explained in detail. This ensured scientific accountability for the study.



CHAPTER 4

RESULTS AND DISCUSSION

CHAPTER 4 RESULTS AND DISCUSSION

4.1 Introduction

The underlying theoretical construct for this study is that children with hearing loss are, in optimal environments, able to develop spoken language to a level that is functional for life in a society at large [Clark, 1997]. Furthermore, early intervention for children with hearing loss is essential to enable release of their maximum potential [Downs, 1994].

Research findings and literature pertaining to children with hearing loss in Mauritius is currently non-existent. Therefore an exploratory, descriptive study was selected to obtain baseline information regarding the current status of intervention for these children.

According to Maxwell and Satake [1997, p.80] “Descriptive studies result in a better understanding of the phenomena as they exist *in the here and now*, thereby establishing the conditions for later scientific work”.

An interview by questionnaire method was used to realise the main aim of this study namely: **to describe from the parents’ perspective the current identification and follow-up process for children with hearing loss in Mauritius.** In view of the current family-centred intervention models proposed for children with hearing loss [Laughton, 1994], the key persons identified to describe this process, were the parents of these children.

The information obtained was analysed using descriptive statistics that is, information obtained was classified, organised and summarised in a manner convenient for numerical evaluation of the available data [Maxwell and Satake, 1997]. The results are presented according to the sub-aims of the study. The presentation includes visual representation of the results in the form of tables, followed by discussions and interpretation of the results. The strengths in the current intervention process followed in Mauritius will be highlighted and the weak links will be indicated. Based on the results, guidelines for the development of an appropriate and effective early intervention programme will be proposed.

4.2 High Risk Indicators

The best **preliminary** screening procedure for early identification of children with hearing loss appears to be a **high-risk register screening** [Gerber 1990]. Established risk indicators have been listed for hearing loss in the high-risk register. According to Mauk *et al* [1991] at least 50% of the children born with or at risk for hearing loss can be identified with the use of the high-risk register. ASHA [1989] and JCIH [1994] strongly recommend the use of the high-risk register to identify children with hearing loss early.

The first sub-aim of the study is to determine the known high-risk indicators that were present amongst the children with hearing loss. As seen in the questionnaire, [Appendix B], **sections 3 and 4** probed information regarding family

history of hearing loss, whether any history of consanguineous marriages was present among the parents and any possible significant maternal history or medical history amongst the children. To facilitate comparison the results of this study and other similar studies are presented in table 4.1.

Table 4.1 High-risk indicators of hearing loss

High-risk indicators of H.L.	N.	%	Stein <i>et al</i> 1990	Mauk <i>et al</i> 1991	Strong <i>et al</i> 1994
Family history of H.L.	8	21.6	12.9%	29%	11%
Twins with both parents deaf	2				
Sibling with H.L.	1				
Relatives with H.L.	5				
Mothers with high-risk indicators	7	18.9	9.5%	Not specified	18%
History of Rubella	6				
History of high fever	1				
Children with high-risk indicators	20	54	65%	57%	20%
Low birth weight, in incubator, premature	11				
History of fever/ convulsions/ meningitis	8				
History of high bilirubin	1				
No known high risk indicator present	13	31.3	48.8%	50%	50%

All the possible high-risk indicators for each child were taken into account. This explains the reason for the total number of children exceeding 37 in the table. It is important to note that some children had more than one high-risk indicator, therefore, the percentages may exceed 100%.

As indicated in table 4.1, 21.6% of children presented with **family history** of hearing loss. This finding was similar to the Mauk *et al* study. Stein *et al* [1990] and Strong *et al*

[1994] in their studies, however, reported family history to be present amongst a much lower percentage of children. Gerber [1990] had explained that family history might not necessarily be known. This argument does not hold true for the current study as the sample is from Mauritius, a country with a small area and population, where the respondents in the study know of their family histories and are also familiar with those persons in the family having hearing loss. Also, Mauritius is a closed community where genetic causes of deafness may be high because of intermarriages. Knowledge of family history of hearing loss can be helpful as a high-risk indicator for hearing loss.

As seen in table 4.1, **6 of the 37** mothers reported **history of Rubella** [16%] which is found to be an important cause of hearing loss in this study. During **open questions** in **section 10** of the questionnaire, the mothers reported that during follow-up at the prenatal clinic they were informed by professionals about the symptoms of Rubella they exhibited and information regarding risks associated with Rubella was given. This finding was similar to the significant maternal history present in the Strong *et al* [1994] study.

According to the research conducted by Stein *et al* [1990], Mauk *et al* [1991], and Strong *et al* [1994], approximately 50% children do not show any known high risk indicators. However, amongst the children in this study only 31% did not have any known high-risk indicators. The research findings indicated that for a high percentage of children [69%] with hearing loss, there were known high-risk indicators. This implies that the high-risk indicator register

could probably be effectively used to identify children with hearing loss.

The high percentage of known high-risk indicators amongst the children with hearing loss may be attributed to the fact that 100% of these children were born under medical supervision either in a public hospital or private clinic as seen in table 4.2.

Table 4.2 Place of birth

Place of Birth	N.	%
Hospital	33	89.2
Clinic	4	10.8
Total	37	100

The fact that birthing place of the children in the study was under medical supervision means that many new-borns survive due to professional prenatal and neonatal care and that a high incidence of children with hearing loss will be identified from this vulnerable group. It is to be noted that in 1997 in Mauritius, 98% of deliveries occurred in a medical institution [Health Statistics Annual 1997]. As seen in table 4.1, 11 of the 37 children, [29%] were born with low birth weight, were premature and had to be placed in an incubator for more than 5 days. In Mauritius, in 1997, 15% of live births were low birth weight [Health Statistics Annual 1997]. Studies from Vanderbilt University [USA] revealed that because of overall improvements in health care, survival rates of very low birth babies have increased. Low birth weight babies experience complications due to extreme

immaturity of their organ systems. It is estimated that about 5.5% of low birth weight babies experience some degree of sensori-neural hearing loss [Bess, 1993].

Harrison and Roush [1996] reported that when high-risk indicators were known, the parents suspected hearing loss a month earlier than when high-risk indicators were not known in the severe hearing-impaired group of children. This means that if the high-risk register is used to identify the children with hearing loss they are likely to be identified early.

It was noteworthy that during the open questions in **section 10** of the questionnaire the respondents added that the medical professionals had indicated to the mothers that they should seek opinion if they suspect a problem in their child. This information had been given to mothers who had Rubella and to some of the parents who had known family history of hearing loss. This is an important strength of the system in Mauritius where professionals are aware of the high-risk indicators of hearing loss and therefore provide valuable information to alert the parents. Maternal Rubella is a preventable cause of hearing loss. Since 1994 girls at pre-puberty age are being vaccinated in Mauritius [Health Statistics Annual 1997]. Therefore in the future, hearing loss due to Rubella will probably be preventable.

Additional information pertaining to high-risk indicators obtained from the respondents was that no history of consanguineous marriages was reported among the parents of the children in the study and that none of the 37 children in the study had any obvious craniofacial abnormalities.



From the results, it can be concluded that the respondents were able to indicate the possible cause of their children's hearing loss and that professional care during the peri-natal period was available. These findings highlight an important strength in the identification process of children with hearing loss. Currently in Mauritius, the high-risk register for hearing loss is not employed to determine **at risk status**. It has been documented that high-risk indicator screening for hearing loss will only include 50% of the children with severe to profound bilateral sensori-neural hearing loss amongst newborns in a given population [Mahoney and Eichwald, 1987; Mauk *et al*, 1991; NIH Consensus statement, 1993 and JCIH, 1994]. In view of this, a more effective early identification programme should be preferred, such as universal new-born hearing screening. The N.I.H. consensus statement [1993] had suggested comprehensive intervention and management programmes must be an integral part of the universal hearing-screening programme. This is an important consideration particularly for a small developing country like Mauritius.

