ESTABLISHING A COMPUTER-BASED DATA SYSTEM FOR EARLY COMMUNICATION INTERVENTION IN SOUTH AFRICA

by

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This thesis is dedicated to the youngest children of South Africa …

… our children, the most valuable citizens in any society and the greatest of our treasures

… we are all of us, as individuals, called upon to give direction and impetus to the changes that are vital to the future of our youth and our country

… our children are our nation’s future

Nelson Mandela
former President of South Africa

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An African proverb says it takes a village to raise a child.
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ABSTRACT

TITLE	Establishing a Computer-Based Data System for Early Communication Intervention in South Africa
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Key words: Early communication intervention, early intervention, relational database, research tool, infants, young children, families, cleft lip and palate, early identification, risk conditions

The study identifies the increase in populations at risk for communication disorders world-wide and in South Africa as one the reasons for research to develop early communication intervention (ECI) services as a societal responsibility in South Africa. Since ECI is largely an unknown entity in the South African health system, but shares several mutual objectives, the dire need for data of populations at-risk validates the development of a computer-based relational data system as a 21st century research tool for ECI. Underpinnings for the development of a research database for ECI were obtained from the use of database management systems for early intervention in the USA, identified as leaders in the application of database technology in the field of Speech-Language Pathology.

The aim of the study was to develop and establish a computerized database system to describe the characteristics of young children at risk for communication disorders enrolled in an existing ECI programme. Using a descriptive survey as research design, a rich description of 153 subjects and their families was obtained. The findings relating to the multiple risk profiles of the subjects revealed results not extensively described or emphasized in the literature, indicating the in-depth analysis of results that is possible when utilizing a database approach to research. The complex risk profile found in the subgroup of subjects with cleft lip and palate is an example of a need for further investigation. The results also indicated the critical importance of early identification of risk events throughout a child's life to improve the efficacy of ECI services. Further results emphasized the important role of parents to identify the early signs of risks for communication disorders in their children, provided they are equipped with the necessary knowledge. A conceptual framework for the early identification of risks for communication disorders is proposed for best practice in ECI in South Africa.

The study concluded that the CHRIB database system was successfully applied in the empirical research and is now established as a versatile 21st century research tool to be utilized in second generation research in ECI in South Africa.

OPSOMMING

TITEL	Die Vestiging van 'n Rekenaargebaseerde Datasisteem vir Vroeë Kommunikasie Intervensie in Suid-Afrika.
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Sleutelwoorde: Vroeë kommuniasie intervensie, vroeë intervensie, relasionele databasis, navorsingsinstrument, babas, jong kinders, gesinne, gesplete lip en verhemelte, vroeë identifikasie, risikotoestande

Die studie identifiseer die toename in populasies met 'n risiko vir kommunikasieafwykings wêreldwyd en in Suid-Afrika, as een van die redes vir navorsing om vroeë kommunikasie intervensiedienste (VKI) as 'n gemeenskapsverantwoordelikheid in Suid-Afrika te ontwikkel. Aangesien VKI hoofsaaklik 'n onbekende entiteit in die Suid-Afrikaanse gesondheidsisteem is, maar verskeie gesamentlike doelwitte deel, regverdig die groot leemte aan navorsing oor risiko-populasies, die ontwikkeling van 'n rekenaargebaseerde relasionele datasisteem as 'n 21e eeu navorsingsinstrument vir VKI. Die fundering vir die ontwikkeling van 'n navorsingsdatabasis in VKI is gegrond op die gebruik van databasis bestuursisteme vir vroeë intervensie in die VSA, wat as leiers in die toepassing van databasistegnologie op die gebied van Spraak-Taalpatologie geïdentifiseer is.

Die doel van die studie was om ‘n rekenaargebaseerde datasisteem te ontwikkel en te vestig, en dit aan te wend om die eienskappe van jong kinders met ‘n risiko vir kommunikasieafwykings in ‘n bestaande VKI program te beskryf. Die gebruik van ‘n beskrywende opname as ‘n navorsingsontwerp, het ‘n ryk beskrywing van 153 proefpersone en hulle gesinne gelewer. Die bevindings wat met die veelvuldige risikoprofiele van die proefpersone verband hou, het resultate wat nie uitgebreid in die literatuur beskryf of beklemtoon is nie, aan die lig gebring, wat dui op die grondige analise van resultate wat met die aanwending van ‘n databasisbenadering tot navorsing moontlik is. Die gekompliseerde risikoprofiel van die subgroep van proefpersone met gesplete lip en verhemelte is ‘n voorbeeld van ‘n behoefte aan verdere navorsing. Die resultate het ook die kritiese belang van die vroeë identifikasie van risikogebeure gedurende ‘n kind se lewe om die effektiwiteit van VKI dienste te verbeter, aangedui. Verdere resultate het die belangrike rol van ouers beklemtoon om die vroeë tekens van risiko’s vir kommunikasieafwykings in hulle kinders te identifiseer, mits hulle toegerus is met die nodige kennis. ‘n Konsepsuele raamwerk vir die vroeë identifikasie van risiko’s vir kommunikasieafwykings is voorgestel as beste praktyk in VKI in Suid-Afrika. .

Die studie kom tot die gevoltrekking dat die KHRIB datasisteem suksesvol toegepas is in die empiriese navorsing en dat dit gevestig is as ‘n veelsydige 21e eeu navorsingsinstrument wat in tweedegenerasie navorsing in VKI benut kan word in Suid-Afrika.

CONTENTS

CHAPTER 1

A RATIONALE FOR DEVELOPING THE FIELD OF EARLY COMMUNICATION INTERVENTION IN SOUTH AFRICA

CHAPTER 2

AN OVERVIEW OF BEST PRACTICE IN EARLY COMMUNICATION INTERVENTION

CHAPTER 3

STRATEGIES TO DEVELOP EARLY COMMUNICATION INTERVENTION IN THE SOUTH AFRICAN CONTEXT

CHAPTER 4

DATABASE SYSTEMS IN EARLY COMMUNICATION INTERVENTION

CHAPTER 5

METHODOLOGY

CHAPTER 6

RESULTS AND DISCUSSION

CHAPTER 7

CONCLUSIONS AND IMPLICATIONS

LIST OF TABLES

LIST OF FIGURES

APPENDICES

CHAPTER 1

A RATIONALE FOR DEVELOPING THE FIELD OF EARLY COMMUNICATION INTERVENTION IN SOUTH AFRICA

CHAPTER 1

A RATIONALE FOR DEVELOPING THE FIELD OF EARLY COMMUNICATION INTERVENTION IN SOUTH AFRICA

Aim: The chapter aims to orientate the reader to the relevance of the study by discussing the various incentives for developing the field of ECI internationally and in South Africa, by presenting a rationale for the study, stating the research problem, clarifying terms, and providing an outline of the organisation of the thesis.

1.1 INTRODUCTION

Early communication intervention (ECI) has developed as a dynamic field of study over the past thirty years. Currently practised in many countries in the world, ECI is shaped by international influences and characterised by diverse scientific bases to meet the needs of families with infants and toddlers with disabilities or at risk for communication disorders at the earliest possible stage.

Contributing to the scientific underpinnings of ECI, research into human genetics, infant development and early mother-infant care-giving practices since the 1960s, has provided new insights into the remarkable capabilities of typically developing infants.

There is, however, an increasing awareness in the field of ECI of the limitations of applying knowledge gleaned from research of populations other than infants at risk for disabilities (Marfo & Dinero, 1991). Medical and care-giving advances in neonatal care are examples of research which is based on the needs of at-risk populations. Watershed research in these areas has been the direct motivation for the development of the modern neonatal intensive care unit with its sophisticated equipment, medicines, procedures and developmentally appropriate care– all of which are practised and utilized exclusively to the benefit of the population of neonates who are in need of critical care.

It is, however, not only the remarkable advances in research which gave an impetus to the development of ECI. Various incentives for the development of ECI have emerged from the clinical demands of the growing population of infants who are at risk and who have disabilities. Epidemiological studies have revealed that increasing numbers of infants at-risk survive as a result of advanced medical care (Lubker, 1991). Those who survive include premature infants and those with low birth weight as well as those who survive malnutrition, infectious diseases and traumatic injury (Scherzer, 1995). The population of infants at risk appears to be growing as new populations, such as infants with prenatal cocaine exposure (MacDonald, 1992) and with paediatric HIV/AIDS (Capobres, 1992), have emerged over the past two decades. This growing population of infants at risk and with disabilities indicates how urgent the need for ECI programme planning, constant evaluation of strategies, and an ever-increasing knowledge about the effects of risk conditions on the development of these infants is.

The vast amount of information currently available which may be utilized effectively to improve the outcome of infants at-risk and infants with disabilities, implies that the provision of ECI services should no longer be seen as a choice, but rather as an ethical obligation. Guralnick (1997) states unequivocally that it is a societal responsibility to provide EI programmes to young children with disabilities and to those who are at risk for developmental delays. The passing of the USA Public Law 99-457*, Education of the Handicapped Act Amendments* in 1986 formally gave recognition to the consensus that society has a responsibility to provide ECI to those who require these services. The USA law requires all states to extend the scope of their services to families with children with disabilities so as to include infants and toddlers between birth and three years old. This act, since amended and currently known as *IDEA (Individuals with Disabilities Education Act*, 1991) (Kurtz, Dowrick, Levy & Batshaw, 1996), stresses the need for a state-wide, comprehensive system of EI services for all infants and toddlers with special needs, from birth onwards and with the full involvement of their families. The American legislation serves as an example of effective collaboration between different government sectors such as health, education and social services and the formalization of EI so that policy objectives, strategies and programmes can be monitored, evaluated and adapted to effectively meet the needs of young children at-risk and their families.

The overview of some incentives that led to the development of ECI indicated how scientific advances and the recognition of a growing population of infants requiring ECI, contributed to the formalization of ECI service delivery in the USA. This process has culminated in the acknowledgement of society's responsibility to deliver ECI services to those who need it and the passing of appropriate legislation in the USA. Globally, ECI is therefore well established in developed countries and already directing research efforts towards so-called second generation research (Guralnick, 1997), but the developing countries are lagging behind. Despite the remarkable progress over the past thirty years ECI services are not yet available to *all* infants and toddlers at risk for communication disorders in developing countries.

New directions for the development of ECI services originated from international trends in health care management, such as those spearheaded by the World Health Organisation (WHO). The *Global Strategy for Health for All by the year 2000* (WHO, 1981) proposed the provision of primary health care services as close as possible to where people live and work, an emphasis on health promotion and disease prevention, and a focus of health care on vulnerable groups such as mothers and children. These proposed actions can be viewed as strategies that are directly relevant to ECI. The emphasis on maternal, child and women's health implies that disease and disabilities will best be prevented if women are contacted before or during pregnancy, if mothers are educated, and if the infant population is targeted. The global objective is therefore to develop various processes, of which ECI should be an integral one, for the attainment of the highest possible level of health for all people. ECI should be integral to these courses of action as early communication skills represent the only developmental domain which directly relates to school success (Capute, Palmer & Shapiro, 1987).

The global challenge to progressively improve the health status of *all* people provides the field of ECI with new reasons to adapt and expand beyond the present boundaries of services to infants at risk and with disabilities and to their families. If the aim of ECI is to reach all infants and their families who require these services as early as possible, it is the communities in developing contexts that experience a dire need for ECI. The challenge for early communication interventionists in a country such as South Africa is to effectively collaborate with the health sector to be active role players in community-based rehabilitation endeavours as this is the only way to reach clients with limited resources.

1.2 RATIONALE FOR DEVELOPING ECI IN SOUTH AFRICA

In contrast to developed countries where ECI programmes are established and proven to be effective (Rossetti, 1996), the provision of ECI services is limited and fragmented for most of those who need them in developing countries. The necessity to develop effective and relevant ECI programmes in developing contexts is of great importance, as the majority of the population of children with disabilities and those at risk for developmental delays, live in developing countries (Helander, 1993). This is particularly true of the South African context which is characterised by pockets of developed areas but where the majority of the population live in poverty in urban, peri-urban and rural areas and no adequate ECI services exist (Fair & Louw, 1999).

It is estimated that 80% of black children with disabilities in South Africa live in extreme poverty and inhospitable environments, with poor access to health care and rehabilitation facilities *(White Paper on an Integrated National Disability Strategy*, 1997). The disadvantaged environmental circumstances of many children in South Africa (Patel, 1993) increase the risk for disabilities or double the risk for those infants and toddlers already displaying risk conditions

(Escalona, 1987). Table 1.1 was compiled to illustrate the conditions of children with disabilities in South Africa, as described in the *White Paper on an Integrated National Disability Strategy* (1997).

Table 1.1 Distribution of population groups, unemployment and people with disabilities in SA

Population group	African	White	Coloured	Indian
Population figures	76,3%	12,7%	8,5%	2,5%
Unemployment figures as % of the economically active population	87,5%	3,5%	7,5%	1,5%
Number of people with disabilities in thousands Total: 41 544 Total South African population: 37,9 million	**31 676**	**5 215**	**3 602**	**1 051**

Source: All figures are based on the 1995 October Household Survey and released by Central Statistical Services, 1997a.

Table 1.1 provides an indication of the prevalence of poverty and disability among the different population groups in South Africa. Unemployment figures are used as an indicator of poverty (Woolard & Barberton, 1998). As no reliable figures on the current prevalence of disability in South Africa among children could be obtained, figures on adults with disabilities (i.e. adults with serious eye defects, hearing and speech impairments, physical disabilities and mental disabilities) are quoted. It is estimated that 53% of South Africans live below the R301 a month poverty line and that 95% of the country’s poor people are black (Stucky, 1998). It is therefore clear that the majority of the children and infants with disabilities in South Africa will be African and from poor and unemployed households. It is now generally accepted that children under five who are living in poverty not only suffer from poor health, but are also at greater risk for developmental, behavioural and education delay than their middle class counterparts (Kaplan-Sanoff, Parker & Zuckerman, 1991;

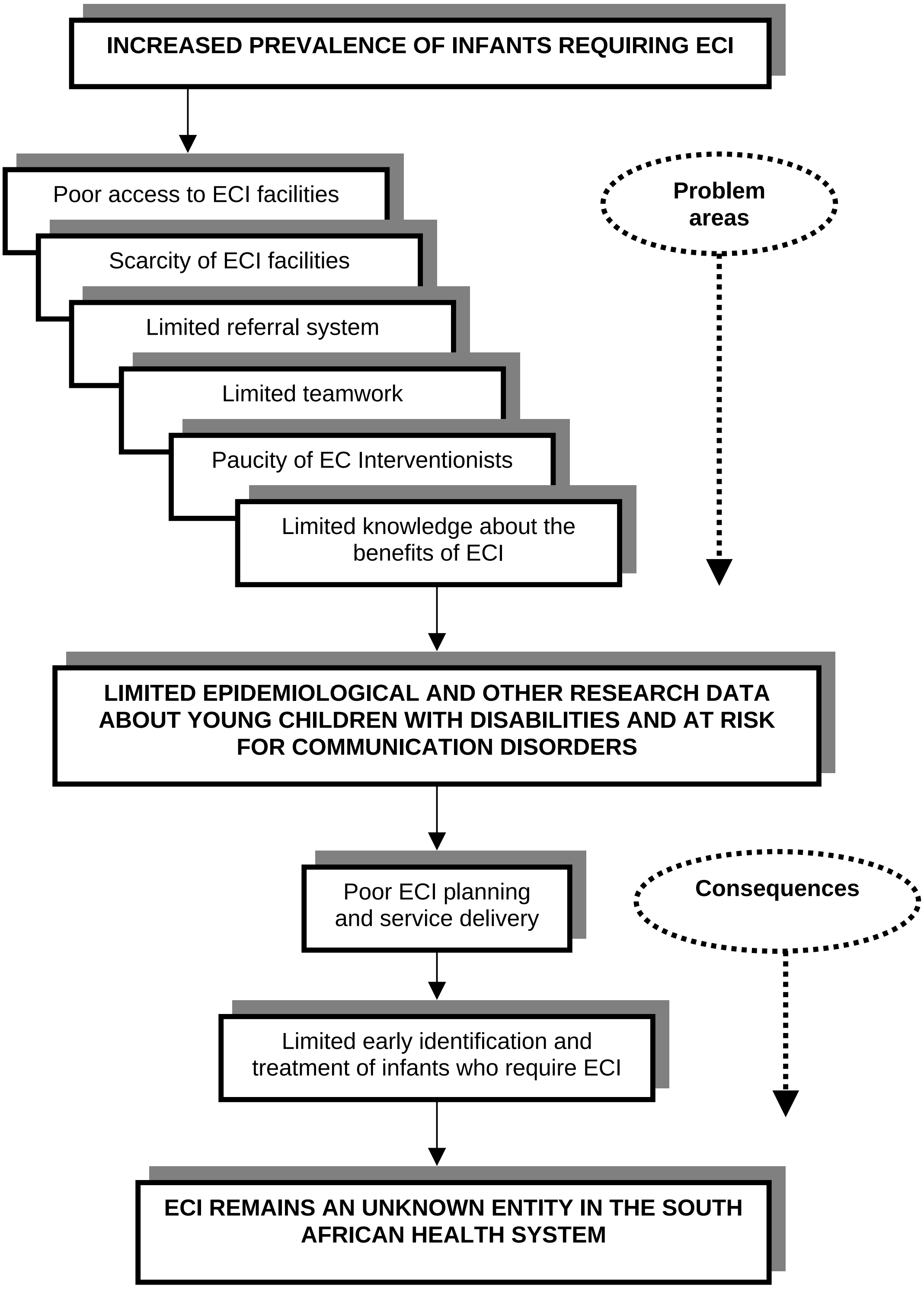

Figure I.I Analysis of the problem areas relating to ECI service delivery in South Africa

Lequerica, 1997). The relevance of research to develop ECI in South Africa becomes clear when one considers the local multifaceted problem areas in service delivery and their consequences. Figure I.I provides an analysis of the complexities currently facing ECI service delivery in South Africa and gives rise to a rationale for further research to develop ECI.