4.3 Identification of Hearing Loss

Early identification of hearing loss and appropriate follow-up is the first line of defence in reducing the negative consequences of hearing loss [Lutterman *et al*, 1999]. The Healthy People 2000 Goals [1990] set as a goal identification of children with hearing loss by 12 months of age. Lowering the age of identification is the primary objective of any early intervention programme [Hitchings and Haggard 1983]. To



realise the sub-aim of the identification of hearing loss in the children, the following information will be presented: age of suspicion of hearing loss, age of referral for hearing assessment, age of the identification of the hearing loss and the referral process.

4.3.1 Ages of Suspicion, Referral and Identification

Section 5 of the questionnaire was used to obtain information regarding the ages of suspicion of hearing loss, referral for hearing assessment and identification of hearing loss amongst the children in the study.

Details concerning the 37 children with hearing loss are given in table 4.3. For clarity, all ages are expressed in months. Maxwell and Satake [1997] state that if the sample size is small and the distribution of data is relatively skewed in either positive or negative direction, the means may not be a good reflection of the central tendency because of biasing effects of the extreme scores. To prevent this from occurring the median ages rather than the mean ages are provided.

Table 4.3 Identification of hearing loss

N=37 children with H.L.	Present ages		Suspicion of H.L.		Referral for assessment		Identification of H.L.	
	N.	%	N.	%	N.	%	N.	%
Age Group								
0 to under 6 mths	0	0	3	8.1	0	0	0	0
6 to under 12 mths	0	0	11	29.7	6	16.2	4	10.8
12 to under 18 mths	0	0	8	21.6	9	24.3	9	24.3
18 to under 24 mths	1	2.7	4	10.8	6	16.2	5	13.5
24 to under 30 mths	2	5.4	7	18.9	8	21.6	10	27.0
30 to under 36 mths	5	13.5	3	8.1	3	8.1	2	5.4
36 mths and over	29	78.3	1	2.7	5	13.5	7	18.9
Median age in mths	45		12		22		24	
Age range	22 to 94		3 to 36		6 to 66		6 to 66	

*Key: H.L.= hearing loss N.=number of children

% =percentage mths=months

**[In all the tables that follow the key is the same].

As seen in table 4.3 the **median age of suspicion of hearing loss, by the parents, is 12 months** amongst the children in the study. In response to question 5.02 in the questionnaire, regarding which specific behaviour of the child alerted the parents to a possible hearing loss, the parents answered that

the child was not responding to environmental sounds, not responding to voice, not beginning to talk and a combination of these observations.

Though the parents suspected their child's hearing at median age 12 months, the median age of identification is very late at age 24 months. This is probably due to delays in the referral process for hearing assessment. It is also apparent from table 4.3 that once referred to the Audiology and Speech Therapy Unit for hearing assessment the diagnosis was made fairly quickly. **Median age for referral for hearing assessment was 22 months and the median age for identification of hearing loss was 24 months.** Table 4.3 also indicates that nearly 60% of the parents are alert to the signs of hearing loss by 18 months of age. However, by 18 months, only 35% of the children were identified as having hearing loss. The reasons for the time lapse from the age of suspicion to the age of identification of hearing loss need to be probed.

The findings in this study indicate that the parents suspect hearing loss at an early age [median age 12 months] but the identification is delayed due to the time lapse from the suspicion to the referral for hearing assessment. Hitchings and Haggard [1983] state that the objective of early identification can be realised if parental concerns are incorporated in the hearing-screening programme. However, professionals do not always take parental concerns into consideration. In this study, during open questions in **section 10** of the questionnaire some parents reported that they had been placated by professionals regarding their

concerns of their child's hearing and some were told by professionals that it was not possible to test very young children.

Kile [1993] had reported that the age of identification of hearing loss and degree of hearing loss are inversely proportional. Children with severe hearing loss were selected in this study, therefore, the identification median age of 24 months is very late. Another unfortunate finding is that a high percentage, 18.9%, of the children in the study was only identified after the age of 36 months.

Table 4.3 also indicates that the system is in place in Mauritius but it is not functioning equally well for all children with hearing loss. As seen in table 4.3 parents suspect hearing loss at median age 12 months. Unfortunately the referral for hearing assessment is at median age 24 months. This is problematic, as children who are identified late will obviously have late intervention with devastating effects on the communication development of the children [Bench, 1992]. Maximum delay appears to occur from age of suspicion of hearing loss to age of referral for hearing assessment. This indicates a need for determining the cause of delay in referral for hearing assessment.

4.3.2 Referral Process

Section 5 of the questionnaire also posed questions to the respondents to find out whom the parents contacted in the first instance when they suspected hearing loss in their children. The results are presented in table 4.4.

Table 4.4 Referral process

Child first taken to	N.	%	Child seen by	N.	%
Mediclinic	3	8.1	Paediatrician	13	35.1
Hospital	20	54.1	E.N.T specialist	12	35.1
Private Clinic	3	8.1	Other Specialist	2	5.4
Private Doctor	11	29.7	General Practitioner	10	27
Total	37	100	Total	37	100

Results presented in table 4.4 indicate that more than 50% of the parents contacted the hospital services when they suspected hearing loss in their children. In fact, specialists in E.N.T and Paediatrics saw 60% of these children. The referral to the Audiology and Speech Therapy Unit for hearing assessment was often only a third step. As seen in table 4.4, 13 of the 37 [35%] respondents contacted the Paediatrician when they first suspected hearing loss. However, as seen in **table 4.5**, the main referral source for hearing assessment in the sample were the E.N.T specialists [51.4%]. For medical clearance, it is important that E.N.T. specialists see the children with hearing loss. It will be important to research further to find out **how the referral route should be shortened** and to make the parents aware of whom to contact for hearing assessment when they suspect hearing loss in their child.

Table 4.5 Referral source for hearing assessment

Referral Source	N.	%
E.N.T specialist	19	51.4
Paediatrician	11	29.7
General Practitioner	3	8.1
Other	1	2.7
Total	37	100

McCormick *et al* [1984] suggest that it is important to document who the persons are that the parents contact and who refers the children with hearing loss for hearing assessment. This information can form the basis of planning and organising the services involved in hearing care for children. They also recommended that parents should have direct access to the hearing assessment centre whenever in doubt about their child's hearing [McCormick *et al*, 1984]. In fact, when 'open access' to the hearing assessment centre by the parents was implemented in the Nottinghamshire Hearing Centre, the problem of late detection was reduced and parents who came forward for hearing assessment of their child had genuine reason to be concerned.

In this study, it was found that when the parents suspected hearing loss in their child they contacted specialists such as E.N.T. specialists and Paediatricians in the hospital services. Appointments for specialists are given after long delays and this could probably contribute to the delay in the referral for hearing assessment.

Referral process in the sample was unlike in the U.K. where health visitors were the highest source of referrals for hearing assessment [McCormick *et al*, 1984]. In Mauritius, community-based rehabilitation workers and community health nurses have frequent contact with the mothers and the children during the post-natal period. The scheme of service of the community-based rehabilitation workers lists survey and identification of persons with disabilities [Public Service Commission, scheme of service 1994] as part of their duties. This system even though in place in Mauritius, has not been identified as a referral source for children suspected with hearing loss as revealed in table 4.5. To shorten the delay in referral for hearing assessment, the community health workers might be considered as potential early referral sources.

An additional fact pertaining to referral process of children with hearing loss is that parents and general practitioners do not know the Audiology service. Knowledge of the Audiology service could shorten the route to identification of hearing loss.

4.4 Diagnostic Process

The diagnostic process is considered as a watershed in the intervention process. The goal of early diagnosis of hearing loss is to confirm whether a child actually has a hearing loss, to ascertain, and to clarify the exact nature and severity of the confirmed hearing loss [Mauk and Mauk, 1995]. A diagnostic hearing assessment includes a battery of test

procedures namely, behavioural testing and /or objective testing [Auditory evoked potentials or Otoacoustic emissions]. The confirmation of hearing loss is the focal point to which the hearing screening process leads and from this point the management process takes off.

The sub-aim of description of the diagnostic process was realised by **section 6** of the questionnaire where respondents were asked at what age the hearing loss was confirmed. In **table 4.3** [p.87] the column **identification of hearing loss** indicates that the median age of confirmation of hearing loss amongst the children in the sample was **24 months**. However, the ages ranged from 6 to 66 months. A very small percentage of children in the study, [only 10.8%] were confirmed as having hearing loss by age 12 months. 70% of the children with hearing loss were diagnosed by the age of 30 months. A fairly large percentage [24%] was diagnosed after the age of 30 months when it is very late to start the development of verbal language skills.

In USA, the Strong *et al* study [1994] based on the SKI HI home programme reported the age of diagnosis of hearing loss as 15.2 months. Harrison and Roush [1996] reported the median age of diagnosis of hearing loss as 13 months. In UK, the median age of diagnosis of hearing loss as reported by Bamford and McSporrان [1993 based on Davis and Wood study] was 12 months. **For the study in Mauritius, the median age of diagnosis of hearing loss is very late [median age 24 months] and the age range was wide [6 to 66 months].**



It is important to determine the age of diagnosis of hearing loss to set realistic goals regarding reducing the age of identification of hearing loss and to propose plans for audiology test battery to suit the age group referred for hearing assessment. For example, the majority of children [78%] referred for hearing assessment in the Audiology and Speech Therapy Unit were children less than 30 months. This implies that test equipment must be available to assess hearing in children of this age group. ASHA [1991] strongly recommended the importance of test battery approach in diagnosis. The use of behavioural testing, immittance measures and electrophysiologic tests for the neurodevelopmentally delayed and very young children was recommended. Presently in Mauritius, electrophysiologic tests are not available. This can delay the diagnosis of hearing loss amongst very young children referred for hearing assessment.

In **section 6** of the questionnaire, respondents were asked whether they sought second opinion after diagnosis of the hearing loss. Table 4.6 indicates whether the parents were in doubt of the diagnosis of hearing loss and sought a second opinion.

Table 4.6 Acceptance of hearing loss

Second opinion from:	N.
E.N.T specialists in private	2
An audiometrician in private	1
Went abroad	3
Did not seek second opinion	31
Total	37

It appears from table 4.6 that a large majority of the parents [31 of the 37 i.e. 83.7%] were convinced of the diagnosis of hearing loss and did not seek a second opinion. Lutterman [1999, p.51] explains that most testing for suspected hearing loss is parent-driven, as parents slowly become aware that there might be something wrong with their child's hearing. In the sample, the median age of diagnosis was 24 months. The underlying fact is that parents had been seeking opinion from professionals when they suspected hearing loss in their child and finally when the Audiologist confirmed the hearing loss, they readily accepted the diagnosis. This is unlike the case when hearing screening is carried out amongst newborns and parents are unprepared to accept the diagnosis of hearing loss [Lutterman *et al*, 1999].

4.5 Management Process

Management of the child with hearing loss is a monumental challenge. In learning to understand the spoken language of others and to speak it, there is no substitute for the intact auditory system. Without normal hearing, it is extremely difficult to acquire an adequate communication system. Because so much of the language learning process occurs within the first few years of life, there has been considerable emphasis on early identification and intervention for young children with hearing loss. Efforts towards early identification will have limited effect upon development of the child with hearing loss if for a number of reasons there is an additional delay in intervention [Vesterager and Parving, 1994]. **Intervention must include adequate parent-child**

management, wearable amplification, speech and language training and development of perceptual and cognitive skills [Bess and Humes, 1995, p.262].

For children with pre-lingual severe hearing loss, the emphasis is to focus on such critical issues as early amplification; parental guidance and a comprehensive habilitation package designed to facilitate communication development. After the hearing loss has been diagnosed, the intervention process referred here as '**management process for children with hearing loss**', primarily involves placement of hearing aids, medical and therapeutic follow-up and schooling [Diefendorf *et al*, 1990].

The sub-aim of describing the management process for children with hearing loss was realised by obtaining answers to the questions in **sections 7, 8 and 9** of the questionnaire.

4.5.1 Placement of hearing aids

The core of the habilitation programme for children with hearing loss is the placement of appropriate hearing aids on the child [Bess and Humes, 1995]. Clark [1997] has stated that it is impossible to start a habilitation programme without appropriate hearing aids for each child. Consistent amplification for the young child with hearing loss is one of the most important aspects of habilitation.

In **section 7** of the questionnaire the sub-aim of placement of hearing aids was realised by obtaining the following information pertaining to: age of referral for hearing aids and age of placement of hearing aids on the child.

Table 4.7 Referral for and placement of hearing aids

Age in mths	Referred for H.A		H.A. Placement	
	N	%	N	%
Age Group				
0 to under 6 mths	0	0	0	0
6 to under 12 mths	3	8.1	2	5.4
12 to under 18 mths	8	21.6	6	16.2
18 to under 24 mths	5	13.5	4	10.8
24 to under 30 mths	10	27.0	5	13.5
30 to under 36 mths	4	10.8	10	27.0
Over 36 mths	7	18.9	10	27.0
Total number	37	100	37	100
Median age in mths	24		30	
Age range	6 to 66		7 to 66	

* Key H.A. = Hearing aids.

From table 4.7, it appears that though 77% of the children were referred for hearing aids placement at ages less than 30 months, more than 50% were fitted with hearing aids **after the age of 30 months**. Strong *et al* [1994] report the median age of hearing aid fitting in the SKI HI project is 20 months. Harrison and Roush in their study [1996] reported that children with severe hearing loss were fitted with hearing aids by 15 months. In UK, Bamford and McSporrán [1993] cite the Davis and Wood study [1992] and state that three quarters of the children with severe hearing loss were wearing hearing aids by 16 months. Research studies [Markides 1986 and Yoshinaga- Itano 1995] have shown that the speech intelligibility of children with hearing loss who started using amplification in their first 6 months of life was significantly superior to that of similar children who started

using hearing aids later in life. The median age of hearing aids placement in the sample, as seen in table 4.8 is 30 months, this is very late in relation to the studies referred to earlier.

Table 4.8 indicates the time lapse from diagnosis of hearing loss to referral for hearing aids and the time lapse from referral to actual placement of hearing aids for the first time on the child.

Table 4.8 Time Lapses for hearing aids placement

Time Lapse	Median time interval	Time range
From hearing assessment to referral for H.A.	Less than 1 month	0 to 8 mths
From referral for H.A. to placement of H.A.	5 mths	0 to 14 mths
From hearing assessment to placement of H.A.	6 mths	0 to 14 mths

This table indicates that the delay is mainly from time of referral for hearing aids to placement of the hearing aids. In Mauritius, the children with hearing loss are referred by the professional staff in the Ministry of Health to the Ministry of Social Security for supply of free hearing aids.

The following table 4.9 indicates the waiting periods before being provided with hearing aids.

Table 4.9 Waiting periods for provision of hearing aids

Waiting Period for H.A.	N.	%
Less than 1 month	8	21.6
1 to under 3 mths	9	24.4
3 to under 6 mths	12	32.4
Over 6 mths	8	21.6
Total	37	100

A majority of the children [57%] in the study were provided with hearing aids between 1 and 6 months of applying for the hearing aids. Some children received the hearing aids within a month of applying but there was a large percentage [77%] who had to wait more than a month for provision of hearing aids. Any wait over one month is not acceptable and in the case of a child, 30 days are very important. From this table, it appears that the system of hearing aids provision is not working equally well for everyone.

Table 4.10 indicates who provided the children with hearing aids.

Table 4.10 Provision of hearing aids

H.A. provided by	N.	%
Parents	8	21.6
Ministry of Social Security	26	70.3
Other	3	8.1
Total	37	100

As seen in table 4.10 the majority [70.3%] of the hearing aids was provided to the children in the sample by the Ministry of Social Security and National Solidarity. The hearing aids were behind the ear type and custom ear moulds were made to fit each child at the local ear mould laboratory at the School for the Deaf. A small percentage of parents who could afford to buy hearing aids and did not wish to wait for Social Security to provide free hearing aids had purchased hearing aids. They were later provided with hearing aids by the Social Security. The WHO [1995] conference had highlighted the constraint in fitting children with hearing loss with hearing aids and the financial burden to the family and society that could not afford hearing aids. The provision of free hearing aids to children with hearing loss is a very positive strength in Mauritius but the waiting period negates this strength.