With reference to Figure I.I, the problem areas of ECI service delivery and the consequences in South Africa are highlighted:

- South Africa has *an increased prevalence of infants and toddlers at risk for disabilities*. Since delayed communication development is the most common symptom of developmental disability in children under three years of age (Rossetti, 1996), South Africa also has an increased population of young children requiring ECI services.
- *Poor access to health care and rehabilitation facilities* for communities who live in poverty and in rural areas, implies that early identification of disabilities and risk conditions, followed by early treatment, cannot take place (Christianson, 1997).
- It is, however, not only a problem of poor access to facilities. There are *too few public or private ECI facilities* available to serve the whole population of infants and toddlers at-risk and their families (Haasbroek, 1999). Currently, these ECI facilities are run from clinics at a few hospitals and some universities. At this stage, only a few primary health care clinics offer ECI services (Department of Health, Welfare and Gender Affairs, Mpumalanga, 1997).

  As an example of limited ECI services rendered at public hospitals, the results of a recent survey in Pretoria are presented in Table 1.2.

Table 1.2 Age profile of clients receiving rehabilitation services in public hospitals in the Pretoria Region

Age Intervals	**0-1y**	**1-8y**	**8-16y**	**17-35y**	**35-65y**	**66-85y**	**86+y**
# of Clients	95	292	123	750	824	218	13
Percentage	4.1%	12.6%	5.3%	31.7%	35.6%	8.6%	0.5%

Adapted from Smith, 1997. Pilot Survey of Conditions Treated by Rehabilitation Personnel in Hospitals in the Pretoria Region. Preliminary report prepared for the Gauteng Department of Health and the Pretoria Regional Office.

According to Table 1.2 the findings of a survey of rehabilitation services rendered at public hospitals in the Pretoria region indicate that infants between 0 to 12 months old received only 4.1% of the total number of services provided by the rehabilitation team. It appears that the largest percentage of rehabilitation services are rendered to the adult population, i.e. 31.7% to the 17 - 35 years age group and 35.6% to the 37 - 65 years age group respectively (Smith, 1997). Since the complete spectrum of conditions requiring rehabilitation services, such as neurological, surgical, mental and medical conditions, trauma and congenital abnormalities, were covered by the rehabilitation services, the number of infants receiving services appears to be very low.

Although no ideal proportional figures can be cited as rehabilitation contexts can differ significantly, it is preferable that more time should be allocated to rehabilitation services to infants. The consequences of limited ECI services in public hospitals in Pretoria require further explanation. All the districts in Pretoria, which act as referral bases of the hospitals participating in the study, display an increased prevalence of neonates with low birth weight (Pattinson & Hay, 1999; Rautenbach, Terblanche & Venter, 1997). Table 1.3 was compiled to indicate that all the districts of Pretoria display an increased prevalence of infants born below 2 500g birth weight, a population of infants who require ECI services, but is currently underserved in public hospitals in Pretoria. In contrast, the prevalence of low birth weight in developed countries is below 10% (Rossetti, 1990a).

Table 1.3 Low birth weight rate in the Pretoria Districts, 1996-1997

District	Low Birth Weight Rate %
Atteridgeville	16.3%
Pretoria Suburbs	12.9%
Pretoria Academic Hospital	17.0%
Mamelodi	12.7%

Source: Pattinson & Hay, 1999

Another implication of the scarcity of ECI facilities is that valuable opportunities to render effective services are missed. It is now widely accepted that rehabilitation services have the greatest possibility for success in the infant and toddler population and have been proven to be effective (Rossetti, 1996; Guralnick, 1997; McConkey, 1995a). The results of the *Infant Health and Development Program* in the USA, a large follow-up study of 985 subjects, indicate that, depending on timing, duration and intensity, EI services are effective for infants with low birth weight and prematurity (Blair, Ramey & Hardin, 1995; McCarton, Brooks-Gunn, Wallace, Bauer, Bennett, Bernbaum, Broyles, Casey, McCormick, Scott, Tyson, Tonascia & Meinert, 1997). As EI may effect secondary prevention, with the possibility that no further treatment is necessary for certain clients *(White Paper on an Integrated National Disability Strategy*, 1997), a decrease in the future caseload of rehabilitation services is possible. This, however, is not possible if sufficient ECI facilities are not available.

- As further indicated in Figure I.I, the implications of the scarcity of ECI facilities are that health care workers who have to make referrals, are not aware of the importance of ECI as the starting point of rehabilitation services to infants at risk, as well as its benefits for the prevention of further disabilities. *Limited referrals* and a lack of a co-ordinated referral system therefore contribute to the fact the ECI is largely unknown in the South African health care system (Malan, 1993; Mulder, 1998).
- The *lack of well-structured teamwork* further adds to the dilemma of ECI case finding. This implies that, even if infants with disabilities, especially those with externally visible congenital anomalies, are identified early, they

may not be successfully enrolled in an ECI programme (Venter, Christianson, Hutamo, Makhura & Gericke, 1995). If infants with more easily identifiable disabilities are lost to ECI, case finding from the population of infants at-risk could be even less successful. This may be attributed to the limited of knowledge of the health care team about risk factors and their developmental sequelae for the acquisition of communication skills. A high risk register as an indicator of an infant's risk status for communication delay and a resource for early identification, is currently not widely available (Kritzinger, Louw & Hugo, 1995).

- The scarcity of ECI facilities also implies that there are *not enough early communication interventionists* to provide services and to train other health care workers to make services accessible to more clients (Delport, 1998; Haasbroek, 1999; Louw & Weber, 1997; Malan, 1993; Moodley, 1999). Training for early communication interventionists is university-based and until 1998 there was only one university offering modules in ECI as part of the undergraduate coursework for a degree in Communication Pathology. The implication is that not all qualified speech-language therapists and audiologists have training in ECI (Louw, 1994) and are therefore ill-equipped and too limited in numbers to provide adequate services.
- If there are not sufficient numbers of early communication interventionists and they do not have a visible presence at facilities where services are rendered to infants and toddlers, there will be limited knowledge about the benefits of ECI and limited research will be done. The consequences of limited ECI services are fragmented planning of ECI service delivery, limited identification and treatment of those who require ECI and ECI remains largely an unknown entity in the South African health system.

The most important rationale for research to develop ECI in South Africa is, however, *the increased prevalence of risk conditions for communication disorders in certain communities*. Based on available data, Table 1.4 provides examples of the risk conditions for which there is an increased prevalence in South Africa. The list is not complete since epidemiological data of risk conditions in South Africa is incomplete and difficult to obtain. The reasons for lack of accurate data relate to failures of recording systems, incomplete identification of cases and diagnostic inaccuracies (Yach, 1991), which in itself indicates the dire need to collect data on populations requiring ECI in order to develop the field in South Africa. If epidemiological data is incomplete, the planning of ECI services is severely hampered.

Table 1.4 Increased prevalence of risk conditions associated with communication disorders in the infant population in South Africa

Risk condition	Local community relating to subjects	Prevalence in South Africa and source	Prevalence in developed countries and source
Low birth weight >2 500g	General population	12% (WHO Report, 1990)	6-8% (WHO Report, 1996)
Low birth weight >2 500g	Kalafong Hospital, Pretoria	33% (Rautenbach, *et al*., 1997)	6-8% (WHO Report, 1996)
Down syndrome	Rural hospital, Northern Province	2.10 per 1000 live births (Venter, *et al*., 1995)	1.53 per 1000 live births (Gorlin, Cohen, Levin, 1990)
Cleft lip and palate	Coloured community	1.40 per 1000 live births (Department of Health and Welfare, 1985)	1.30 per 1000 live births (Department of Health, 1995)
Cerebral palsy	General population	Figures unknown, but estimated to be higher than in developed countries (*White Paper on an Integrated National Disability Strategy*, 1997)	2 per 1000 live births (Molteno & Arens, 1991)
Fetal alcohol syndrome	Wellington District, Western Cape	4,8% (Viljoen, 1999)	1 - 2 per 1000 live births (Kurtz, *et al*., 1996)
Significant bilateral sensori-neural hearing loss	General population	1% (DEAFSA, 1995)	1 - 2 per 1000 live births in Europe (Hall, 1991)

According to Table 1.4, the prevalence of low birth weight is increased for the general population as a whole, but may still be higher in certain communities such as the urban and peri-urban poor black communities served by Kalafong Hospital, Gauteng. The fact that all the conditions listed in Table 1.4, even those with a hereditary component such as cleft lip and palate and sensori-neural hearing loss, display an increased prevalence in South Africa, points to the debilitating effect of the adverse environmental conditions in a developing country on the prevalence of disabilities (Wilson & Ramphele, 1989).

Other developing countries may also display an increased prevalence of risk conditions listed on Table 1.4, but the alarmingly high prevalence of fetal alcohol syndrome may be unique to South Africa. The increased rate of alcohol related diseases found in the Western Cape (Viljoen,1999) is associated with the custom to give farmworkers daily rations of wine as part of their wages. This custom is now widely criticised, but dates back to the time of colonisation and slavery in the 17th century (Viljoen, 1995). The result of the widespread alcohol abuse in the wine producing areas of the Western Cape, especially the Wellington district, is an increased prevalence of children with fetal alcohol syndrome. An epidemiological study completed in 1997 revealed that 48 children of 992 (4,8%) school-entry children from the Wellington district were found to have clinical features and developmental deficits consistent with fetal alcohol syndrome (Viljoen, 1999).

The increased prevalence of risk conditions listed in Table 1.4 is of special significance for ECI. Although all these conditions can result in a number of developmental disorders, a specific risk for communication delay is inherent in all of them. In other words, no matter what the risk factor for a specific condition may be, the most frequently reported area of delay is in regard to communication skills. As delayed communication development is directly linked to school failure and lower earning potential later in life (Rossetti, 1996), it is clear that the development of communication-based EI services should receive priority in South Africa. Although incomplete, the local epidemiological data emphasises the urgent need to develop not only ECI services, but also comprehensive collaborative intersectoral efforts to support employment, housing, nutrition, literacy as well as medical, social and rehabilitation services for affected families, especially those in disadvantaged communities (Lequerica, 1997).

It is clear that limited clinical application of ECI in South Africa takes place since no co-ordinated national programme currently exists, limited training of professionals is undertaken, and there is little general appreciation of the value of ECI as the starting point of rehabilitation services for infants with disabilities or infants at-risk and their families (Delport, 1998; Haasbroek, 1999; Malan, 1993; Moodley, 1999). The question now arises how to provide appropriate ECI services to an increased population of infants at risk for communication disorders, of whom the majority are also associated with the adverse social, medical and educational conditions of a developing country (Wilson & Ramphele, 1989).

Vast resources, in the form of research, legislation and a global strategy, are available to make ECI relevant to all infants at-risk, to their families and to their communities. According to Moodley (1999) conventional approaches and traditional institution-based models of service delivery need to be reassessed in order to ensure the relevancy and effectiveness of these programmes in developing contexts, either in poor rural or urban communities.

The disadvantaged environments of black children with disabilities in South Africa necessitate a transition from institution-based services to community-based services and to use primary health care facilities as a platform to launch appropriate ECI services (Fair & Louw, 1999; Moodley, 1999). In order to ensure best practice, ECI programmes employed in community-based rehabilitation need to be appropriate, culturally sensitive, and community orientated, and teamwork should be expanded to include local personnel and appropriate technologies which can be afforded and maintained by the community (McConkey, 1995a; Hammer, 1998).

Since the health system has been identified as an important basis for ECI service delivery, a discussion of the South African national health policy and disability strategy is warranted.

1.3 SOUTH AFRICAN NATIONAL HEALTH POLICY AND DISABILITY STRATEGY

In the light of the urgency of the problem of limited ECI services for individuals, families and communities in South Africa, it is helpful to consider the policy objectives of health care in South Africa. Two of the priority issues mentioned in the *White Paper on the Transformation of the Health System* (Department of Health, 1997), are primary health care and maternal, child and women's health. These priority issues provide a direct link with ECI services as the approach in ECI is to target caregivers, i.e. to inform, train and support them, and to facilitate the communication development of their infants with disabilities or at risk for developmental delays (Louw & Kritzinger, 1991). This preventative approach in ECI creates the possibility of *preventing disabilities* such as fetal alcohol syndrome, and of *preventing an increase* in developmental delay or of *slowing down* the rate of progression of a disability or of *preventing secondary complications*, thus limiting the possibility of minor problems becoming major disabilities. (ASHA, 1991b; Rossetti, 1990a*; White Paper on an Integrated National Disability Strategy*, 1997).

A preventative approach is also proposed in the *White Paper on the Transformation of the Health System* (Department of Health, 1997) as a way of transforming the South African health system, i.e. of promoting health and development and preventing disease and disability. The means of preventing disabilities is also the same strategy that is being employed in ECI, namely the promotion of the educational status of women. It is widely recognised that the most important factor for improving a family's health is the mother's educational status (Department of Health, 1997). If mothers are trained and their literacy skills are increased, positive change in a family's health and development may be expected (Bryant & Maxwell, 1997).

Therefore, although EI is not specifically mentioned in the *White Paper on the Transformation of the South African Health System* (Department of Health, 1997), its philosophy is compatible with the aims, objectives and priorities for the restructuring of the health system. ECI could be employed as an effective strategy for the prevention of disabilities and the early identification and treatment of risk conditions at all levels of health care, i.e. in primary, secondary and tertiary health care.

It is clear that government policy guidelines favour approaches such as ECI, but some gross discrepancies exist between policy objectives and the current clinical situation. These problems can only be studied by means of systematic scientific research as there is a lack of reliable information about most aspects of disability (*White Paper on an Integrated National Disability Strategy*, 1997).

As there is a dearth of research in ECI in South Africa (Haasbroek, 1999; Moodley, 1999), the first step is to identify the local needs and describe the population in need of these services. The need for relevant research as one of the objectives for restructuring the health sector, is also recognised in the South African government's *White Paper on the Transformation of the Health System* (Department of Health, 1997). The White Paper stresses the need for Essential National Health Research (ENHR) and a research agenda which addresses the country's major health problems.

In order to facilitate the measuring and monitoring of the health status of the South African population, the development of a national health information system is further proposed in the White Paper (Department of Health, 1997). A comprehensive information system will provide data to improve national planning, evaluation of services and indicate priority issues so that appropriate interventions can be implemented.

In the light of the dire need for research to develop and formalize ECI services in South Africa, it is clear that the current transformation of the national health system provides opportunities for the development of the field of ECI which cannot be missed. It is not only the primary health care approach which provides clinical solutions to ECI service delivery, it is also the recognition of the importance of a national database and data collection on health issues which provides opportunities for research to develop ECI. Since limited ECI research has been conducted in South Africa and no ECI database currently exists to collect large amounts of data for epidemiological research, the research problem and rationale of the current study may be formulated as follows.

1.4 STATEMENT OF PROBLEM AND RATIONALE

South Africa presents a unique context of developed as well as developing communities, an increased prevalence of different populations of infants at risk for communication disorders, but no adequate or formalized ECI service delivery system. Since the new national health policy (*White Paper on the Transformation of the Health System,* 1997) and national disability strategy (*White Paper on an Integrated National Disability Strategy,*1997) clearly offer invaluable opportunities for the development of ECI in South Africa, the urgent need for relevant research to guide ECI planning is apparent. A computer-based data system specially designed to meet the needs of the infant population at risk for communication disorders, will provide immediate and long-term empirical evidence for the development of the field of ECI in South Africa.

The study proposes to develop and establish a computerized database system to generate descriptive data of infants and toddlers at risk for communication disorders in an existing ECI programme and present a conceptual framework for effective service delivery which can be implemented in the South African context.

1.5 TERMINOLOGY

The following terms are defined according to their specific use in the study.

1.5.1 ‘Established risk’, ‘at-risk’ and ‘high risk’

These concepts are used in EI to distinguish between two categories of risk that contribute to developmental delays (Rossetti, 1996). Infants in the established risk category are expected to exhibit developmental delays and are therefore not at risk for future delays which cannot be predicted. Established risk categories include chromosomal and genetic disorders, neurological disorders, congenital malformations, inborn errors in metabolism, sensory disorders, atypical developmental disorders, severe toxic exposure, chronic medical illness and severe infectious disease (Rossetti, 1996). Throughout this study the term *infants with disabilities* will be used to refer to those with an established risk condition.

In contrast to the infant with an established risk condition accompanied by developmental delay, is the infant with biological and/or environmental risk conditions. The infant at risk for developmental delay does not necessarily have to display delayed development in order to qualify for ECI services. As Rossetti (1996: 2) suggested: “Anything that interferes with a child’s ability to interact with the environment in a normal manner is a potential cause or a contributing factor for developmental delay and, more specifically, communication delay”. The terms at-risk and high risk were both used in the thesis to indicate infants at an increased risk for developmental delay as a result of adverse biological and/or environmental conditions.

Numerous factors interfere with normal environmental interaction and may therefore increase the risk for delay. Currently, consensus exists that the environment is as powerful a factor in establishing risk as biological and constitutional factors (Escalona, 1987).

Of all the different conditions having the potential negatively to impact on an infant's development, low birth weight and prematurity are considered the main determinants of risk status (Rossetti, 1996). The link between low birth weight and prematurity and risk is an indirect link, hence is it possible that some infants will not display developmental delays. According to Stuart (in Rossetti, 1986) infants with low birth weight and prematurity are potentially normal at birth, but they are at risk for a variety of adverse conditions which are the complications of low birth weight and prematurity. These conditions result from the following:

- Immaturity of the structure and function of organs, which may cause death or permanent organ impairments. The most devastating conditions include chronic lung disease or bronchopulmonary dysplasia, intraventricular haemorrhage, retinopathy of prematurity and necrotizing enterocolitis.
- A mismatch of the fetal brain's expectation for experience and the neonatal intensive care unit can occur. Infants with low birth weight and prematurity are born at a time when their brains are growing more rapidly than at any other time in their life and their neurophysiological, neuropsychological, psycho-emotional and psychosocial development can be affected.
- A disruption of the expected completion of the full-term pregnancy and preparation for birth, and the shock of having an ill child with an array of life threatening medical conditions, adversely influences the parent-infant attachment, interaction and caregiver adjustment.

(Als, 1997; Rossetti, 1996)

As a result of these conditions infants with low birth weight and prematurity are at risk for developmental delays.

Note: The spelling “at-risk” occurred in the thesis when the term was used as a noun, but when used as part of a prepositional phrase, such as “at risk for communication disorders”, it was spelled without hyphenation.

1.5.2 ‘Early communication intervention’ and ‘early intervention’

Intervention is any professional-initiated activity intended to deal with a problem affecting health or development. The specific services rendered to an infant or toddler with a disability or at risk for developmental delays and his/her family, from birth to three years, are known as EI (Hall, 1991). EI services include both assessment and intervention (ASHA, 1989).

EI programmes covering all developmental areas but with the focus on communication skills are considered as ‘best practice’, since communication skills are regarded as the best predictor of future school success and disorders of communication are the most common developmental disability in children (Capute, *et al*., 1987). ECI therefore refers to EI services from a communication-based perspective (Rossetti, 1996).

1.5.3 ‘Impairment’, ‘disability’ and ‘handicap’

There are important distinctions between these three terms. *Impairment* refers to any abnormality of body structure or function. *Disability* implies a reduction in a person’s ability to carry out particular tasks, functions or skills. The term *handicap* refers to the social consequences of the impairment or disability which prevent a person from realising his/her potential. Discrimination and isolation from the mainstream of society are two examples of handicapping conditions as a result of a disability. Handicaps can be prevented if the needs of an infant with a disability are met within a framework of inclusive development. Disability affects not only the disabled individual, but also the family and the immediate community (Hall, 1991; *White Paper on an Integrated National Disability Strategy*, 1997).

1.5.4 Infant mortality

Since infant mortality rates (IMR) are utilised in ECI to determine which populations of infants are most at risk for survival and developmental delay (Rossetti, 1996), it is important to define the term. Infant mortality refers to deaths in the first year of life and numbers are usually cited per 1 000 live births. The 1990-95 average IMR for both sexes in South Africa is 52.8, which indicates a decrease from 89 in 1960. South Africa has the lowest IMR in southern Africa. There are significant inequities in IMR among the black and white population. The IMR among the black population is up to 7 times higher than that for the white population (WHO Report, 1996).

According to research the major risk factors for infant mortality in the USA include the following:

- *Gender:* Regardless of race, males experience higher birth weight-specific infant mortality than do females.
- *Gestation age:* Infant mortality decreases with increasing gestational age.
- *Live birth order*: Second-born infants experience lower infant mortality than do infants of other birth orders.
- *Maternal age:* Infant mortality decreases with increasing maternal age through 30 to 34 years of age, but increases for infants born to women 35 years and older.
- *Maternal education:* Infant mortality declines with increasing maternal education.
- *Prenatal care:* Infants born to mothers who obtain prenatal care beginning in the first trimester experience substantially lower IMR.

(CSS, 1997c; Kibel & Wagstaff, 1991; Rossetti, 1993; Rossetti, 1998; WHO Report, 1996)

1.5.5 Levels of health care

The health services in South Africa are divided into the following six levels of health care:

Level I Provision of basic needs

- Safe drinking water and environmental health
- Sewerage and refuse removal
- Provision of adequate food
- Infrastructure and basic housing

Level II Health education

- Minimum level of education
- Training and education

Level III Primary health care

- Self-help
- Community nursing services
- Community health clinics, centres and community service organisations

Level IV The community hospital
Level V The regional hospital
Level VI Academic hospitals
(Bouwer, Dreyer, Herselman, Lock & Zeelie, 1997)

Primary health care mainly operates on Levels I, II and III, and implies a person's first contact with the health system. Community and regional hospitals assume responsibility for secondary care and academic hospitals mainly provide tertiary care (Power, 1991).

Primary, secondary and tertiary health care operate on the principle of a co-ordinated referral system. Secondary level care is delivered at the first level of referral from the primary contact. Tertiary level care is all health care delivered at the second level of referral (Bouwer *et al*., 1997)

1.5.6 Poverty

A functional description rather than a technical definition of poverty is given for the purpose of this study. Various factors can contribute to poverty, but in Africa it has existed for centuries on two levels. On one level poverty exists when people are forced to struggle continuously to preserve themselves and their dependants from physical want. Another level, which may be described as affecting the very poor or destitute, occurs when people have permanently or temporarily fail in the struggle to obtain the basic provisions of life and have so fallen into a state of physical destitution and extreme need (Wilson & Ramphele, 1989). It is also generally accepted that children under five who are living in poverty not only suffer from poor health, but are also at greater risk for developmental, behavioural and educational delay than their middle class counterparts (Lequerica, 1997).

1.5.7 Prevention

Prevention has three components: primary, secondary and tertiary prevention (Gerber, 1990). *Primary prevention* implies measures taken to avoid the occurrence of a condition in such a way that a reduction in the prevalence of disability or disease becomes noticeable.

Secondary prevention involves obstructing the development of a disabling condition by early identification and treatment of the risk condition. ECI is an example of secondary prevention.

Tertiary prevention involves impeding the progress of an established disability by appropriate treatment (ASHA, 1991a; Hall, 1991).

1.5.8 ‘Rehabilitation’ and ‘community-based rehabilitation’

Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions and enabling people with disabilities and with handicaps to achieve social integration.

Community-based rehabilitation includes all the basic elements of rehabilitation, but goes beyond the personal level to include the community. It involves measures taken at the community level to use and build on the resources of the community, including the people with disabilities themselves, their families and their community as a whole.

Community-based rehabilitation is to traditional rehabilitation as primary health care is to hospital care. The site of rehabilitation activities is mainly in the home or in community facilities. Rehabilitation strategies are broken down into simplified tasks, facilitated by the use of relevant literature, aids and appliances and home programmes are carried out by family members and supervised by community level workers with minimum levels of education.

Strategies to ensure community participation in rehabilitation measures comprise analysing needs, planning, implementing and evaluating the outcomes together with the community (Thorburn, 1994).

1.6 ABBREVIATIONS

The following abbreviations were used in the thesis:

ADD	Attention Deficit Disorder
ANC	African National Congress
ASHA	American Speech-Language-Hearing Association
CHILDES	Child Language Data Exchange System
CHRIB	Clinic for High Risk Babies

CHRIB ID	CHRIB Database identification number of subject
CSS	Central Statistical Services
CT Scan	Computed Tomography
DAISEY	Developmental Assessment and Instruction for Success in Early Years Data System
DAS	Developmental Assessment Schema
DASI II	Developmental Activities Screening Inventory
DEAFSA	Organisation formerly known as the South African National Council for the Deaf
DNA	Deoxyribonucleic acid
ECI	Early Communication Intervention
EI	Early Intervention
ELM Scale	Early Language Milestone Scale
ENHR	Essential National Health Research
ERIC	Educational Resources Information Centre
HELP	Hawaii Early Learning Profile Checklist
HIV/AIDS	Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome
ICD-10	International Statistical Classification of Diseases and Health Problems, ICD Tenth Revision.
IDEA	Individuals with Disabilities Education Act
IMR	Infant Mortality Rate
ISEI	International Society on Early Intervention
LSA	Language Sample Analysis
MICP	Mother-Infant Communication Project
MICS	Mother-Infant Communication Screening
MRI	Magnetic Resonance Imaging
NASHI	National Adolescent Sexual Health Initiative
NICU	Neonatal Intensive Care Unit
NIDCAP	Newborn Individualised Developmental Care and Assessment Program
OCI	Observation of Communication Interaction
PAUP	Computer software package for phylogenetic analysis of data

PDD	Pervasive developmental disorder
PHYLIP	Computer software package for phylogenetic analysis of data
PLASTER	Pediatric Language Acquisition Screening Tool for Early Referral
SABC	South African Broadcasting Corporation
SALT	Systematic Analysis of Language Transcripts
SAS®	Statistical Analysis System
SASLHA	South African Speech-Language-Hearing Association
SCN	Special Care Nursery
SIDS	Sudden Infant Death Syndrome
SPECT scan	Single Photon Emission Computed Tomography
TCCT Center	Twenty-first Century Conceptual Tools Center
UK	United Kingdom
UNESCO	United Nations Educational, and Scientific, and Cultural Organisation
UNICEF	United Nations Children's Fund
USA	United States of America
WHO	World Health Organisation

1. 7 USE OF ITALIC TYPE IN THE THESIS

Italic type was used in the following instances in the thesis:

- The titles of all published documents were typed in italic.
- The Latin expressions *per se, ad hoc, ex post facto, in cognito, per se and et alia*, abbreviated as *et al.,* were typed in italic.
- Italic type was used to emphasise an important word or paragraph in the text.

1.8 ORGANISATION OF THE STUDY

Chapter 1 A Rationale for Developing the Field of ECI in South Africa

Chapter 1 provides an overview of the various incentives which led to the establishment of ECI and the formalization of ECI services in the USA. While ECI is now available to most young children at–risk and their families in developed countries, the problems of limited ECI services in developing countries such as South Africa are discussed. Since South Africa has increased populations of young children requiring ECI services new approaches to service delivery in the different communities are indicated. The dire need for research to guide ECI planning in South Africa validates the development of a research database system for ECI. The rationale, statement of the problem and aim of the study is presented, key concepts to be used throughout the study are defined and an outline of the chapter organisation is given.

Chapter 2 An Overview of Best Practice in Early Communication Intervention

A review of the literature relating to best practice in ECI is provided. The ECI service delivery process is used as a framework to discuss current strategies and methods for early identification, assessment and treatment of infants and toddlers and their families requiring ECI. Guidelines for effective ECI service delivery are presented as a continuum of parameters which can be used as the underpinnings of a model for best practice in ECI.

Chapter 3 Strategies to Develop Early Communication Intervention in the South African Context

In order to develop ECI in South Africa to serve all communities requiring the services, three different approaches in health care, education and community-based services are proposed to be used as strategies to expand ECI. Primary health care, ECI preschool programmes and community-based rehabilitation offer strategies which can be utilised to serve diverse populations of clients requiring ECI in South Africa. Based on available data a profile of ECI clients revealed that the population displays characteristics of diverse linguistic, cultural and literacy backgrounds and that the majority of clients requiring ECI are infants with low birth weight and prematurity and those suffering from diseases associated with poverty. The literature review indicates that more data is required to effectively plan ECI services in South Africa.

Chapter 4 Database Systems in Early Communication Intervention

The chapter's aim is to provide the underpinnings for a database system in second generation research in ECI. The features of database systems and their applications as management and research tools in EI are discussed. An overview of the literature indicates that EI is already a leader in database application in the field of Communication Pathology. A rationale for a uniquely designed database system as a contemporary ECI research tool meeting the needs of the local South African context is provided.

Chapter 5 Methodology

The chapter describes the planning and implementation of the empirical study. The first main aim of the study is to design a database system as an ECI research tool and a detailed description of the database structure and features was provided. The database system is modeled on the assessment materials and procedures employed at CHRIB, an ECI service delivery facility. A quantitative survey methodology is selected to conduct the second main aim of the empirical study. Data of 153 subjects assessed at CHRIB is collected and entered into the database system over a period of three and a half years. The data analysis procedures are described so that use of the database as a research tool may be demonstrated when the specific population of infants and toddlers receiving ECI services at CHRIB is described.

Chapter 6 Results and Discussion

In order to demonstrate the capabilities of the CHRIB database and the functions of the different software programs linked to one another when used for data manipulation and data analysis, a rich description of selected characteristics of the 153 subjects and their families is provided. The results indicate the critical importance of early identification of risk conditions throughout a child's life and the roles of parents in the identification process. The results of a multiple risk profile of the subjects, using the *ICD-10* (CSS, 1996) reveals findings not extensively described in the literature. The use of descriptive methodology reveals remarkable detail and unique characteristics of the 153 subjects and their families employed in the empirical study which would not have been possible without a relational database system.