Clark [1997] pointed out that the provision of hearing aids alone is insufficient to ensure that the child will have the opportunity to use residual hearing. Two other areas must also develop simultaneously. There must be an efficient maintenance service and parents must be well trained in the management of the child's hearing aids. The day-to-day management of the hearing aids falls to parents and must be backed by reviews at the local Audiology Centre [Bamford and McSporrان, 1993].

The questions in **section 7** of the questionnaire also probed the very important issue of whether the children were using the hearing aids. Table 4.11 indicates the answer to this question.

Table 4.11 Acceptance of the hearing aids

Children	N.	%
Using H.A.	32	86.5
Not using H.A. as out of order	3	8.1
Not adapting to H.A	2	5.4
Total	37	100

At the time of the study, it was found that 86.5% of the children were using their hearing aids. Children who were not using their hearing aids totalled 5 [13.5%]. For 3 of these children, the reason was attributed to the fact that the hearing aids were out of order and they were awaiting new hearing aids. Clark [1997] had rightly pointed out that hearing aids maintenance and care was an issue that has to be dealt with whenever planning a habilitation programme. It was a positive strength that the majority of the children used the hearing aids. Parents in the study appeared well informed about the hearing aids and participated in the therapy of their children. This is a positive factor in the management process. Lutterman *et al* [1999] emphasise that the ultimate success in hearing aid use by the child is often directly related to parental attitude.

4. 5.2 Medical and Therapeutic Follow-up

Matkin and Roush [1994] have stressed the importance of interdisciplinary approach for children with hearing loss. An interdisciplinary team ideally consists of Paediatrician, E.N.T specialist, Social Worker, Psychologist, Audiologist, Speech – Language Pathologist, Special Educator and Caregiver amongst others. It is this team approach that will provide

the child with hearing loss with the highest quality of care [Diefeldorf *et al*, 1990 p. 395].

Section 8 of the questionnaire posed questions to the respondents regarding the follow-up of the children with the E.N.T specialist and the Audiologist and Speech Therapist. The results are summarised in table 4.12.

Table 4.12 Medical and Therapeutic Follow-up

Frequency of follow-up	With E.N.T specialist N.	With A.S.T. N.
Once a mth	1	25
Once every two mths	2	3
Once every three mths	4	4
Less often	10	3
No follow-up	20	2
Total	37	37

* Key A.S.T. =Audiologist and Speech Therapist month= mth

From table 4.12, it is obvious, that the follow-up with the E.N.T specialist was infrequent. The reasons for this must be researched and the situation improved. It is essential that in the case of children with severe sensorineural hearing loss the management involves a closely-knit team comprising otologist, audiologist, speech-language pathologist and teacher of the deaf. The E.N.T specialist plays an important role in diagnosis and treatment of sensorineural hearing loss in children. Children with sensorineural deafness have the

same risk of developing secretory otitis, the most common cause of childhood hearing loss, as otherwise normally hearing children. The effect of a superimposed conductive hearing loss on a child with sensorineural deafness may reduce the benefit of even the most powerful hearing aid [Gibbin, 1993 in McCormick, p.54].

Regarding the follow-up with the Audiologist and Speech Therapist, it was encouraging to note in response to **section 7 question 7.03** that all the children in the sample were on follow-up while waiting for hearing aids. The follow-up involved parental group meetings and guidance regarding communication skill development. When the children had been provided with hearing aids, follow-up involved counselling regarding effective use of amplification to develop language and speech learning. The Audiology and Speech Therapy Unit provides the **diagnostic service for hearing loss and the follow-up for language and speech development**. Diefendorf *et al* [1990, p. 403] say “by working as a team the audiologist and speech therapist are equipped to determine which hearing aids provide the greatest amount of information regarding incoming speech and environmental signals”. The same person in the Mauritian context provides the Audiology and Speech Therapy service. However as seen in table 4.12 the follow-up was only once a month and for some children even less frequently. As there was no other support group or home therapy programme offered to the children with hearing loss in the sample, the follow-up in Audiology and Speech Therapy is considered to be very infrequent. Most parents in the open question **section 10** indicated that they would like

more frequent follow-up. This would have been desirable and possible if there were more personnel available to provide the follow-up. It will perhaps be necessary to build a network of persons such as community-based rehabilitation workers who could provide home-based therapy rather than centre-based follow-up. Also, specialised pre-primary school or perhaps playgroups for children with hearing loss could be set up with help from the Speech Therapist and Audiologist.

Mauk and Mauk [1996] have emphasised the imperative nature of aggressive, appropriate and co-ordinated audiological and medical follow-up and early intervention for children with hearing loss and their families. In the management programme the most important of all is close involvement of the parents in the management team [McCormick, 1993, Glover *et al*, 1994, Clark, 1997]. The strength of the follow-up process is that parents in the study were very closely involved in the management process. The weak links identified were the lack of follow-up with the E.N.T specialist and the infrequent follow up with the Audiologist and Speech Therapist.

4.5.3 Means of Communication

In **Section 8** of the questionnaire, question 8.05 was asked to find out how the children in the sample communicate. The results are indicated in table 4.13.

Table 4.13 Means of Communication

Communication	N.	%
Verbal	3	8.1
Non-verbal	18	48.7
Both	16	43.2
Total	37	100

In view of the fact that the children in the study were identified late [median age 24 months] and hearing aid placement was very late [median age 30 months] it is not surprising that the results indicate that the means of communication of 48% of the children in the study was non-verbal. It is a positive sign that both verbal and non-verbal communication was present amongst 43.2% of the children in the sample. This finding implies that with proper planning and effective intervention programmes many more children with hearing loss in this context can learn to communicate verbally.

Strong *et al* [1994] reported the choice of the communication methodology in the SKI HI programme was:

- Total communication for 64% of the children
- Aural/oral method for 35% and
- Other communication [primarily cued speech] choice was made for 1% of the children.

In the Mauritian context the choice of methodology is non-existent as total communication, sign language or cued speech are neither taught nor advocated. The only choice available to the parents is verbal communication or informal/ natural signs.

4.5.4 Schooling

The present age range of the children [as seen in table 4.3: 22 months to 94 months] was that of school going age. Therefore, **section 9** of the questionnaire asked about the type of school attended by the children in the sample and the results are presented in table 4.14.

Table 4.14 Type of school attended

School	N	%
Ordinary	20	54.1
Special	12	32.4
Not attending	1	2.7
Not yet 3 years	4	10.8
Total	37	100

It was also deemed necessary to find out who made the decision regarding the type of school these children attended. In table 4.16 the results are presented.

Table 4.15 Decision-maker regarding type of school attended

Decision-maker	N.	%
Parents	29	90.6
Suggested by AST	3	9.4
Total attending school	32	100

From table 4.14, it can be seen that 54% of the children with hearing loss in the study were placed in regular classroom in ordinary school with no support. Certain prerequisites are necessary for successful mainstreaming of children with hearing impairments. The child must have the necessary communication ability to handle the academic, linguistic and social demands of a mainstream classroom. An array of **support services** is required for the child with hearing impairment, the child's teacher and the child's parents [audiologists, speech language therapists and teachers of the hearing impaired generally comprise the support service team]. Selection and provision of support services must be followed by co-ordinated efforts [Katz 1978]. From table 4.15, it is apparent that more than 90% of the parents in the study decided on the type of school themselves. In response to the open question, **section 10**, of the questionnaire, the parents stated that practical issues such as location of the school dictated their choice. Clark [1997] has indicated that where choices regarding special education are not available children with hearing loss benefit from early experience in a

regular pre-primary school. However, the early pre-primary school teachers must be able to liaise with the Audiologist and Speech Therapist regarding the development of communication skills of children with hearing loss or must have support service from teachers for the deaf. This co-ordination and support is lacking in Mauritius.