Chapter 7 Conclusions and Implications

The chapter provides the final conclusions to the entire study. The use of the CHRIB database system as an established ECI research tool with its vast possibilities to contribute to second generation research in EI is discussed. The conclusions to the findings of the empirical study are presented, emphasizing the risk profile of subjects with cleft lip and palate as an example of a subgroup of subjects requiring further investigation. A conceptual framework for the early identification of risks for communication disorders is proposed and its clinical applications discussed. The clinical and theoretical implications of the study are discussed, a critical review of the methodology and results are presented and further research is indicated.

REFERENCES

A complete list of all the references used in the thesis is presented in alphabetical order.

APPENDICES

Following the thesis, supplementary material valuable to understand the text more completely, is included. The five appendices include a copy of the CHRIB Information Letter to Parents, the CHRIB Case History Form (Louw & Kritzinger, 1995a), the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b), a printout of the structure of the CHRIB Database and a table containing the subjects and their *ICD-10* (CSS, 1996) classifications.

1.9 CONCLUSION

As a dynamic field of study, ECI has already progressed tremendously over the past thirty years (Guralnick, 1997). Advances in research and the clinical demands of a growing population of infants requiring ECI services acted as incentives for the remarkable development of the field. ECI has proved to be an effective means of service delivery to young children at risk for communication disorders and their families and is well established in developed countries. The advancement of ECI in developed countries has culminated in public recognition of the responsibility to provide ECI to young children at-risk and the formalization of the services by means of legislation. With the current emphasis on prevention of disease and vulnerable groups in international health care, alternative models for effective ECI service delivery in developing countries are proposed.

ECI is of particular importance in South Africa as there is an increased prevalence of different populations of infants at risk for communication disorders and the majority of these infants live in poverty. Although the principles, strategies and methods of ECI are recognised in proposed legislation for a national disability strategy and for the transformation of the health system in South Africa, it is not mentioned as such. ECI is largely an unknown field in South Africa and is currently not formally recognised by the health sector or rehabilitation services. The challenge is to convince clients, i.e., families, communities, legislators and team members, of the indispensable role of ECI services to infants at-risk and with disabilities. Since the intention is to fulfil an essential role in the health and rehabilitation services, research is required to serve as the basis on which to create a national policy statement regarding an ECI strategy.

In order to propose a solution to the problem of limited ECI services, the current study aims to develop and use a computer database system to describe the profiles of infants at-risk and of their families in a clinical setting so that the key elements of a conceptual framework for relevant ECI services in South Africa may be identified. The vantage point of this research is a theoretical study of the current developments of the field, which will be followed by an empirical study.

1.10 SUMMARY

Chapter 1 provides an overview of the various incentives that led to the establishment and formalization of ECI services in developed countries. Since the aim of ECI is to provide services to all young children at risk for communication disorders and their families, it appears that limited application of ECI exists in developing countries such as South Africa. An analysis of the problems facing ECI in South Africa indicates the need for research to formulate a conceptual framework for ECI service delivery which could comply with the principles of the proposed national legislation on health care and a disability strategy. The development of a database system to provide data for the intended research is proposed. The discussion ends with the statement of the research problem, rationale and aim of the study. Key terms are defined in order to provide some of the basic theoretical perspectives of the study. The chapter ends with an outline of the remainder of the study and a conclusion.

CHAPTER 2

AN OVERVIEW OF BEST PRACTICE IN EARLY COMMUNICATION INTERVENTION

CHAPTER 2

AN OVERVIEW OF BEST PRACTICE IN EARLY COMMUNICATION INTERVENTION

Aim: The chapter aims to present a literature review of current research on best practice in Early Intervention, which applies to Early Communication Intervention as well, in order to provide the theoretical underpinnings for the empirical research of the study.

2.1 INTRODUCTION

A critical review of research is an essential element in the social science process as it serves to integrate the present study into a wider framework of relevant theory (Mouton & Marais, 1990). A review of the literature will also provide guidelines for a valid and systematic description of the spectrum of concepts, theories and their clinical applications that serve as the building blocks of Early Communication Intervention (ECI) as a discipline.

Since ECI has made such remarkable progress in recent years the question now arises whether a common philosophy about the optimal practice of ECI can be gleaned from the many concepts, theories and their clinical applications that constitute the discipline. According to Rossetti (1996) optimal or best practice represents an effort to integrate and synthesise emerging empirical data into everyday applications in order to bring about qualitative changes in the lives of young children and their families requiring ECI services.

With rapid advances in research and new discoveries integrated into existing knowledge, ECI strategies and methods must be continuously adapted to facilitate best practice in ECI. Improved clinical practice therefore relies on the scientific process of the accurate and reliable interpretation of research findings in order to provide the maximum of benefits to the different populations of young children at risk for communication disorders. According to Rossetti (1992) understanding the particular time frame and the population being studied is critical in interpreting ECI research in order to glean guidelines for best practice. This is of particular importance in the South African context since the populations of infants and toddlers and their families requiring ECI services differ from those in the USA or other countries (See Table 1.4).

The populations of young children at risk for developmental delays world-wide have shown significant changes over the past four decades and new knowledge about the effects of risk status on infant development has emerged. New populations are appearing, such as infants of mothers who abused substances during pregnancy, and especially in Africa, infants with HIV infection (Bobat, Coovadia, Moodley & Coutsoudis, 1999; Eley & Hussey, 1999). Certain populations, such as infants with cerebral palsy are increasing as the survival rates of those with low birth weight and prematurity improve (Mutch, Alberman, Hagberg, Kodama & Perat, 1992). On the one hand the use of vaccines have sharply reduced the number of infants born with the effects caused by rubella (Sparks, 1984), although on the other hand the figures could be increased in developing countries such as South Africa. According to Christianson (1998), rubella vaccination was never extensively administered to pre-adolescent girls in the racially segregated black schools of the past and it appears that no studies to date have been conducted to determine the numbers of infants affected by prenatal rubella exposure. These changes in populations of young children at-risk demand continuous research for documentation and constant revision of the whole ECI process in order to ensure best practice and improve its effectiveness in different contexts.

As the discipline of ECI has already produced much research and clinical tools the aim of the chapter is to investigate and carefully select those strategies and methods which can be used as a framework for best practice in ECI. The importance of investigating best practice in ECI is to provide underpinnings for the current empirical study to design a database system for ECI.

2.2 THE EFFECTIVENESS OF ECI

Since the aim of ECI is to prevent communication disorders or to decrease their effects as early as possible in the lives of infants and toddlers at-risk or with disabilities and their families, proving its effectiveness has gained increasing attention in the literature of the past decade. According to McLean and Cripe (1997) one of the major challenges in the field of communication disorders is the persistent gap between the knowledge base and current clinical practices which must be bridged in order to improve the effectiveness of ECI services.

2.2.1 Introduction

Demonstrating the effectiveness of ECI has always been important, as questions to prove the justification of ECI have been asked since the emergence of the discipline (Rossetti, 1996). So-called first generation research in early intervention (EI) concerned itself with the feasibility of EI programmes for young children born at-risk as well as for those with established disabilities (Guralnick, 1997). For example, during the 1970's and 1980's a whole body of research was directed at documenting the development of infants with low birth weight and prematurity in order to find evidence for their need for intervention (Kritzinger, 1994). The questions raised in earlier studies were whether the development of infants with low birth weight and prematurity was significantly delayed to warrant intervention and whether they would not spontaneously catch up on their delays. This led to the further question whether *infants, including neonates,* at-risk or with disabilities require intervention and if they do, will it make a significant difference to their future development? (Field, 1980; Guralnick & Bennett, 1987; McCormick, 1989; Scott, 1987).

As similar questions will continue to be asked every time ECI is established in a new context, such as in South Africa, it is important to state that it is now generally accepted and affirmed by authorities such as Rossetti (1998) and

Guralnick (1997) and many others, that infants with established conditions or displaying developmental delays and those who are at risk for developmental delays, require EI and that it has positive effects on their developmental progress. EI, capitalising on the sensitive period of early life, is effective in decreasing the effects of disabilities and preventing developmental delays in certain circumstances. The consensus regarding the efficacy of EI and ECI is not a matter of academic concern only, but is also reflected in public policy of which the USA legislation is an example. The agreement regarding the efficacy of ECI services came as a result of the early research efforts in EI.

Guralnick (1997) coined the phrases *first generation* and *second generation research* in EI to indicate the differences in research conducted prior to the passage of USA legislation (PL 99-457) and afterwards. First generation research answered the question of effectiveness of EI and indicated guidelines for best practice by providing the context for developing and evaluating approaches, curricula and specific therapeutic techniques.

EI research conducted in the 1970's and 1980's therefore tended to be exploratory and descriptive in nature. Recent studies, benefiting from the knowledge gained in earlier findings, are explanatory and determine the effects of EI (Blair, *et al*., 1995; Haney & Klein, 1993; Kurdahi Zahr, Parker & Cole, 1992; McCarton, *et al*., 1997; McDowell, Saylor, Taylor, Boyce & Stokes, 1995; Norris, 1991; Olswang & Bain, 1991; Smith, Landry, Swank, Baldwin, Denson, Wildin, 1996). The question therefore no longer is whether infants at risk for communication disorders require ECI as soon as possible after birth, even when they may not yet display the sequelae of their risk condition. The question regarding the efficacy of ECI is now whether these infants will continue to demonstrate progress over an extended period of time (Rossetti, 1996).

One of the best examples of the effectiveness of EI is the positive results of developmental appropriate care in the neonatal intensive care unit. Research findings on the efficacy of EI in the neonatal intensive care unit, the earliest intervention possible, indicate short-term and long-term benefits for both the infant and the family (Als 1997; Rossetti, 1996). According to Als (1997) the move away from protocol- and procedure-driven care to a relationship-based, family-centered developmental care approach in the neonatal intensive care unit has brought about far-reaching changes. Research indicates positive medical and developmental outcomes in the graduates of the neonatal intensive care units who follow a developmentally appropriate care approach (Rossetti, 1996).

Longitudinal studies employing large numbers of subjects demonstrate the effectiveness of EI for various populations of infants at-risk. For example the results of *The Infant Health and Development Program* (McCarton *et al*., 1997) for premature infants with low birth weight showed improved cognitive functioning in the intervention group when compared to the control group at three years of age. The intervention group did, however, not retain their advantage over the follow-up group at eight years of age, indicating that intervention should continue beyond the toddler years. To date this was one of the largest follow-up studies to evaluate the efficacy of early intervention for infants born with low birth weight and prematurity, with a total of 985 children participating in the programme across eight sites in the USA (McCarton, *et al*., 1997).

The same pattern of results was found in follow-up studies evaluating the effectiveness of EI for infants and their families living in poverty. Results from *Project Head Start* which was launched nation-wide in the USA in 1964 (Smith & McKenna, 1994), the *Carolina Abecedarian Project* (Ramey & Ramey, 1992) and *Project CARE* (Wasik, Ramey, Bryant & Sparling, 1990) confirmed that early educational intervention beginning shortly after birth and continuing throughout the nursery school years for infants from poor families, can significantly improve the children’s intellectual performance and academic achievement. It is now generally accepted that EI for infants at risk for developmental delays associated with poverty, has long-term effects which result in improved school success and reduced dropout figures (Gomby, Larner, Stevenson, Lewit & Behrman, 1995). It appears that EI has immediate gains for infants and their families from various populations at-risk, but long-term progress can only be sustained if intervention continues beyond the toddler years (Guralnick, 1997). This finding holds important implications for service delivery policy and raises further questions as to what constitutes best practice in ECI.

2.2.2 Current Questions regarding the Efficacy of EI

Second generation research in EI is typically concerned with questions as to what must be done to gain maximum benefits for the clients requiring EI services and how to measure the change in order to demonstrate the effectiveness of the services. The current debate on the efficacy of EI is not only concerned with its long-term effects on young children’s development, but has expanded to include all levels of service delivery. The challenge to ECI professionals is to demonstrate which models, strategies and methods involve the most promising practices and to illustrate which of those are cost effective. These considerations are most important for the continued enhancement of the discipline of ECI in developed countries as well as the promotion and establishment of ECI policy in developing contexts. Since ECI must still be expanded and formalised as an essential component of public services to young children at-risk and their families in South Africa, it is important to take cognisance of the current questions and their solutions regarding efficacy in EI.

Based on a literature review the myriad of questions now being asked in second generation research of EI were identified and include the following:

- What form of EI is the best?
- What is the most efficacious way to conduct the assessment activity?
- How do EI programmes make their impact?
- What is the best way to measure EI effectiveness?
- Which teamwork approach contributes to successful EI outcomes?
- To whom must the intervention be directed, to the infant, the parents or both?

- Who must be the primary provider of EI services in the various stages of the child's life?
- How intensive and for how long must the intervention be continued?
- Where must the intervention take place?
- Is EI cost-effective?
- How are infants and families from diverse linguistic and cultural backgrounds served best?
- Which programme features best serve the needs of families living in poverty?

(Guralnick, 1997; Johnson, 1994; Lee & Kahn, 1997; Marfo & Dinero, 1991; Rossetti, 1990a; Rossetti, 1996; Smith & McKenna, 1994).

These questions serve to illustrate the complexities and inter-relatedness of EI issues currently being investigated to provide guidelines for best practice. In an overview of EI research in the past, Guralnick (1997) identified a dearth of information regarding certain topics and proposes that second generation EI research should concern itself with three critical issues, namely:

- Child and family characteristics
- Programme features
- EI outcomes

These three issues indicate the conceptual as well as practical challenges the early interventionist is currently confronted with and are concerned with every step of the EI service delivery process. In order to provide a literature overview of current research in best practice in EI, which applies to ECI as

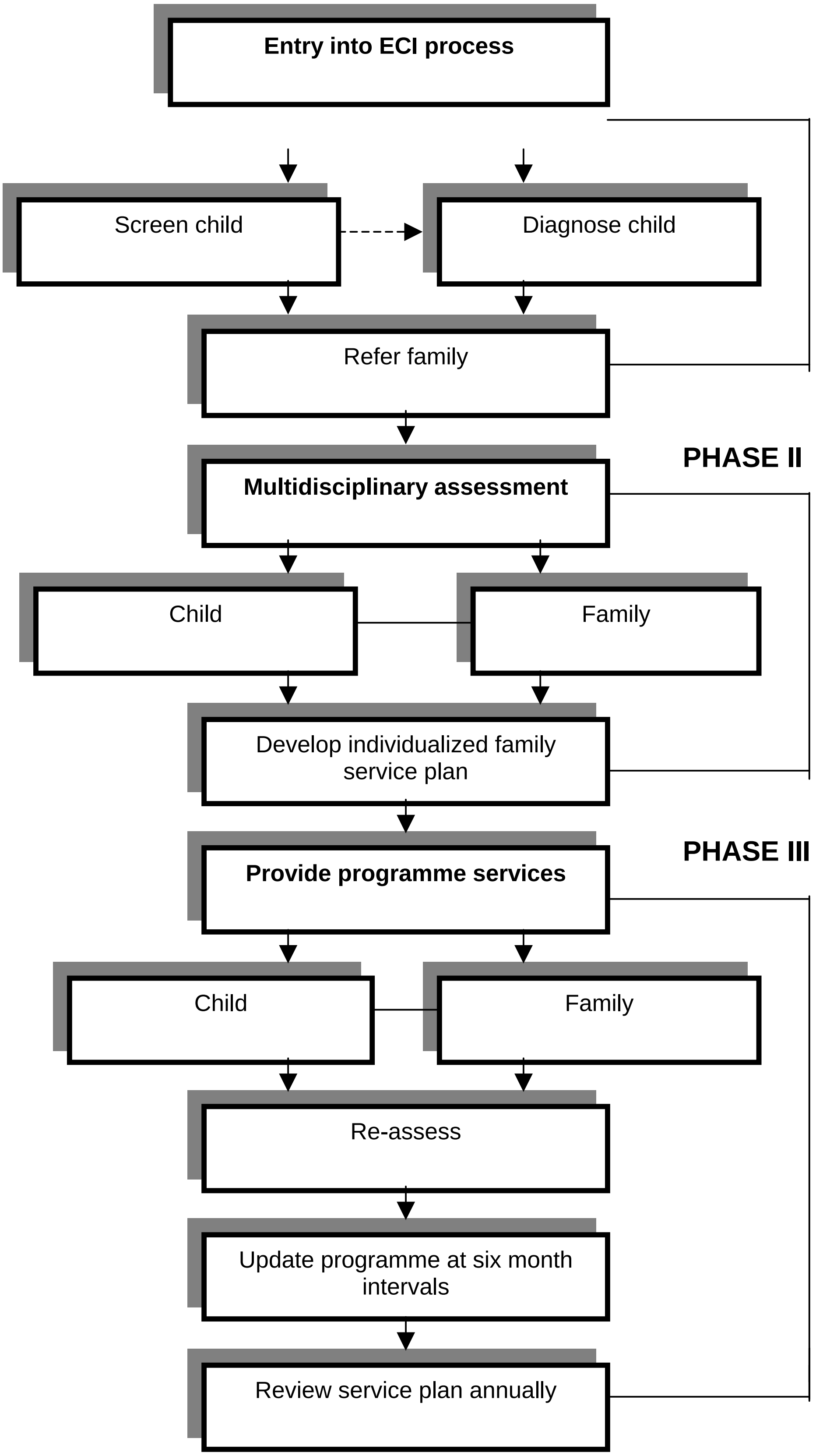

Figure II.I **The early communication intervention process**
Adapted from Hutinger, 1994

well, the different components of the EI service process as proposed by Hutinger (1994) and depicted in Figure II.I will be used as a framework.