The parents of the children attending special school in the study commented in the open questions **section 10** that they were hoping that eventually if their child learned to speak they would consider ordinary school for their child. **From these findings, it is clear that there is no choice but only one solution available to the parents dictated by the reality of the situation.**

Penn and Reagan [1994] have discussed the need for a National Policy for deaf education in South Africa. The same holds true for Mauritius. It is important to have a clear, focussed and articulate sense of direction in areas related to educating children with severe hearing loss. In USA a bill known as IDEA, Part H, PL102-119 lays out a policy for infants and toddlers with special needs including children with hearing loss. The aim is to reduce the educational costs to society by minimising the need for special education and related services after handicapped infants and toddlers reach school age. Implementation of this bill involves a multidisciplinary evaluation to determine eligibility and to develop an individual educational plan designed to detail the child's educational plan [Bess and Humes, 1995]. Downs [1997, p.244] states that "the expenditures for the early therapy and training that follows upon identification at birth

are 1.1% of the costs of later education. Yet it is the early therapy that can give children the language skills that will allow them to succeed in the lesser expensive school placements”. The legislation in Mauritius provides free education for all children from age 3 years to 12 years but there is no policy regarding children with special needs.

4.6 Relationship between aspects of suspicion, identification, management of hearing loss and biographical information

The data pertaining to biographical information obtained in **section 2** of the questionnaire were analysed and tabulated with reference to two main concepts:

- Relationship between educational background of the parents and age of suspicion of hearing loss in the child. The findings are presented in table 4.16.

Table 4.16 Relationship between educational background of the parents and the age of suspicion of hearing loss.

Educational Background of the Parents						
Parent	Mother			Father		
Educational level	Primary	Secondary	Tertiary	Primary	Secondary	Tertiary
N.	17	18	2	15	21	1
Median time	10	6.5	8	7	8	1
Lapse in mths						

Since the number of children in the study was small [37], no scientific co-relation could be made in relation to parents education and age of suspicion of hearing loss therefore, no reliable conclusion could be drawn.

- Relationship between parental income and time lapse from the age of identification of hearing loss to the age of placement of hearing aids on the child. The findings are presented in table 4.17.

Table 4.17 Time lapse between identification of hearing loss and placement of hearing aids according to parental income

Monthly Income in Maurtian Rupees				
Income	< 5000	5000-10000	10000-20000	>20000
N.	23	10	2	2
Median time Lapse in mths	14	11	16.5	10.5

The fact that 26 out of 37 children [table 4.10 p.99] in the study were provided with free hearing aids from the Ministry of Social Security and National Solidarity indicates that even those belonging to the lower income group have an equal chance of being fitted with hearing aids.

Further research will need to be carried out to determine whether there is a relationship between the biographical data and the ages of suspicion, identification and hearing aids placement. Seewald [1995, p. 5] states that “Regardless of the specific procedures that are applied or the general



structure that is associated with the identification programme; regardless of the age at which the identification is made; regardless of the device with which the child is fitted; **effective habilitation must be universally accessible to all infants and children with hearing loss and their families”.**

4.7 Conclusion

The results and findings were presented with tables and each aspect of identification and management process was discussed. The purpose of documenting these findings and discussing the results is to ensure that based on these results and discussion a comprehensive plan to promote family-centred community-based co-ordinated care for children with hearing loss can be proposed and implemented.

The strengths and positive factors present within the Mauritian community offer opportunities for creative problem solving. The high-risk register implementation to identify children early appears to be a feasible and effective way to start the hearing-screening programme. As the parents in the sample suspect hearing loss at median age 12 months, it appears that professional and parental awareness campaigns are likely to build on this positive factor in the Mauritian context. The system is in place but the parents need to be informed of the services available. The referral process can be shortened with effective planning and a network of referral

sources with persons, who are working in the community for example, community-based rehabilitation workers.

The diagnostic procedure can be facilitated with availability of equipment and more personnel. The management process is currently fragmented as the services for diagnosis and provision of hearing aids function under two different ministries and co-ordination in their work is lacking.

The means of communication is not a matter of choice in the sample. The accepted approach to communication is the auditory-verbal approach. The strength of this approach is that most children are learning the language of their family and culture [Gatty 1996]. However, without a back up support service to the children and their families, the success of the auditory-verbal approach is questionable. Sign language is not established and auditory-oral approach is not possible in view of late diagnosis. Educational philosophy is an important consideration for parents when they are choosing an approach to use with their children [Gatty 1996]. The type of schooling is dictated by the reality of the situation where only two special schools for children with hearing loss are available in the urban areas. Parents therefore have to choose ordinary mainstream schooling.

Families of infants and young children with hearing loss face a range of difficulties and frustrations in obtaining services and utilising existing service delivery system. The difficulties appear to be surmountable with effective planning.



4.8 Summary

The results and discussion chapter aimed to describe and document the current identification and follow-up of children with severe pre-lingual hearing loss in the sample based on the empirical research carried out. The strengths in the current system were identified and the weak links were also outlined. The gaps in the system particularly from the age of suspicion to the age of identification and from the age of identification to the age of hearing aids placement are surmountable. As seen from the various tables, the system appears to be in place but the parents need to be empowered to use the system to their advantage. The present study was also viewed in the context of other relevant research findings. Planning early intervention requires a team approach and sharing of professional roles. The weakness that is apparent in the current system, based on the results and discussion, is late identification of children with hearing loss followed by late intervention and a fragmented service provision.



Chapter 5 Conclusions and Recommendations

CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Lutterman [1999 p.21] states that “Research is supposed to illuminate, enlighten, and point us in the right direction.” The paucity of literature pertaining to children with hearing loss in developing countries makes it very difficult to see the right direction and to propose an early intervention programme. Hence, the priority of this study was to carry out a descriptive research study to explore and document the current identification and follow-up process of hearing loss among children in the context of a small developing country, Mauritius.

The aim of this chapter is to discuss the conclusions drawn from the theoretical and empirical research study as described in the previous chapters and to make recommendations that have practical implications for an early intervention programme.

From the descriptive study, it can be concluded that for children with hearing loss in Mauritius **change is possible**, as the building blocks are present. Parents are involved in their child’s identification and follow-up process. Professionals in hearing care, though scarce, are available. The public service structure namely health, education and social security aid is well established. Yet the results of this study also show that identification of hearing loss is late and the follow-up for children with hearing loss is a fragmented and an inconsistent process. Concern about the lack of

co-ordinated service points to the necessity of having a well-planned programme for **early intervention** based on realistic and realisable goals applicable to the context.

5.2 Conclusions and Practical Implications

Early intervention for children with hearing loss is a comprehensive term that includes early identification and follow-up provided to these children and their families. From the literature review it is clear that hearing screening procedures must be planned to identify hearing loss early [before 12 months of age] so that timely and appropriate follow-up can be initiated. **Programme implementation should be technologically sound, socially acceptable, simple, economical and practical.** WHO [1991] recommended that effective programmes require systematic community-based approaches to eliminate and control avoidable hearing impairment and deafness and that early detection should be possible through family, community and health workers with support from audiology trained personnel. Based on the empirical research carried out, as explained in the research methodology section and discussions of the results and findings, an early intervention programme is proposed.

In addition to this, the WHO [1991] recommended that **preventive measures** for hearing loss, through appropriate vaccination programmes be effected. As described in this study in Mauritius, the Rubella vaccine has been implemented since 1994. Furthermore, public awareness of



high-risk indicators would serve as a preventive measure to some extent. However, in this study, public knowledge in Mauritius was not evaluated and it is possible that this may well be insufficient for incorporation in a prevention programme. Furthermore, primary prevention is not entirely possible, as there are many unknown causes of hearing loss. Basic research in this area is needed in Mauritius.

In developed countries the **early identification of hearing loss among children** is advocated as a secondary preventive measure to minimise the negative consequences of late identification of hearing loss. In Mauritius, no National Hearing Screening is implemented at present. The empirical research in this study indicated that when parents suspect hearing loss, they would of their own accord come forward with their concerns regarding the child's hearing. Unfortunately, as there is no active public awareness campaign, some parents only suspect hearing loss at a late stage. The median age of suspicion of hearing loss in the study was 12 months. N.I.H. Consensus statement [1993] stated that 70% of infants and children with hearing impairment are identified because of parental concern about their child's hearing. Professionals whom the parents contact may or may not refer the child to an appropriate service for hearing assessment. Undue delay in referral process is avoidable through **public and professional awareness campaigns**. The awareness campaign could involve posters, brochures at the various immunisation and well baby clinics where the attendance is very high [87 % children in Mauritius follow the immunisation programme]. These are known to be less expensive methods of ensuring

early identification. Gatty [1996 p.3] summarises the campaign issue as: *“listen to parents when they express concerns about their child’s hearing or describe behaviour that may be indicative of hearing loss, and refer the child for hearing test to a Centre that specialises in testing young children”*.

The literature review indicated that high-risk register screening would not identify all children with hearing loss. Eventually it must be supplemented by a full identification programme which can, and should, include additional measures such as universal hearing screening.

In this study, it was found that parents were the first to identify hearing loss among their children and undue delays were reported in the referral process to the appropriate service for hearing assessment [median age of referral for hearing assessment was 22 months]. This implies that professionals are not as involved as they should be and professional education programmes are indicated. Professional education involves dissemination of knowledge in areas such as neonatal risk factors for hearing impairment, risk factors of acquired hearing impairment, early behavioural signs of hearing impairment and the ineffectiveness of crude measures of hearing sensitivity [N.I.H. Consensus statement 1993].

The empirical research data in this study indicated that among 69% of the children, known high-risk indicators could be identified. The high-risk register should be a valuable checklist to select the population to be screened for hearing impairment as indicated by Joint Committee on Infant

Hearing, 1982. **As a first priority, the high risk screening register procedure seems a viable concept in Mauritius** where there are well-established peri-natal care services available and the majority of the births take place under medical supervision. This method would successfully identify at least 50% of the children with severe hearing loss at an early age. The equipment cost [for example Otoacoustic Emissions] and training of personnel to use this equipment is a financial hurdle that will have to be overcome.

The screening process must be supported by participation of professionals [E.N.T specialists and Audiologists] **and equipment** necessary [auditory evoked potential audiometer] for the early diagnosis of the hearing loss. The present diagnostic procedures in general use is inadequate for infants and young children. The back up of an objective test such as evoked potential audiometry is indicated, as the median age of referral for assessment in the study [table 4.3 p.86] was 22 months. In 1997, the number of births in Mauritius was 19331 and the crude birth rate was 17.4 per 1000 mid-year population [Health Statistics Annual 1997, Mauritius]. Therefore the number of children referred for hearing evaluation following the screening process is likely to be very limited. This fact, combined with the limited number of professionals [such as Audiologists, Speech and Language Therapists and E.N.T. specialists] needed in Mauritius, will enhance the institution of an early identification programme.

Presently the median age of **diagnosis** of hearing loss among the children in the study is 24 months. With the proposed

screening process, professional and public awareness campaigns and the necessary back-up service to diagnose the hearing loss, a median age of diagnosis of hearing loss of at least 12 months earlier can be targeted.

Hitchings and Haggard [1983] state that it is generally beneficial to encourage referral since a marked increase in referrals resulted in early identification of hearing loss. In this study, the **referral process** was found to be slow with delay from the time the parents suspect hearing loss to the time the child is referred for hearing assessment. The awareness campaign should therefore include information on the identification and diagnostic process. Aspects such as whom the parents should contact when they suspect hearing loss and where the diagnostic facilities for hearing status of infants and children are available should form part of the awareness campaign. The participation of community health workers and community-based rehabilitation workers as referral sources can further improve the referral process as children from the community health centres can then be referred early for hearing assessment.

Bess and Humes [1995] suggest that the management of children with hearing loss requires a comprehensive service of diagnosis, recommendation, fitting of hearing aids and habilitation of the child and the child's family. The underlying principle is that once a child is suspected of having hearing impairment, a comprehensive assessment must be completed in a timely fashion in order to initiate medical referrals and complete entirely aural rehabilitation and educational management [ASHA 1991].

Efforts towards early identification will have limited effect if, for a number of reasons, there is an additional delay in the provision of hearing aids. In Mauritius, the Ministry of Social Security and National Solidarity plays a valuable role in service delivery to the hearing impaired by providing hearing aids to the needy and the aged.

In this study 70% of the children with hearing loss were provided with hearing aids by the Social Security. However, the waiting period for the provision of hearing aids varied among the children; some children were provided with hearing aids within a month and a majority [53%] had to wait more than 3 months. The median age for hearing aids placement in the study, was 30 months. Presently the E.N.T specialists, Audiologist, and Speech Therapist refer children who have been diagnosed with hearing loss and need hearing aids to the Ministry of Social Security and National Solidarity. For effective service delivery, the social security service must be **co-ordinated** with the health service, particularly the Audiology and Speech Therapy service, so that the children can be provided with the **hearing aids** as soon as diagnosed.

Maintenance of hearing aids is an additional aspect that should not be ignored [Clark, 1997 and WHO, 1999] although, it was not studied in this research project. The companies supplying the hearing aids must be under contract for repairs and servicing of the hearing aids. Parental guidance for effective use of the hearing aids by the child must be initiated and frequent contact with the Audiologist and Speech Therapist particularly during the

period the child is first provided with the hearing aids is important. It is suggested that the management process including diagnosis, provision of appropriate hearing aids, habilitation and parental guidance be provided as a **one-stop service**. This is a feasible system in Mauritius because of the geographical size of the area and the relatively low population.

The current worldwide trend is to have parent-professional partnerships during the identification and follow-up process [Briggs, 1991, Roush and Matkin, 1994]. **Parents of children with hearing loss** are the most important human resource identified but they need to be empowered with knowledge that can lead to action in helping their child develop communication skills. The scarcity of relevant professionals, specifically Audiologists and Speech Therapists [only 2 are currently available] makes it mandatory that there is some form of **role release**. The parents and other health personnel such as community-based rehabilitation workers should be able to follow-up the child's communication therapy at the home level rather than the centre-based model currently practised. Carney [1996] suggests identifying resources available within the community. Rossetti [1996] described the Home-Centre programme that combines centre-based child programmes and home visiting components. This would involve **training parents and community-based rehabilitation workers** to carry out the communication intervention programme in the most natural setting of the child namely, the **home**. The community-based rehabilitation service has been initiated under auspices of WHO and the Ministry of Health and Quality of

Life, since 1990 and is therefore an existing resource to be utilised.

Early identification followed by hearing aids placement and parental participation in developing communication skills, before the child is ready for pre-primary schooling, should result in **better communication skills**. This is an important criterion for integration of the hearing impaired child in the ordinary pre-primary school [Bench, 1992]. The role of the **pre-primary school teacher** in continuing the communication intervention programme thus becomes very important. It implies training these teachers to cope with a child with hearing loss in the class. The UNICEF in Mauritius, in collaboration with the Ministry of Health and Quality of Health has initiated a training programme for pre-primary school teachers in health care and child development [including communication development] of children between 3 and 5 years. It is recommended that the training regarding communication development should include aspects of communication skill development of children with hearing loss. Health, Social Security and Education Services are available but are currently offering fragmented services to children with hearing loss. It is imperative that all services involved in the care of children with hearing loss and their families work in co-ordination. [Katz, 1978, Briggs, 1991, Bess and Humes, 1995].

To summarise, an early intervention programme for children with hearing loss needs to provide a co-ordinated service at various levels namely:

- **The child** with hearing loss needs to be identified early during the first year of life through public and professional awareness campaigns.
- **The parents** and family members of the child with hearing loss need to be empowered with the knowledge that will help identify the problem early and lead to positive action in developing communication skills of the child with hearing loss.
- **Professionals should function as a team** in the assessment and follow-up of children with hearing loss. It is important to be sensitive to the fact that no single profession can provide the total habilitation needs of the hearing impaired child. The child with hearing loss will require medical referral, audiologic assessment, hearing aid evaluation, selection and procurement, communication training, family counselling, educational, psychosocial and vocational counselling, financial planning and assistance.
- **Health care personnel** such as the nursery staff, the community health workers, and the social worker need to be trained and must participate in the identification and follow-up process for children with hearing loss. As an initial step the use of a high-risk register can be implemented for early identification of hearing loss.
- The pre-primary, primary school **teachers** and teachers for children with special needs should be provided with the training necessary to cope with a child with hearing loss in the classroom.