Figure II.I was selected as a framework for the discussion of best practice in ECI as it provides a systematic dissemination of the essential processes related to identification, assessment, programme planning, implementation and monitoring in ECI. The flow diagram contains the widely accepted elements of ECI in a logical sequence and will allow a comprehensive discussion of the issues relating to each of these processes. Although Figure II.I reduces ECI to a two dimensional flow diagram, the discussion of each element will allow a multidimensional perspective on second generation research issues on best practice in ECI.

2.3 FRAMEWORK FOR BEST PRACTICE IN ECI

The aim of the discussion is to present an overview of best practices in ECI in order to formulate guidelines which can be used in the empirical component of the current study.

2.3.1 PHASE I: Entry into the ECI Process

The manner in which a family with an infant with a disability or at risk for a communication disorder enters into the ECI service delivery process is by way of identification of the risk condition. The early identification of infants eligible for ECI and the extent of parental involvement in the ECI process are the two strongest factors proven to significantly enhance the efficacy of the services (Rossetti, 1993). The importance of early identification of communication disorders is based on the assumptions that the successful treatment of all communication disorders depends on early detection and treatment of the disorder or risk factors leading to a delay (ASHA, 1991a) and that a strong correlation exists between communication skills and future school success (Capute, *et al*., 1987). *An active identification programme to ensure entry of* *all infants eligible for ECI at the youngest age possible is now widely advocated* (Eddey, Robey, Zumoff & Malik, 1995). Yet the early identification of infants with communication disorders or at risk for delays is still one of the biggest challenges of ECI which threatens its efficacy (Bland, 1996; Squires, Nickel & Eisert, 1996). One of the problems which still requires clarity is the nature of formalized identification programmes and the identification strategies to apply to different populations of young children at-risk.

2.3.1.1 Developmental Screening

As indicated in Figure II.I, Hutinger (1994) suggests two different approaches to identify infants eligible for ECI. The one approach involves *developmental screening* with the aim to separate those who need ECI from the population of typically developing infants (Hock Long, 1996). The other approach is the *diagnostic evaluation*, which is a medical process and aims to describe the symptoms and determine the aetiology of the communication delay displayed by the infant.

Various strategies and measures for screening are used for different age groups in the infant-toddler population, but the desirable characteristics of screening instruments should include the following:

- High sensitivity: The test succeeds in identifying children with delays.
- High specificity: The test succeeds in identifying children without a delay.
- High levels of reliability: Different examiners will administer, score and interpret the test in the same way (Glascoe, 1995).

The choice of screening strategies depends largely on the specific population of infants at-risk being targeted and the different clinical settings where infants at-risk may be detected (Squires, *et al*., 1996).
An example of a screening strategy is universal screening programmes which imply the rapid individual testing of all the members of a whole population. This approach, however, can only be an effective identification strategy if

indeed all infants can be screened and if an efficient referral system for follow-up services can be guaranteed (Fowler & Fowler, 1994).

The universal screening of all neonates for hearing loss appears to be the best strategy for early identification of this population as epidemiological studies indicate that the application of a high risk register, which acts as a guideline for hearing screening of at-risk populations (ASHA, 1994), fails to identify those infants with a hearing loss of unknown origin (Northern, 1993). It is estimated that screening programmes employing high risk registers for infants at risk for hearing loss, overlook 50% to 70% of all children born with hearing loss (Boswell, 1998). Reported problems experienced in hearing screening programmes are also low return rates for follow-up evaluations, which implies a time lapse between identification and intervention (Roush, 1991). It is clear that well planned and managed screening programmes is of critical importance in ECI as late identification of infants requiring intervention seriously undercuts the efficacy of the whole process. Rossetti (1993) pointed out that the age of identification is one of the most important factors determining the success of ECI. According to Downs (1994) it was found that the age of identification of hearing loss determined the level of a child’s language proficiency and not the degree of the hearing loss. *The goal therefore is to identify and treat infants at risk for communication delays already at birth as this determines their school performance and their future.*

The use of a risk register, although found to be ineffective to detect hearing loss of all origins, can be used in other populations of infants such as those at risk for communication delays.

The use of a checklist of risk factors known to be associated with delayed communication development is another strategy for the early identification of infants requiring ECI services. According to Rossetti (1996) knowledge about infant mortality rates and the causes of death, provide valuable information about infants eligible for ECI. As the causes of infant death are also the causes of infant morbidity or disability, early communication interventionists should be involved in medical contexts such as the Neonatal Intensive Care

Unit (NICU) and primary health care clinics to screen and monitor those infants whose health and development are under threat.

Knowledge of specific predictors of communication disorders, such as prolonged feeding problems in infants at biological risk (Kritzinger, 1994) can improve the reliability of screening measures employed. In this regard Rossetti (1986) listed a useful risk register for infants with low birth weight and prematurity who are at risk for major neurological and cognitive sequelae. The risk register indicates the increasing percentage of risk when birth weight decreases as well as the increased risk percentage when the infants experience conditions such as respiratory distress syndrome, seizures, meningitis, small-for-gestational age and broncho-pulmonary dysplasia. The increased risk percentages are depicted as follows:

- Birth weight higher than 2 500g: Less than 5% risk
- Birth weight 1 501-2 500g: 10% risk
- Birth weight lower than 1 500g: 10-30% risk

(Rossetti, 1986)

A risk register may be used by all health care professionals, provided that the information is available to them and that they are aware of the importance of identification of infants at biological risk already at birth. Best practice for the identification for infants at risk for communication disorders is at birth, but a risk register should not be the only screening strategy employed in ECI.

2.3.1.2 Developmental Surveillance

Another strategy for early identification of infants at risk for communication disorders is developmental surveillance which has been adopted by the American Academy of Pediatrics and the British Working Party on Child

Health Surveillance (Squires, *et al.,* 1996). Developmental surveillance entails brief evaluations of developmental skills over a period of time and applied to the total population of children with the aim to monitor child progress. *This strategy, carried out by medical practitioners and nursing staff, could play a most important role in recruiting infants and toddlers at risk for communication disorders, provided that the surveillance is carried out routinely and sensitive screening instruments are used.*

According to Ensher (1989) earlier screening tests, some of which are still being used, concentrated on motor milestones and were therefore not reliable to identify delayed communication and cognitive development. The sensitivity and specificity of screening instruments for communication disorders are still a concern. The late identification of children with autism and pervasive developmental disorders (PDD) is a concern being raised in the current literature (Golding, 1998). As the early indicators of autism and PDD relate to a limited range of communication functions, difficulty in acquiring conventional means of communicating and a restricted ability to develop symbolic play (Wetherby, Prizant & Hutchinson, 1998), communication-based screening instruments will be the only screening measurements to identify these infants early enough for effective ECI.

Examples of screening tools to detect infants and toddlers at risk for communication delays are the *Denver Developmental Scale-R* (Frankenburg, Dodds & Fandal, 1988 In Hess, Dohrman & Huneck, 1997), the *Pediatric Language Acquisition Screening Tool for Early Referral (PLASTER)* (Schulman, 1991, in Sherman, Schulman & Trimm, 1996) and the *Early Language Milestone Scale (ELM Scale)* (Coplan, 1983). These instruments are published and some evidence of their use reliability and validity could be found in the literature.

According to Hess, *et al*. (1997) the *Denver Developmental Scale-R* (Frankenburg, Dodds & Fandal, 1988 In Hess, *et al*., 1997) is a popular screening tool and used in pediatric offices in the USA. The test can be administered by either the pediatrician or a nursing professional in a short period of time, as the test items relating to communication development focus on basic observable behaviours. In a study to determine the concurrent validity of *PLASTER* (Schulman, 1991 In Sherman, *et al*., 1996) it was found to be a quick and efficient tool and comparable to the *ELM Scale* (Coplan, 1983) in its use to identify infants and toddlers at risk for communication delays.

Even though these useful screening instruments are available, it appears that the use of formal screening tools to detect communication delays is not widely encountered. Mulder (1998) found that only 9% of the pediatricians participating in a survey in South Africa used formal screening instruments for developmental surveillance. Hess, *et al.* (1997) found the same trend in a study conducted in the USA. The paediatricians made limited use of formal screening tools and mostly asked informal questions to parents regarding their young child's communication development. Although the use of parental opinion about their children's development was found to be reliable (Rossetti, 1998), not all parents are concerned about their infants' communication development and infants requiring ECI can be overlooked if this is the only identification strategy employed.

It is clear that multiple strategies such as developmental screening, the use of a high risk register and developmental surveillance, utilised by various health care professionals in contact with neonates, infants and toddlers should be applied to detect those at risk for communication disorders as early as possible. These identification strategies should be well co-ordinated and part of a comprehensive ECI programme. The use of epidemiological data can greatly enhance such a programme to provide guidelines for prioritisation in local contexts.

2.3.1.3 Epidemiological Data

Epidemiological data, if available, can provide estimates of the total number of infants in certain communities to be at risk for communication delays. Epidemiological data presented in Table 1. 4 (See Chapter 1) as well as a study by van der Merwe (1999) who found an increased prevalence of risk conditions and poverty in the Eersterust community outside Pretoria, alert the early communication interventionist of the high prevalence of risk conditions for communication delays in certain communities in South Africa which should be targeted in early identification programmes. Much research needs to be carried out in South Africa in order to plan and conduct effective identification programmes in contexts where infants with established, biological and environmental risks are most likely to be found. Data on the distribution of different risks found in young children is essential to provide guidelines for best practice regarding clients from different contexts in ECI in South Africa.

2.3.1.4 Diagnosis of Infants with Established Risk Conditions

According to Figure II.I another way an infant can enter the ECI process is by way of diagnosis. Since the diagnosis of infants with established risk conditions are often carried out by health care professionals not directly involved in the ECI process, the diagnostic tests employed are considered as identification procedures for entry into the ECI process and not as ECI assessment procedures *per se*.

The process of diagnosis entails an assessment to *diagnose* or label a specific condition in an infant with the aim of finding the cause of a developmental disorder. The process often involves the use of diagnostic tools, such as computed tomography (CT scan), magnetic resonance imaging (MRI), single photon emission computed tomography (SPECT scanning), ultrasonography, different types of X-rays, angiography, echocardiography, enzyme or hormone assays or tissue biopsy (Louw & Kritzinger, 1998). The objective is to identify perpetuating factors (variables which are currently continuing the condition), precipitating factors (agents which brought the condition to its present state) and predisposing factors (agents such as genetic factors which inclined the infant toward a specific condition) (Nicolosi, Harryman & Kresheck, 1996).

The two processes, screening and diagnosing, are not mutually exclusive but complement one another. The purpose of screening is only to identify and refer infants at risk for communication disorders and not to determine the cause of the disorder, i.e. to diagnose or to describe the nature of the disorder in detail, i.e. to assess. Developmental screening involves larger numbers of infants than the process of diagnosis, as not all infants eligible for ECI require a medical diagnostic procedure.

According to Rossetti (1996) it is, however, the minority of infants and toddlers in the ECI caseload who display established risk conditions and require medical diagnostic procedures. Established risk conditions include the following nine categories proposed by the State of Michigan, USA (Rossetti, 1996): Chromosomal anomalies or genetic disorders, neurological disorders, congenital malformations, inborn errors in metabolism, sensory disorders, atypical developmental disorders, severe toxic exposure, chronic medical illness and severe infectious disease. Although the cause of 40 – 60% of all congenital anomalies is still unknown, the diagnosis of an established condition implies that the risk of recurrence is known (Sadler, 1995).

The knowledge about an established risk condition in a young child directly impacts on the family of that infant as they are now in an empowered position to make informed decisions and the recurrence of the condition in the same family can be prevented. Rapid advances made in the location of specific genes on human chromosomes and their function and dysfunction are increasing knowledge about genetic disorders which will result in improved genetic services to families in the near future (Hayes & Northern, 1996; Louw & Kritzinger, 1998).

The other advantage of diagnosing an established condition implies that known patterns of developmental delay can be detected in the infant which will guide ECI decision making and extends the ECI team to involve members from the medical disciplines and paediatric audiologists.

For the majority of infants who require ECI no precipitating biological events, such as the nondisjunction of chromosome 21 during meiosis resulting in Trisomy 21 and one of the aetiologies of Down syndrome, can be traced back as causes of their communication disorders. The majority of infants eligible for ECI do not display the sequelae of concluded biological events that cannot be altered, but display communication developmental delays as a result of the continuous transactions between the environment and the child's constitution. The transactional model of causation, first described by Samerhoff (1986), proposes that biological as well as environmental factors impact on the development of an infant at-risk which results in continuous changes of which a negative or positive outcome cannot be predicted. Hence the population of infants referred to as at risk for communication disorders constitutes the largest section of ECI clients (See also Chapter 1, 1.2).

The important aspect in early identification of infants requiring ECI is therefore not to *diagnose* them as early as possible, as the cause for the communication delay can often not be attributed to an established risk factor, but the issue is to *identify* as early as possible their delayed communication development or the different risk factors that could still lead to such a delay so that intervention can start without interruption. This ideal is, however, not possible without the active participation of the caregivers of the infants requiring ECI.

2.3.1.5 Caregiver Participation and Prevention of Communication Disorders

Identification strategies would, however, be ineffective if the caregivers of these infants are not actively involved. As stated earlier, active parental involvement holds the second key to ECI efficacy (Rossetti, 1993). Recent studies from the medical field as well as ECI recommend the tapping of parents' knowledge of their infants' development (Hall, 1991). It is now generally accepted that parents are reliable informants on their infants' behaviour and that they could be the first to detect developmental delays

(Squires, *et al*., 1996). Delayed identification of communication disorders often results when professionals do not act on parents' suspicions and when both professionals and parents are not aware of ECI and its benefits. Parents' expertise and concerns about their developing infants are currently used as the motivation for screening, parents are employed to complete screening questionnaires and to assist in the screening process of their infant (Bland, 1996; Eddey, *et al*., 1995).

If parents are to participate in the early identification of their infants with communication delays, they must be well informed and educated. ECI has an important role to play not only to convince potential clients of its efficacy, but also to prevent conditions contributing to communication disorders by promoting health and normal communication development in the general public. Issues relating to drug and alcohol abuse, the prevention of HIV/AIDS, safety measures to prevent trauma, the serious effects of smoking and other environmental toxins on fetal development and child health and the control of infectious diseases such as measles and poliomyelitis by universal vaccination programmes, should be targeted in public awareness programmes (ASHA, 1991a). The ideal situation would therefore be well-informed families and communities pursuing healthy life styles and a decrease in the prevalence of preventable conditions associated with disabilities. As programme features is one of the issues in second generation research (Guralnick, 1997), a publicly supported ECI case-finding programme would be the first step towards effective service provision.

The discussion on the entry of infants and their families into the ECI process emphasises the pivotal role of family participation from the initial stages of intervention. This has led to the adoption of a family-centred approach which permeates through all ECI service delivery processes (ASHA, 1989; Beckman, Robinson, Rosenberg & Filer, 1994).

In summary, the implication is that best practice in ECI case finding is not possible when relying on one identification strategy only. As all the different strategies described have merit, it appears that a comprehensive programme for the early identification of communication disorders would actively involve parents, employ universal neonatal screening for hearing loss, the use of a high risk register, routine developmental surveillance carried out by different health care professionals, screening in the neonatal intensive care unit and at primary health care clinics, using epidemiological data and specific predictors of communication delays as well as the process of diagnosis (Hock Long, 1996; Boswell, 1998; Squires, *et al.,* 1996; Rossetti, 1986).

2.3.2 PHASE II: Assessment in ECI

As indicated in Figure II.I the next phase in the ECI process is the assessment of the infant and its family. In developed countries, the timely assessment of an infant and its family is supported by a co-ordinated and functional referral system. The ideal situation would be that primary referral sources, such as hospitals, primary health care clinics and physicians direct infants and their families to ECI (Hutinger, 1994) as a country's entire population of infants are seen by these health professionals at least once early in their lives. Yet, the most effective method seems through community referral sources (Rossetti, 1986) which include individual community members and private agencies such as parent support groups and churches (Hutinger, 1994). Referrals from non-medical sources demonstrate a community's level of understanding of disability, trust in ECI and the family's adaptive response to an infant who may have a communication disorder.

Since timely referrals can lead to the early assessment and commencement of ECI services of young children and their families, it must be seen as one of the key aspects of best practice in ECI. In order to provide further guidelines for best practice in ECI an in depth discussion of current assessment approaches and assessment procedures in ECI will be presented.

2.3.2.1 Critical Elements of the ECI Assessment Process

The importance of the assessment process in ECI and its unique characteristics of a multidisciplinary team approach, family-centred perspective and assessment procedures are described by various authors (Hammer, 1998; Linder, 1993; Rossetti, 1991; Rossetti, 1996; Teti & Gibbs, 1990). According to Rossetti (1996) the most challenging clinical activity in ECI is to obtain reliable and accurate assessment results. Since assessment results provide essential baseline data upon which the entire intervention programme will be designed, a discussion of the critical elements of the ECI assessment process is warranted.

Figure II.II was compiled to provide a diagrammatic presentation of the assessment process defined by Lahey (1988) and to illustrate the adaptations for assessment currently being implemented in ECI. Lahey (1988) includes the following four operational steps in the assessment process and refers to assessment as *describing* a child’s language behaviour for the purpose of *identifying* a problem, *planning* intervention and *estimating* a prognosis. The broad framework of the Lahey assessment model is relevant to communication-based infant-toddler assessment, as the rationale for both assessment processes is to make inferences relating to a child’s developmental level and not to diagnose the cause of the problem. However,

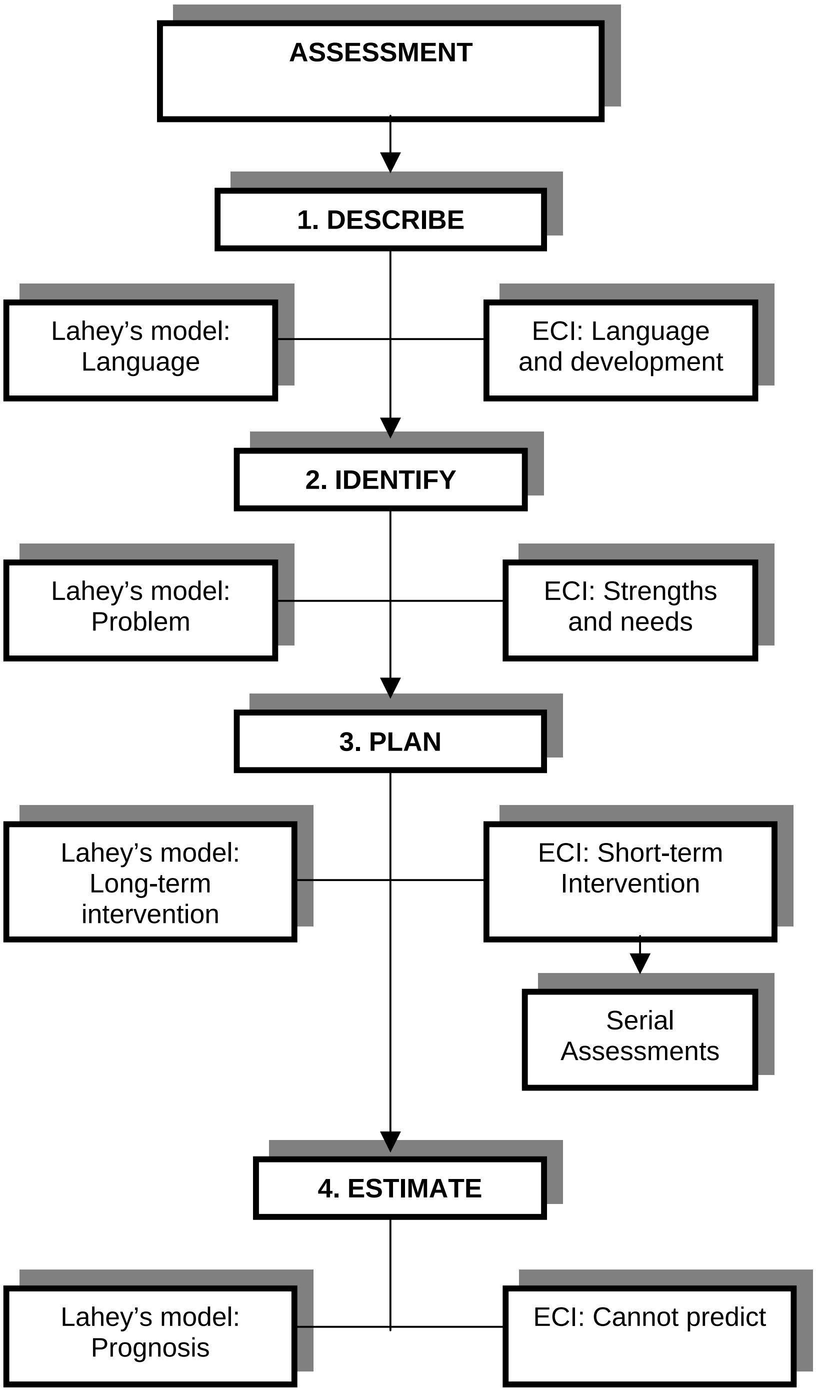

Figure II.II **Diagram to indicate the difference between Lahey's assessment model (1988) and assessment in ECI**

there are certain critical differences, developed mainly by Rossetti (1990a; 1991; 1996), in the assessment process when applied to ECI. There is a stronger emphasis on including the different developmental domains i.e. the language, motor, cognitive domains and family assessment in communication-based infant-toddler assessment than in the Lahey model.

The ECI assessment is not limited to the language domain only, as a holistic approach to development is the objective of the multidisciplinary team involvement. The language domain, however, remains the focus of a communication-based infant-toddler assessment and is not seen as a function of the cognitive domain as reflected in assessment instruments of infant mental ability such as the *Bayley Scales of Infant Development* (Bailey, 1969), the *Batelle Developmental Inventory* (Newborg, Stock, Wnek, Guidubaldi & Svinicki, 1984) and the *Cognitive Abilities Scale* (Bradley-Johnson, 1987).

A further difference of assessment in ECI, indicating the strong partnership with families, is to identify, build on, and reinforce family and infant strengths and not to focus on the problems only (Briggs, 1997). The emphasis on strengths signifies a move away from the deficit model which only identifies problems with the aim of remediating deficits (Bailey & Simeonsson, 1988).

Another element to be added to the ECI assessment process is that infant-toddler assessments bear limited predictive value (Gibbs & Teti, 1990; Rossetti, 1990a) and the estimation of a prognosis or long-term predictions about treatment outcomes does not apply to the same extent in ECI as in the assessment process according to the Lahey model. The variability of day to day infant behaviour implies that only a sample of an infant’s overall skill repertoire is observed during one assessment occasion and Rossetti (1991) proposes a series of assessments over a period of time which will produce more examples of behaviour upon which short-term intervention decisions could be made. The assessment process of ECI therefore relies on a developmental perspective to monitor the effectiveness of treatment, again indicating the multidisciplinary team involvement which will be discussed in the next section.

2.3.2.2 Multidisciplinary Team Approach to Assessment in ECI

The multidisciplinary collaborative team approach to infant assessment has evolved from the realisation that no single profession can provide in the diverse and complex needs of a family with an infant at-risk or with a disability (Butler, 1993) and a movement away from the medical or biological model to explain the aetiology of disabilities. The emergence of the medical model of causation, in contrast with the prevailing moral model of that time which ascribed diseases and abnormal behaviour to moral wrongs, marks the advent of modern scientific understanding of the biological basis of disabilities in the second half of the 19th century in the western world (Foley, 1990).

As indicated earlier, the medical model provides the basis for the diagnosis of conditions of which the risk for communication disorders is well-known and established, but cannot adequately explain conditions with no direct and immediate relationship between causal factors and their effects. The transactional model of causation, implicating that infant developmental outcome is the result of ongoing child and family change over time (Samerhoff, 1986), is now widely accepted. This model more effectively reflects the developmental and educational perspectives of the array of disciplines, such as child development, special education, social work, psychology, nursing and medicine, speech-language therapy, audiology, occupational therapy and physiotherapy collaborating in the assessment process of ECI.

In the light of so many different disciplines representing various perspectives on teamwork, different team models for service delivery in ECI have emerged in an attempt to provide the most effective assessment and treatment services for families with infants at risk for communication delays.

The transdisciplinary model of team collaboration has gained much support in the current literature (Foley, 1990; Briggs, 1997), as the implications of a family-centred approach to ECI have become clearer. From a family's perspective, the direct and personal involvement of all team members, as in the case of the multidisciplinary and interdisciplinary team models, can be intrusive, disempowering and confusing when not well co-ordinated. The transdisciplinary team model as applied to the assessment process in ECI is an integrative approach and has the following characteristics and advantages:

- The philosophy of team collaboration is multi-competency. Team members commit themselves to teach, learn and work across disciplinary boundaries to plan and provide integrated services. In this way the services can be cost effective as more tasks can be performed without assigning a large number of specialised people.
- The transdisciplinary team model is fully family-centred as families are always members of the team and are able to determine their roles on the team. Families do not meet with different disciplines separately. The team and family develop an intervention plan together based on the family's concerns, priorities and resources.
- The lines of team communication are formalised as the team meets regularly to share information and to teach and learn across disciplines. In the case of multidisciplinary and interdisciplinary teamwork the contact between team members is *ad hoc* and often only through reports.
- Team development across disciplines is formalised and critical to role release. This implies that the team meets on a regular basis.
- The assessment process is characterised by the simultaneous participation of team members in the arena assessment and no separate or parallel assessments are conducted by the different disciplines as in the multidisciplinary and interdisciplinary team models.
- The treatment plan is implemented by one team member (the implementer), together with the family under the supervision of another team member as case manager.

(Adapted from: Briggs, 1997; Foley, 1990; McGonigel, Woodruff & Roszmann-Millican, 1994; Rossetti, 1990a).

According to Rossetti (1990a) the transdisciplinary approach in infant-toddler assessment appears to be the most effective way to provide intervention to the increasing populations of infants and their families who require these services. Moreover, the transdisciplinary team approach is viewed by Johnson (1994) as a model to achieve authentic family-centred EI services. Since EI service providers search for effective ways of relating to families, the transdisciplinary team model is increasingly seen as well suited to the demands of family-centered EI services (McGonigel, *et al.,* 1994).

2.3.2.3 A Family–Centered Approach to Assessment in ECI

The family's initiative to report for an assessment marks the beginning of a client-professional relationship that is unique to ECI. The role of families in ECI programmes have undergone a remarkable transformation in the past two decades and they, and not their children, are now regarded as the primary clients in ECI service provision (Krauss, 1997). One of the reasons for the prominence of the family in ECI can be attributed to the notion described by Guralnick (1997) as the unique opportunity of early childhood to influence children's development and to support their families to do so. This opportunity is now believed to deliver long-term positive outcomes for both the family and the infant at-risk or with a disability (McCollum & Hemmeter, 1997).

Marking the issues of second generation research in EI (Guralnick, 1997) and for the purpose of assessment, the characteristics of the family with an infant at risk or with a communication disorder are currently described within the framework of the family systems theory, first advocated by Minuchin in 1974 (Briggs, 1997) and the ecological theory, as developed by Bronfenbrenner in 1979 (Hammer, 1998) and applied to ECI.

According to family systems theory the infant is never assessed in isolation, but always seen as a member of a dynamic family system, progressing through life-cycle transitions. Family characteristics are transmitted down generations and combined with cultural patterns of behaviour, fashion beliefs, values, celebrations, everyday rituals and expectations which contribute to the uniqueness of a specific family as ECI client (Hammer, 1998; Schuck & Bucy, 1997).

In criticism of prominent exponents of developmental psychology, such as Piaget whose views regained popularity at that time, Bronfenbrenner (Hammer, 1998) stressed the importance of exploring the context in order to understand child development and behaviours. Ecological theory emphasises the different degrees of complexity of interrelated systems within which a child develops. The first system represents the immediate relationships of the infant and includes parents, siblings, relatives, day care personnel and early interventionists. The second system refers to the relationships among these settings of which the infant is a member, i.e. the home, day care and ECI programme. The third system includes settings where the infant is not directly involved, but can influence development, namely the parents' workplaces, community agencies and ECI policy. The last system is the broadest and involves the social-cultural environment of the infant (Hammer, 1998).

The first system, particularly the family, is considered the infant's most valuable resource for learning, especially for communication development (Gulker, 1992; Lester, 1992). According to Guralnick (1997), the following three family patterns of interaction are strongly associated with a child's developmental outcome, irrespective of that child's disability or risk status:

- The quality of parent-child transactions. Contingent, encouraging, affectively warm, nonintrusive, appropriately structured, discourse-based and developmentally sensitive patterns of caregiver-child interactions enhance a child's development.
- Family-orchestrated child experiences increase the stimulation value of the environment enriched by toys and learning materials.
- Ensuring the child's health and safety.

As depicted in Figure II.III the interaction patterns to be considered in assessment represent two levels of proximity to the child. Parent-child interactions represent the closest interactional pattern provided by the family, stressing the necessity of an intimate relationship in a child's life which cannot be replaced by any other distal relationship but can be facilitated when deficient. Parent-child interaction patterns evolve before birth and form the intimate relationship of attachment between the parent and the newborn to become the platform for communication development. The provision of stimulation and protection as well as the promotion of health by the family represent the broader context of interaction between the child and the environment and can be augmented when insufficient (Billeaud, 1998; Guralnick, 1997).

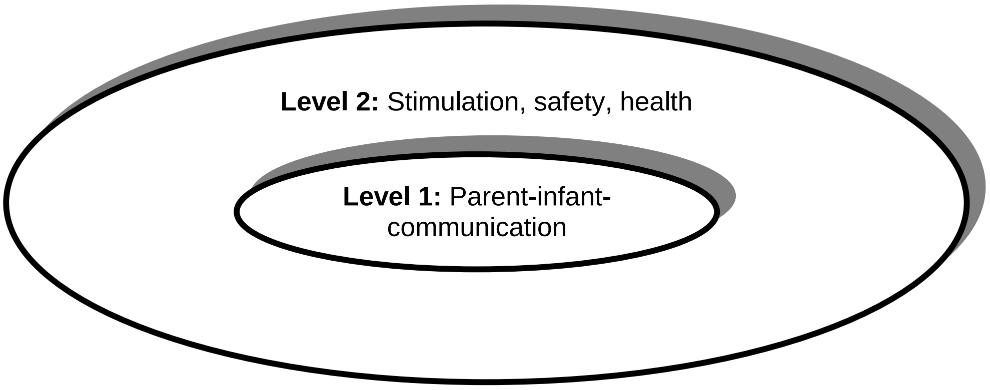

Figure II. III Levels of family interaction patterns
Based on Guralnick, 1997.