- **Government** has an important role in providing **co-ordinated services** for implementing the awareness campaign, **policies** regarding early identification of hearing loss, intervention services, provision of hearing aids and policies regarding educational opportunities for children with hearing loss. Also, appropriate support services should be provided.

- **The community at large** to which the child with the hearing loss belongs needs to be sensitised regarding the importance of early intervention of children with hearing loss.

Above all, co-ordination and commitment among all the persons involved for the common goal of providing early intervention services to the child with hearing loss is necessary.

These conclusions and recommendations are based on empirical research findings in Mauritius. However, these recommendations may be adapted to suit the local context of any country, which has a context similar to Mauritius. It is true that each situation pertaining to hearing impaired children is unique and plans have to be tailored to suit that area's specific needs, but it is also true that in working with hearing impaired children what stands out is not the differences but the similarities [Clark 1997].

5.3 Critical Evaluation of the Study

Critical evaluation of the study is important as it can provide insight regarding the value of the research study. There is a need to reflect on the positive and negative elements of the study.

The main critique of this study is that not enough information from the **literature** was available regarding the identification and follow-up of children with hearing loss in **developing countries**. There is a possibility that other developing countries have found solutions that are viable for the problem of identification and follow-up of children with hearing loss in Mauritius. Unfortunately, as these findings are not well documented the researcher did not have access to this information.

The **questionnaire** did not cover in-depth information. This was an exploratory, first study of its kind. The baseline information obtained from the parents covered the main parameters such as identification, diagnosis and management process. The questionnaire formulated for this study [Appendix B] could be used in other contexts to obtain baseline information to describe the identification and follow-up process for children with hearing loss. However, further information will need to be probed through formulation of a more detailed questionnaire.

The focus of this study was on **parents' perspective of** identification and follow-up process among children with hearing loss. Professionals' and the policy makers' points of view were not considered in this study. Professionals form

an integral part of the team in identification and follow-up of children with hearing loss. Policy makers act as facilitators in implementing any intervention programme on a national basis. A description of the identification and follow-up from point of view of professionals and policy makers is important and should be the focus for research to provide further information regarding children with hearing loss in Mauritius.

The value of this study is that it is the first study of its kind in Mauritius and the main aim of providing baseline information regarding children with severe, pre-lingual, sensori-neural hearing loss was accomplished. Based on the study, priorities in an early intervention programme could be proposed. As the early intervention programme is implemented, further research can be carried out to improve and refine the programme to improve the future of children with hearing loss.

5.4 Recommendations for Further Research

The description of the current identification and follow-up process has raised several important issues for further research.

- The first priority would be to study the **financial costs** involved in implementing the suggested **early intervention programme**. These include the costs for active public and professional awareness campaign regarding the high-risk indicators and the referral process for children with hearing loss as well as the training of

personnel. The equipment and maintenance costs must also be taken into account.

- Also, survey research needs to be carried out to evaluate **public knowledge** regarding auditory behaviour and hearing loss in children, if it is to form part of a prevention strategy. The results of this research will enable appropriate and effective awareness campaigns.
- Another priority would be to carry out evaluative research to document the **outcome of the current identification and follow-up process**, for example the effects of late identification of hearing loss, the educational levels these children are able to achieve and the professions or vocations they are following can be valuable indications. The findings of such a research study would provide baseline information. Against this background, the benefits of implementing the early intervention programme could be objectively discussed. In view of financial constraints common to developing countries, it will be necessary for children, families and professionals to demonstrate that early identification and intervention enable children with hearing loss to reach their full potential.
- Research into **epidemiology and prevalence** of children with severe pre-lingual sensori-neural hearing loss in Mauritius is needed to provide evidence for investing in an early intervention programme.
- Every section of the **questionnaire**, requires an in-depth study to further describe and understand the current

situation pertaining to identification and follow-up of children with hearing loss in Mauritius.

5.5 Conclusion and Summary

Permanent childhood hearing impairment is a serious public health problem affecting at least one baby in one thousand. Intervention is proven to be most successful if commenced in the first few months of life. Effective programmes for early intervention of children with hearing loss must be established. Local constraints and limitations must be considered when implementing recommendations for early intervention. This should not deter our effort to resolve any constraints and limitations on best practice [ASHA 1990 p.63].

Parent education and counselling, family support and the identification of community resources are important components in the management process of infants with hearing impairments. An important statement by Diefendorf *et al* [1990 p.405], applicable to this study is *to be creative when there are needs and be persistent in pursuing available options*.

A great deal of further clinical research and data collection is necessary to answer the multiple questions that remain. These above-mentioned recommendations based on theoretical and empirical research will hopefully stimulate further research efforts in the field of children with hearing loss.



Clark [1997 p.248] states “*one of the biggest lessons I have learned since becoming involved in international work, especially in developing countries, is just how much can be achieved with amazingly limited resources.....what really counts in the end is the quality of human resources who manage the programmes and whether they have their priorities right*”. The aim in developing countries should be to identify and concentrate on the priorities and utilising the available resources to provide early intervention services to children with hearing loss.

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List of Appendixes

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Appendix A

Letter for consent from the Health Authorities

Mrs. R. Gopal
Senior Speech Therapist
E.N.T./ Victoria Hospital
2nd Feb. 99

Permanent Secretary
Ministry of Health

Through: Regional Health Director
Victoria Hospital

Dear Sir,

Re: Permission to carry out research

**Topic: Identification and Follow-up of children with hearing loss, in
Mauritius**

You are aware that I am a distance learning student of University of Pretoria, studying for Masters degree in Communication Pathology.

The second part of Masters degree involves planning, carrying out Research and writing theses on a topic concerned with my chosen theme namely Paediatric Audiology. I am planning to carry out Research on the topic: "Identification and Follow-up of children with hearing impairment in Mauritius".

I request your permission to:

1. Select a sample, children with severe hearing loss from the hospital records in the Speech Therapy Unit.

2. Call the parents of the selected children for questionnaire based interviews in the Speech Therapy Unit after obtaining informed consent for their participation in the study.

The questionnaire will probe information regarding the ages of suspicion of hearing loss, referral routes the parents take, hearing assessment and the subsequent follow-up. Enclosed is a copy of the questionnaire on which the interviews will be based.

This in-depth study of the current status of identification and follow-up process for children with hearing loss in Mauritius will give us an understanding of the intervention process. Based on this study, an early intervention programme for children with hearing impairments will be proposed.

I shall be very grateful for your permission to carry out the Research.

Thanking You,

Yours faithfully,

Mrs. R. Gopal
Senior Speech Therapist

Copy: Consultant-in-Charge, E.N.T. Hospital



Appendix B:

The Questionnaire

IDENTIFICATION AND FOLLOW UP OF CHILDREN WITH HEARING LOSS IN MAURITIUS

SECTION 1. IDENTIFICATION OF SUBJECT **CASE NUMBER**

1.01 SURNAME:.....

1.02 OTHER NAMES:.....

1.03 TELEPHONE NUMBER:.....

1.04 RESIDENTIAL ADDRESS:.....

.....