The extent to which parents are able to effectively perform these child-rearing roles depends on the following factors, which can also be the sources of stress:

- The personal characteristics of the parents
- Aspects not related to the child’s disability or risk status, such as social support, marital relationship, financial resources and child temperament
- Stressors created by the child’s disability or risk status

(Guralnick , 1997)

Various stressors are viewed as centrifugal forces contributing to move the family apart and interventions are seen as centripetal forces operating to organise and bring the family together (Bailey & Simeonsson, 1988; Briggs, 1997). Centrifugal forces acting as stressors are directly related to the degree and severity of the infant's disability, the degree of specialised care required, the visibility of the disability and the family's coping ability (Rossetti, 1990a).

According to Hammer (1998) multiple sources of information must be used in assessment to form a "thick" description of the family, a term derived from anthropological sources. This implies that observations of the family and infant are made in natural contexts and reported from the family's perspective, resulting in clinicians and families beginning intervention from the same point of view. This clearly suggests a departure from the deficit model of assessment towards an assets model of assessment. Ammerman & Parks (1998) propose the identification of assets and capacities of individuals and their contexts to foster better collaboration and culturally responsive services.

As pointed out earlier, Rossetti (1990a) views the assessment of parent-infant-interaction as part of a comprehensive assessment of language functioning in the infant. Various instruments have been developed to assess different aspects of parent-infant communication interaction patterns, such as the *Infant-Parent Social Interaction Code* (Baird, Haas, McCormick, Carruth & Turner, 1992), *Observation of Communicative Interaction (OCI)* (Klein & Briggs, 1987), *Mother/Infant-Communication Screening (MICS)* (Raack, 1989), interaction-attachment (Rossetti, 1990b) and guidelines to identify specific language facilitation techniques used by the parent (Gulker, 1992). According to Krauss (1997) first generation research in EI concentrated extensively on the dyadic relationships between mother and infant, but has now shifted focus to describe the capacities of parents to meet the general needs of the entire family. Characteristic of these parent-infant interaction assessment strategies was that, while providing valuable and essential information, data collection was fully controlled by the ECI clinician and parents have limited participation in offering information and decision making.

The challenge is now to offer families increased choices and control in preparing for the assessment process, participating in assessment activities and the sharing of assessment results (Crais & Wilson, 1996). According to Krauss (1997) the mechanisms for achieving the goal of family-friendly assessment are not yet clear. Crais (1993) suggests alternative roles or families in infant assessment but cautions that it is important to honour whichever roles are chosen by family members and to avoid pressuring them into other roles. The different roles can be viewed on a continuum from the lowest level of participation to the highest level of involvement. The different roles are: Receiver, observer, informant, describer, interpreter, validator, participant and evaluator (Crais, 1993). Involving parents on all these levels of participation in the assessment process is attainable as recent findings demonstrated a high correlation between parents’ and professionals’ judgements of a child’s developmental level (Crais, 1993; Rossetti, 1996).

In a study conducted to determine the effectiveness of a family-centred approach in EI Griffer (1997), reports enhanced active involvement of parents in the communication-based assessment of their infants and toddlers. The subjects were 20 families of infants enrolled in an ECI programme and they found the following family-centred strategies to be most beneficial:

- Discussing the purpose of the assessment and options for family participation in pre-assessment meetings with the team.
- Creating opportunities that facilitated active parent involvement.
- Conveying to families that their strengths, concerns and particularly their input regarding their infant’s development was sought, valued and seriously considered throughout the assessment process.

Although employing a small number of subjects, the study indicates client satisfaction on family involvement in the assessment process which is an important aspect in improving the effectiveness of ECI services.

The basis of the family-centred assessment process in ECI can be summarised as a paradigm that recognises the interaction between infant, parents and the environment (Rossetti, 1990a). The unique characteristics of a family and its cultural values and beliefs as well as physical and social resources to cope with an infant with a disability or at risk for developmental delay, yet avoiding professional intrusiveness into family life, should transpire in the assessment process. The family-centered assessment approach is clearly one of the elements of best practice in ECI. Further challenges regarding best practice in ECI assessment involves the question of the most efficacious way to conduct the assessment activity.

2.3.2.4 Assessment Procedures in ECI

Rossetti, as one of the main exponents of communication-based intervention in EI, has defined infant-toddler assessment as *" …. any activity, either formal through the use of norm-referenced standardised criteria, or less formal, through the use of developmental profiles or checklists, that is designed to elicit accurate and reliable samples of behaviour upon which inferences relative to developmental skill status may be made"* (Rossetti, 1996, p77).

The definition implies that any activity is valid as an assessment procedure in ECI, provided that accuracy and reliability of the data can be assured. As a wide choice of assessment procedures are now available to the multidisciplinary team, designing a comprehensive communication-based assessment protocol is possible.

The use of criterion-referenced assessment procedures have gained preference in ECI as these instruments demonstrate the infant's mastery of the specific behaviours under observation (Rossetti, 1996). Norm-referenced instruments compare the functioning of an infant to the performance of the population at large, but provide limited information to be used for treatment goals and objectives. Norm-referenced instruments are standardised on the population of typically developing infants and can therefore only demonstrate the weaknesses and needs of infants with disabilities. This inflexible way of assessment is particularly misleading and unproductive in the case of infants with severe disabilities (Bagnato & Hofkosh, 1990; Rossetti, 1990a).

A criterion-based assessment approach is therefore more suitable for infants and toddlers as it describes the infant's functioning along a continuum of developmentally sequenced objectives. The information gained provides developmental levels as well as curriculum guidelines. According to Bagnato and Hofkosh (1990) characteristics of effective assessment instruments for infants and toddlers include the following:

- The instruments are designed to reflect a developmental basis in their content and structure.
- Provide a profile of all the different developmental domains.
- Use different sources of information, including parents and team members
- Supply treatment links in the form of programme goals and strategies.
- Allow adaptive options of assessment procedures in order to accommodate the infant’s sensory and response impairments.
- Reflect an ecological and family systems perspective to adequately describe the parent-infant communication interaction aspects of the environment that influence infant development.
- Supported by research data in terms of reliability, validity and treatment utility.

Examples of assessment instruments meeting these criteria are the *Hawaii Early Learning Profile (HELP) Checklist* (Furono, O’Reilly, Inatsuka, Hosaka, & Falbey, 1993) and a communication-based assessment scale, *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b).

The HELP (Furono, *et al.,* 1993) is a comprehensive assessment and curriculum system, incorporating six developmental domains, i.e. cognitive, language, gross motor, fine motor, social-emotional and self-help, ranging from birth to 36 months of age. Each of the developmental domains were designed by an interdisciplinary specialist most expert in the area, thereby facilitating its acceptance as a useful assessment instrument for the whole team. The curriculum invites parent participation by means of easily implemented instructional strategies. This assessment instrument is therefore valuable in ECI as it in provides developmental information regarding a child’s general development and does not focus on one developmental domain only. The following assessment instrument provides an in depth analysis of one developmental domain, i.e. communication development.

The Rossetti Infant-Toddler Language Scale (Rossetti, 1990b) is currently the most widely used infant-toddler communication assessment instrument (Rossetti, 1998) and was designed in accordance with his philosophy that socio-communicative skills represent the only developmental domain that consistently separates low-risk from high-risk children (Rossetti, 1996). The scale is a comprehensive assessment instrument, involving high levels of parent participation by including a parent questionnaire, an interview guide and parent report is added next to observation and elicitation of communication behaviour as a valid method of data collection. The three dimensions of language, i.e. use, content and form (Lahey, 1988) are embedded in the six sub-scales which include interaction-attachment, pragmatics, gesture, play, language comprehension and language expression. The scale is a criterion-based assessment instrument and provides a comprehensive description of socio-communicative skills of infants and toddlers, which can be implemented as intervention goals, objectives and strategies. Of all the communication assessment instruments currently available, this instrument is one of the most comprehensive scales and most valuable in any ECI programme.

Both these assessment instruments are flexible to suit various settings such as the arena assessment which is based on a transdisciplinary team approach where information, knowledge and skills are deliberately exchanged and pooled in the simultaneous assessment of the infant.

The transdisciplinary play-based assessment procedure as developed by Linder (1993) has gained acceptance in ECI as its design accommodates the arena assessment. Within the context of the arena assessment the infant is engaged in structured and instructional play situations which provide opportunities for functional, natural and transdisciplinary observation of behaviours across developmental domains.

The question arises whether the transdisciplinary play-based arena assessment is the most effective model to assess infants and toddlers at risk for communication delays. A comparative study between a play-based assessment format using *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) and a formal standardised measurement instrument, conducted by Calhoon (1997), indicates a favourable outcome for the play-based model. Four subjects with a language delay were assessed employing both assessment methods and the results indicated that the play-based assessment produced higher performance scores and provided a broader picture of the toddlers' emerging skills (Calhoon, 1997).

It therefore appears that a play-based arena assessment model using criterion-referenced instruments could be advantageous to the infant or toddler at risk for communication delays. The play-based transdisciplinary arena assessment model is currently regarded as an appropriate approach for obtaining an accurate view of an infant or toddler's strengths and needs. According to Parette, Bryde, Hoge and Hogan (1995) the specific advantages of the model include the following:

- Team participation is enhanced as a unified approach is achieved.
- Fatigue is limited as the infant or toddler is assessed in one session only.
- More reliable samples of behaviour can be obtained as the team member with the best rapport with the infant is utilised as the facilitator.
- The whole team is available to the family at one time.
- The team members benefit as all information is immediately available, leading to improved programme planning.
- This approach is cost-effective as multiple separate assessments are not necessary.

The guidelines for best practice regarding communication assessment in ECI are clear and involves the utilisation of criterion-referenced assessment instruments and a play-based transdisciplinary arena approach. There is empirical support for the play-based transdisciplinary arena approach in the assessment of infants and toddlers at risk for or with communication disorders and its benefits are known.

As pointed out in Figure II.II the content of infant-toddler assessment covers all the different developmental domains. Rossetti (1990a) indicated the specific assessment domains as the language, motor and cognitive domains and family assessment, with the primary focus on language in order to obtain comprehensive information to plan a communication-based curriculum for an infant or toddler requiring ECI.

According to Prizant and Wetherby (1995) infant-toddler language assessments tend to focus on communication milestones and forms, i.e. appearance of first words, gestures, phonology and vocabulary and give limited attention to the functions or purposes of communication. Early communication functions include those signals of an infant which have the intention of affecting another person's behaviour in specific ways, such as:

- To regulate another person's behaviour by means of protesting and requesting objects and actions.
-
- To interact socially with another person by means of requesting social routine, requesting comfort, calling, greeting, showing off and requesting permission.
-
- To give attention to another person in turn-taking communication interaction events, by means of commenting, requesting information and providing information on an object, event or a topic.

(Prizant & Wetherby, 1995; Wetherby & Prizant, 1989)

Even though these early signals are not yet intentional, research indicates that parents spontaneously respond to infant cues as if they express different functions, thereby fostering interactive communication development (Pearce, Girolametto & Weitzman, 1996; Prizant & Wetherby, 1995). This implies that communication assessment instruments should be sensitive to evaluate emerging prelinguistic behaviours as they provide important guidelines for parent training in ECI.

Table 2.1 was compiled to provide a framework for infant-toddler communication-based assessment which describes the assessment areas and procedures to be utilised. The framework for assessment provides valuable guidelines for best practice in ECI.

Table 2.1 A framework for infant-toddler communication-based assessment

Assessment Area	Assessment Procedures
1. Expressive Language and Communication - Communicative means - Communicative functions - Phonological development - Range of vocabulary - Semantic complexity of utterances - Morphologic complexity - Reciprocity in communication	- Play-based procedures: Interactive routines, toys and books - Observation of parent-infant communication interaction - Parent report - Eliciting of behaviours by assessor - Parent's developmental diary of infant
2. Receptive Language and Communication - Orientation to sound and speech - Non-linguistic response strategies - Linguistic comprehension	- Hearing screening test - Play-based procedures: Interactive routines, toys and books - Parent report
3. Speech Production - Quality of vocal production - Phonetic repertoire - Structure of babbling patterns - Quality of speech - Oral structure - Oral-motor function and feeding skills - Speech function	- Interactive play-based procedures Interactive routines, toys and books - Eliciting of behaviours by assessor - Observations by assessor - Observation of parent-infant communication interaction - Observation of feeding skills
4. Language related cognitive abilities - Symbolic play and object exploration - Constructive play - Attentional capacities - Imitation	- Play-based procedures: Interactive routines, toys and books - Observation of parent-infant communication interaction
5. Social-Affective Behaviour - Use of gaze for social referencing - Expression of positive affect - Expression of negative affect	- Play-based procedures: Interactive routines, toys and books - Observation of parent-infant communication interaction - Parent report
6. Motor Abilities - Fine motor skills - Gross motor skills	- Play-based procedures: Interactive routines, toys and books - Parent report

Adapted from Prizant & Wetherby, 1995.

As illustrated in Table 2.1 all developmental domains are included in the framework for communication-based assessment. The developmental domains are interrelated and communication acts observed during assessment are the result of the integration of them all. As the aim is to determine the functionality of an infant's communication skills, detailed information requiring accurate observation is necessary. It is therefore clear that a combination of criterion-referenced assessment instruments as well as sampling procedures (to determine the phonetic, babbling, gestural and expressive language inventories) and formal measurements (audiological measurements) need to be implemented for a comprehensive infant-toddler communication-based assessment.

The quality of the multidisciplinary assessment of an infant and family contributes to the effectiveness of the intervention programme to be implemented. The goals for assessment present some of the greatest challenges in ECI, i.e. the early detection of communicative delay, deciding on appropriate intervention, monitoring of child and family change, monitoring of programme effectiveness and predicting infant progress by means of serial assessments (Rossetti, 1996).

The initial assessment is a crucial step in ECI as it initiates the process of treatment. Best practice in infant toddler assessment depends on multidisciplinary team involvement, a family-centred approach, the quality of assessment procedures employed and the skills of the early communication interventionist.

Assessment is not an end in itself. It is the starting point for further activities designed to enhance the young child’s performance level (Louw, 1997), i.e. the provision of an ECI programme.

2.3.3 PHASE III: Provision of ECI Programme Services

The last phase in the ECI process illustrated in Figure II.I involves the provision of ECI programme services. Based on the wealth of information gathered from different sources during the assessment process, an individual family service plan is designed, which forms an integral part of the treatment programme rendered by an ECI service provider. The importance of a discussion on ECI programmes is also stressed by Guralnick (1997), who regards EI programme features as one of the characteristic themes of second generation research in EI.

Within the USA context, with legislation to support the provision of EI services, Guralnick (1997) suggests that an effective EI programme should closely match the needs of individual families and should assist them on three different levels:

- Resource supports which include financial assistance, respite care and the co-ordination of all services.
- Social supports in the form of parent to parent groups, family counselling and mobilising community networks.
- Information and services constitute the most visible component of the EI programme and include the formal intervention programme carried by parent-professional relationships.

In order to determine to what extent existing EI programmes assist families on these three levels a literature survey was conducted to identify a variety of different EI programmes. The aim of including EI programmes in the discussion was to investigate to what extent the special needs of the different populations of young children at risk for communication disorders are incorporated in examples of currently available EI programmes. Twelve programmes were selected on the basis of clear and comprehensive descriptions of their aims, approaches and contents in order to allow analysis and identify indicators for effectiveness.

Table 2.2 provides a summarised description of the twelve EI programmes which were selected for analysis.