1.05 ADDRESS CLASSIFIED AS:..... Urban 1
 Rural 2

1.06 SEX:..... Male 1
 Female 2

1.07 DATE OF BIRTH OF SUBJECT:.....

1.08 AGE OF SUBJECT IN COMPLETED MONTHS:.....

1.09 NO. OF CHILDREN IN FAMILY:.....

1.10 RANK OF SUBJECT:.....

SECTION 2. IDENTIFICATION OF PARENTS/RESPONDENT

2.01 RESPONDENT Father 1
 Mother 2
 Parents 3
 Other 4

2.02 If RESPONDENT IS "OTHER"
 RELATIONSHIP TO THE SUBJECT Grandparent 1
 Uncle/Aunt 2
 Other relationship 3
 Not Related 4



- 2.03 EDUCATION OF FATHER:..... Not beyond Primary 1
 Secondary 2
 Beyond Secondary 3
- 2.04 EDUCATION OF MOTHER Not beyond Primary 1
 Secondary 2
 Beyond Secondary 3
- 2.05 MONTHLY INCOME OF PARENTS:.... Less than Rs. 5000 1
 Rs. 5, 000 - 10000 2
 Rs. 10,000 – 20000 3
 Rs. 20,000 and over 4

SECTION 3. FAMILY HISTORY OF HEARING LOSS

- 3.01 ANY FAMILY HISTORY OF PRELINGUAL HEARING
 IMPAIRMENT ?..... Yes 1
 No 2
- 3.02 IF YES, CLOSEST RELATIONSHIP: Sibling 1
 WITH CHILD Parent 2
 Grandparent 3
 Uncle/Aunt 4
 Cousin 5
 Other 6
- 3.03 IF MORE THAN ONE RELATIVE WITH FAMILY
 HISTORY OF PRELINGUAL HEARING
 IMPAIRMENT ... SPECIFY HOW MANY AND
 HOW ARE THEY RELATED TO THE CHILD:
- 3.04 ANY HISTORY OF CONSANGUNITY: Yes 1
 No 2

SECTION 4. PERINATAL/MEDICAL HISTORY OF SUBJECT

- 4.01 DID MOTHER HAVE ANY SIGNIFICANT HISTORY DURING
 PREGNANCY ?..... Yes 1
 No 2
- 4.02 IF YES, WAS IT A HIGH RISK FACTOR FOR PRESENT
 CONDITION OF SUBJECT?..... Yes 1
 No 2



4.03 PLACE OF DELIVERY OF SUBJECT ?.....	Hospital	1	
	Clinic	2	
	Home	3	<input type="checkbox"/>
	Other	4	
4.04 MATURITY OF SUBJECT AT DELIVERY?...	Premature	1	
	Normal	2	<input type="checkbox"/>
	Postmature	3	
4.05 MODE OF DELIVERY OF SUBJECT?.....	Normal	1	
	Breech	2	
	Forceps	3	<input type="checkbox"/>
	Other	4	
4.06 BIRTHWEIGHT OF SUBJECT (kg to one decimal place):			<input type="text"/> <input type="text"/>
4.07 ANY SIGNIFICANT MEDICAL HISTORY OF SUBJECT?			
	Yes	1	
	No	2	<input type="checkbox"/>
4.08 IF YES, SPECIFY			
4.09 ANY SIGNIFICANT DEVELOPMENT HISTORY OF SUBJECT?			
	Yes	1	
	No	2	<input type="checkbox"/>
4.10 IF YES, SPECIFY			<input type="checkbox"/>
4.11 DID SUBJECT POSSESS ANY CHARACTERISTICS OF REGISTER HIGH RISK FOR HEARING LOSS ?.....	Yes	1	
	No	2	<input type="checkbox"/>
4.12 IF YES, SPECIFY			<input type="checkbox"/>

SECTION 5. IDENTIFICATION OF HEARING LOSS

5.01 AGE (IN COMPLETED MONTHS) OF SUBJECT WHEN HEARING MPAIRMENT WAS FIRST SUSPECTED:.....

5.02 WHAT CAUSED THE SUSPICION?
.....

5.03 AFTER YOUR INITIAL SUSPICION, WHAT DID YOU DO?
.....



5.04 WHERE WAS THE SUBJECT FIRST TAKEN?

- Mediclinic/AHC/CHC 1
- Hospital 2
- Private Clinic 3
- Private Doctor 4
- Other 5

- 5.05 WHO SAW THE SUBJECT?.....
- Paediatrician 1
 - ENT Specialist 2
 - Other Specialist 3
 - Non-Specialist Doctor 4
 - Don't know 5

5.06 WHAT COUNSEL WAS GIVEN THERE?

5.07 WHERE WAS THE SUBJECT REFERRED?

5.08 WHO REFERRED THE SUBJECT TO THE AUDIOLOGY & SPEECH THERAPY UNIT?.....

5.09 AGE OF THE SUBJECT (IN COMPLETED MONTHS) WHEN REFERRED TO THE UNIT?

SECTION 6. DIAGNOSIS OF HEARING LOSS

6.01 TIME ELAPSED BETWEEN FIRST CONTACT OF SUBJECT WITH UNIT AND ACTUAL ASSESSMENT

- Less than 1 week 1
- 1 - < 2 weeks 2
- 2 - < 4 weeks 3
- 4 weeks and over 4

6.02 AGE OF SUBJECT (IN COMPLETED MONTHS) AT TIME OF HEARING EVALUATION?

6.03 AFTER CONFIRMATION OF HEARING LOSS DID YOU SEEK ANOTHER OPINION?.....

- Yes 1
- No 2

6.04 IF YES, FROM WHOM?

SECTION 7. HEARING AIDS

7.01 AGE OF SUBJECT (IN COMPLETED MONTHS) WHEN REFERRED FOR HEARING AIDS RECOMMENDATION:.....



7.02 TIME ELAPSED BETWEEN RECOMMENDATION AND ACTUAL

- RECEIPT OF HEARING AIDS.....Less than 1 month 1
1 - < 3 months 2
3 - < 6 months 3
6 months and over 4

7.03 WAS THE SUBJECT FOLLOWED-UP WHILE WAITING FOR THE HEARING AIDS?.....Yes 1
No 2

7.04 IF YES, GIVE DETAILS.....

7.05 WHO PROVIDED THE HEARING AIDS?

- Parents 1
Social Security 2
Other, specify 3
Aids not yet provided 4

7.06 AGE OF CHILD (IN COMPLETED MONTHS) WHEN HEARING AIDS WERE FIRST WORN?.....

7.07 IS SUBJECT CURRENTLY USING THE HEARING AIDS ?

- Yes 1
No 2

7.08 IF NOT, WHY?

SECTION 8.MEDICAL AND THERAPEUTIC FOLLOW-UP

8.01 IS THERE FOLLOW-UP WITH ENT SPECIALIST ?

- Yes 1
No 2

8.02 IF YES, HOW OFTEN ? Every month 1
Every 2 months 2
Every 3 months 3
Less often 4

8.03 IS THERE FOLLOW UP AT AUDIOLOGY AND SPEECH THERAPY UNIT? Yes 1
No 2

8.04 IF YES, HOW OFTEN?..... Every month 1
Every 2 months 2
Every 3 months 3
Less often 4

Appendix C

Listing of Indicators or High Risk Factors Associated with Sensorineural Hearing Loss

[Adapted from ASHA Joint Committee on Infant Hearing 1994
Position Statement]

- Family history of hereditary, childhood sensorineural hearing loss.
- In utero infection such as cytomegalovirus, rubella, syphilis and toxoplasmosis.
- Craniofacial anomalies including those with morphologic abnormalities of the pinna or ear canal.
- Birth weight less than 1.5 kgs. [3.3 lbs]
- Hyperbilirubinemia at a serum level requiring blood transfusion
- Ototoxic medications including aminoglycosides used in multiple courses or in combination with loop diuretics.
- Bacterial meningitis
- APGAR scores 0-4 at 1 minute or 0-6 at 5 minutes.
- Mechanical ventilation lasting 5 days or longer
- Stigmata or other findings associated with a syndrome known to include a sensorineural hearing loss.



Appendix D

Letter inviting the parents of the children with hearing impairment for a meeting

Mrs. R. Gopal
Senior Speech Therapist
Speech Therapy Unit
E.N.T Hospital
18th Feb 99

Dear

I am carrying out a study on "Identification and Follow-up of Children with Hearing Loss in Mauritius". As your child is following Speech Therapy here, I would like to invite you on **Friday 26.02.99 at 1.00 p.m. in the Conference Room of E.N.T Hospital for a meeting.**

The purpose of this meeting is to explain to you the nature of the study.

If you are unable to attend on this date at this time, please phone Mrs.Gopal, Speech Therapist on 6862061 to take another appointment.

Thanking you for your co-operation. I look forward to your presence.

Sincerely,

Mrs. R. Gopal



Appendix E

Consent Form for participation in the study

Consent Form for participation in the study: **Identification and Follow-up of children with hearing loss in Mauritius.**

I /We the parent/s of

agree to participate in the study which will involve answering questions, during an interview, pertaining to the identification and follow-up of my child.

Signature

Date