Table 2.2 Characteristics and components of a selection of EI programmes

Programme	*The Portage Home Teaching Model of EI* (Cameron, 1997)	*Mother-Infant Communication Project* (Haney & Klein, 1993)	*Hanen Early Language Parent Programme* (Giralometto, *et al.,* 1986)
Location	Started in Wisconsin (USA), then UK, now international	Los Angeles, USA	Toronto, Canada, international
Target group	Families with pre-school children with disabilities	Mothers and families and their high risk NICU graduate infants	Families with infants with communication delays; early childhood educators
Programme approach	* Educational service * Parent mediated intervention	Facilitate mother-infant communication interaction	Child-centred conversational model of language intervention
Years in operation	20 years	3 years	Since 1974
Service delivery options	Home visiting	* Home visiting * Centre-based * Small neighbourhood groups	2 week long evening group training programme for parents, home visits
Frequency of programme input	Weekly	Weekly	Regular follow-up
Team approach	Transdisciplinary: Teachers, health visitors, community nurses, therapists, volunteers	Interdisciplinary: Infant developmental specialists, speech-language pathologists	Speech-language pathologists and trained group leaders
Content of programme	Self-help, motor, language, social, cognitive	Communication and general development, health, nutrition	Communication-based
Training of personnel	* Basic 4 day in-service training * Advanced training	In-service training	* In-service training * Training group leaders (Weitzman, 1994)
Intervention materials	* *Portage Checklist* * *Portage Teaching Cards* * *Portage Activity Chart* (Cameron, 1997)	*Observation of Communicative Interaction* (Klein & Briggs, 1987)	*It Takes Two to Talk* (Manolson, 1993) *Learning Language and Loving it* (Weitzman, 1992)
Management	Service delivery structure; supervisors	Service delivery structure	Service delivery structure
Monitoring	* Regular assessment of child progress * Team meetings * The Portage Code of Practice and Ethical Guidelines	*Quarterly developmental assessments * Staff meetings * Evaluation of services	* Evaluations by programme participants * Monitor family progress
Research	More than 20 studies	4 studies	Various publications
Achievements	* Best-known EI programme in UK * Widely respected approach * Influenced government policy	* Advanced language development and home environments * Peer learning in parent groups	* Effective, widely used approach * Numerous publications of intervention and training materials
Special emphasis	Educational services to families in their homes with various social and cultural backgrounds	* Mother-infant-communication interaction * Mothers: Single, low income and education	Facilitate dialogue skills that support language development

Table 2.2 continued Characteristics and components of a selection of EI programmes

Programme	*The Carolina Curriculum for Infants and Toddlers with Special Needs* (Johnson-Martin, *et al.,* 1991)	*Early Childhood Research and Intervention Program* (Baxter & Kahn, 1996)	*NIDCAP: Newborn Individualized Developmental Care and Assessment Program* (Als, 1997)
Location	North Carolina and internationally available	Chicago, USA	Boston and 10 centres in USA
Target group	EI personnel, children with disabilities 0-24m developmental range	Families with infants at risk and disabilities living in poverty	Families with infants in the NICU
Programme approach	Curriculum to be used under professional supervision	* Parent training * Direct intervention with child	Observation of infant behaviour as a guide to support primary care team and family
Years in operation	Since 1986	Not stated	Not stated
Service delivery options	No direct service delivery	* Home visiting * Centre-based	Daily interventions in NICU
Frequency of programme input	Daily activities of curriculum	Weekly	Full time
Team approach	Transdisciplinary: Educators, day-care workers, psychologists, therapists, nurses	Transdisciplinary: Early childhood educators, social workers, community workers	Multidisciplinary: Developmental specialist, developmental care nurse educator
Content of programme	Cognition, fine motor, communication, social adaptation, gross motor	Developmental activities, family support	Behavioural observation, care-giving, feeding, positioning, family comfort, soothing environment
Training of personnel	Instructions included in curriculum	Not stated	In-service training
Intervention materials	* Curriculum * Assessment Log * Developmental progress Chart * Adaptations for infants with multiple disabilities	* Family Support Services Interview * Questionnaire on Resources and Stress	* *Assessment of Preterm Infant's Behaviour* * *Newborn Individualized Developmental Care and Assessment*
Management	None	Service delivery structure	Service delivery structure
Monitoring	* Updating of curriculum 1986 to 1991 * Field-tested in 22 EI programmes	* Participants evaluate services * Developmental assessments	* Ongoing research * Parent council * Monitoring process
Documented research	Various studies	4 studies	More than 10 studies
Achievements	* Well-known and widely used EI programme	* Descriptive information on needs, stresses and resources low income inner-city families	* 10 NIDCAP Centres * Salaried positions for personnel * Lower mortality rate
Special emphasis	Sensory motor development	* Unique strengths, resources and needs of families living in poverty in the inner-city	Relationship-based developmental Care in the NICU

Table 2.2 continued Characteristics and components of a selection of EI programmes

Programme	*Infant Health and Development Program* (Blair, *et al.,* 1995)	*Communication intervention in the NICU* (Jacobson & Shubat, 1991)	*Hawaii Early Learning Profile (HELP)* (Furono*, et al.,* 1993)
Location	USA, 8 different sites	Kansas City, USA	Hawaii and internationally available
Target group	Infants and toddlers at biological and environmental risk	Families with infants at risk in the NICU	Families and infants at environmental risk
Programme approach	* Parent training * Direct intervention with child	* Parent training * Direct intervention with infant	* Parent training * Direct intervention with infant
Years in operation	1985 to 1988	1983-1987	First published 1979
Service delivery options	* Home visiting < 12m * Centre-based > 12 m * Parent group meetings	Daily interventions in NICU and follow-up after discharge	Daily activities for home and centre
Frequency of programme input	Weekly at home Daily at centre	Daily	Full time
Team approach	* Transdisciplinary: EI team * Multidisciplinary: Medical team	Interdisciplinary: Speech-language pathologist member of NICU team	Can be used in a transdisciplinary EI team
Content of programme	All developmental domains and medical follow-up	Developmental activities, family support, identification of hearing loss and other disorders, care-giving	Social-emotional, cognitive, language, gross and fine motor, self-help
Training of personnel	Professionals specialising in EI	Self-training	Instructional manual
Intervention materials	* Curriculum for very low birth weight infants (Early Partners) * Curriculum for infancy and early childhood (Partners for Learning)	* No formal intervention material developed for programme	* Developmental Assessment Record and Checklist * Activities for Family Participation * Charting Progress * Curriculum Activities * Adapted home activities
Management	Service delivery structure including research component	Service delivery structure	None
Monitoring	* Child assessment at 12, 24 and 36 m * Control group: No EI, only medical care	* Careful documentation * Evaluation of programme	* Ongoing research
Documented research	Numerous publications	3 publications	Numerous publications
Achievements	* Largest EI study ever done: 985 subjects * Proved effectiveness of EI after 3 years in programme	* One of the first articles on role of speech-language pathologist in NICU	* Widely used programme * Numerous resources for professional use * Parents with special needs
Special emphasis	Cognitive development of infants at biological risk	Communication-based intervention in NICU	Comprehensive and integrated approach to EI

Table 2.2 continued Characteristics and components of a selection of EI programmes

Programme	*SKI-HI Programme for families with infants and children with hearing impairment* (Glover, *et al.*, 1994)	*Communication Intervention Programme for Infants with Down Syndrome* (Kumin, *et al.*, 1991)	*Early Communication-Based Intervention for Infants Born with Clefts* (Savage, 1997)
Location	Logan, Utah and throughout USA and Canada	Maryland, USA	Pennsylvania
Target group	Families with infants and pre-school children who are deaf and hard of hearing	Families with infants and toddlers with Down syndrome	Families and infants with cleft lip and palate
Programme approach	* Family-centred * Intervention with child	* Parent training * Intervention with child	* Parent training and support * Intervention with infant
Years in operation	Since early 1970's	Since 1980's	Since 1980's
Service delivery options	* Home intervention * Family support groups * Centre-based	* Centre-based individual therapy and parent training	Craniofacial team management, centre-based intervention
Frequency of programme input	Weekly contacts at home	Weekly therapy sessions	* Feeding therapy as required, monitor communication skills
Team approach	* Multidisciplinary: Parent advisors, trainers, audiologists	Therapy done by 2 speech-language pathologists	Multidisciplinary craniofacial EI team
Content of programme	Program components: Hearing aid, communication, auditory, language (cued speech, total communication, aural-oral, sign language)	Treatment protocol: General behaviour, oro-motor, pragmatic, receptive and expressive language ability	Early feeding and socialisation, family counselling, monitor speech and language development
Training of personnel	Formal training in SKI-HI approach	In-service training	In-service training
Intervention materials	* SKI-HI parent training programme * SKI-HI Resource Manual for Family-Centred Home-Based programming for Infants, Toddlers and Pre-school-aged Children with hearing Impairment	* Diagnostic evaluation report * Therapy lesson plan * Progress report * Programme published	* No specific materials developed for programme
Management	Service delivery and training structure	Service delivery structure	None
Monitoring	* Regular assessment of child * Evaluations of programme effectiveness	* Documentation of intervention	* Ongoing research
Documented research	Numerous publications	4 publications	3 publications
Achievements	* Well-known approach * Proved effectiveness of EI for infants with hearing impairment	Widely used programme for infants with Down syndrome	Continuity in assessment/intervention planning
Special emphasis	Early identification followed by appropriate intervention programming	Total communication to facilitate expressive language	Promote development despite biological and environmental risks

The three programmes designed for specific populations with established conditions for communication disorders, include the *SKI-HI Programme for Infants and Pre-school Children with Hearing Impairment* (Glover, Watkins, Pittman, Johnson & Barringer, 1994), communication intervention for infants with Down syndrome (Kumin, Goodman & Councill, 1991) and communication-based intervention for infants born with clefts (Savage, 1997).

The two communication-based programmes for infants with low birth weight and prematurity, are for communication intervention in the NICU (Jacobson & Shubat, 1991) and a programme for their follow-up, the *Mother-Infant Communication Project (MICP)* (Haney & Klein, 1993). The last programme has the added advantage to provide in the needs of single mothers with low income and limited education, thus including infants with biological as well as environmental risks. In a study to evaluate the effectiveness of the *Observation of Communicative Interaction* (Klein & Briggs, 1987), the assessment scale designed for the MICP, Whites (1992) found the instrument to be a valuable tool in assessing the quality of caregiver interactions with infants and providing treatment guidelines.

The sixth communication-based EI programme, *the Hanen Early Language Parent Programme* (Giralometto, Greenberg & Manolson, 1986), was not designed for a specific population of infants at risk, but is one of the best family-centred EI approaches to be implemented for infants with disabilities and at risk for communication delays. The theoretical underpinnings of the programme ascribe to the central role that early reciprocal interactions between parent and child play in facilitating the child's communicative and linguistic development. The programme, administered from the Hanen Centre in Toronto, trains parents to use naturalistic interaction strategies associated with accelerated language development in normal children (Pearce, Girolametto & Weitzman, 1996).

The remaining six programmes in Table 2.2 were included to illustrate the advantages of general EI programmes which curricula comprehensively cover all developmental domains and offering a wealth of intervention materials and multiple service delivery options. These programmes are also applicable for young children at risk for communication disorders and each programme's strong points are as follows:

- *The Portage Home Teaching Model* (Cameron, 1997), focuses on home-based services.
- *The Carolina Curriculum for Infants and Toddlers with Special Needs* (Johnson-Martin, Jens, Attermeier & Hacker, 1991) emphasises sensory motor development.
- *The Hawaii Early Learning Profile* (Furono, et al., 1993) provides additional materials to assist parents who have disabilities.
- The Infant Health and Development Programme (Blair, *et al.*, 1995) with a strong research basis emphasises the health care needs of infants with low birth weight and prematurity.
- *The Newborn Individualized Developmental Care and Assessment Program* (Als, 1997) includes all aspects of NICU care and provides a new model for the traditional NICU team management.
- The Early Childhood Research and Intervention Program (Baxter & Kahn, 1996) draws attention to the most needy families and infants at double risk for communication developmental delays in the USA, i.e. those living in poverty in the inner cities.

According to Table 2.2, there is a wealth of programme components available for selection to design an individualised family service plan. As language and communication skills represent the most important developmental domain to facilitate school readiness and ensure school success (Capute, *et al*., 1987), the vantage point of any individualised family service plan is a strong focus on communication development. This implies that, irrespective of the infant's disability or risk factors or the parents' resources and needs, a communication-based programme will improve the effectiveness of any EI treatment plan (Rossetti, 1996).

After establishing the focus of the programme content, other ECI service delivery parameters can be considered. As indicated in Table 2.2 and also suggested by Guralnick (1997), parameters to be considered are the programme approach, different service delivery options, the frequency of the programme input, the team model, the role of the parent, the degree of structure that should exist when implementing the curriculum and specific intervention materials. The selection of intervention materials can be guided by background information on the development of the material, research, experience in the ECI field, programme achievements, training of personnel and monitoring for quality control. Evidence of the quality of the programmes can be found in the various studies and publications carried out by most of the twelve programmes reviewed in Table 2.2.

According to the three levels of support required by families (Guralnick, 1997) the strong point of the programmes in Table 2.2 appears to be the support families receive regarding information and services directly related to the child’s needs. None of the programmes clearly stated that they provide financial assistance, respite care or how all services are co-ordinated. It is therefore not clear to what extent resource supports are provided in the programmes.

Social supports are provided by two programmes namely *The Mother-Infant Communication Project* (Haney & Klein, 1993) and the *SKI-HI Programme for Infants and Pre-school Children with Hearing Impairment* (Glover, *et al*., 1994) in the form of family support groups and small neighbourhood groups. It therefore appears that the programmes reviewed mostly focus on programme content regarding the intervention needs of the child and not so much on the wider needs of the family concerning resource and social supports. These two important progamme components relate to the family’s quality of life, their ability to cope with an infant with a disability and their integration into the community where they live. It appears that the twelve programmes reviewed do not adequately attend to stressors impacting on families. Since low family risk can have moderating effects on stressors which can disrupt family interaction patterns, provision of social supports is one of the components of best practice in EI.

As the family-centered approach is at the core EI, meeting the family's needs on all levels is indeed a challenge for best practice in EI. If a family is socially supported and has sufficient resources EI will be able to meet its own goals. As stated by Rossetti (1990) family goals in EI include reducing stress and anxiety associated with parenting a young child with disabilities and to increase the amount of responsibility that parents take for educating that child.

Figure II.I and the ensuing overview of the literature presented a framework for best practice in ECI which included the different phases of the service delivery process, starting with the identification of infants at risk for communication disorders, followed by assessment and the provision of family-centered services. In order to ensure best practice throughout the intervention phase of ECI, certain measures for quality control to increase effectiveness are included in the remainder of the ECI process. The provision of programme services is followed by re-assessments, updating of the programme at regular intervals and the annual review of the service plan. Once the individualised family service plan is in operation, the scheduling of serial assessments at six month intervals is of vital importance to update programme goals and to review the service plan annually (Rossetti, 1996). As ECI programme outcomes are one of the issues of second generation research, the practice of regular programme monitoring to improve effectiveness is of critical importance.

2.4 CONCLUSION

The initial question regarding a common philosophy of best practice in ECI can now be answered. An overview of the literature provided extensive guidelines to identify those strategies and methods which can improve the effectiveness of ECI and address the challenges of matching child and family characteristics to provide effective ECI programmes, selecting and implementing critical programme features to provide individualised services and producing positive ECI outcomes (Guralnick, 1997). Based on second generation research of best practice discussed in the chapter, Figure II. IV was compiled to present the most important parameters which are considered to influence the effectiveness of ECI. The 14 parameters are displayed on a continuum as it is not always possible to indicate programme effectiveness on discrete points.

As depicted in Figure II.IV one parameter regarding the consideration of culturally sensitive programmes was added since it was not sufficiently dealt with in this chapter, but constitutes one of the current challenges of best practice in ECI which cannot be ignored (Heath & Levin, 1991). The need for appropriate ECI services to culturally diverse families in different contexts is one of the demands of second generation research which must be investigated further. Figure II.IV therefore illustrates the progress of ECI in finding solutions to the challenges of second generation research and can be used as an underpinning for a conceptual model for best practice in ECI. The parameters for effective service delivery in ECI can now be used to provide guidelines for further research to develop the field of ECI in order to improve existing ECI programmes and adapted develop new programmes in new contexts such as South Africa.

Figure II.IV was conceptualised from: Als, 1997; Briggs, 1997; Cameron, 1997; Gomby, *et al*., 1995; Guralnick, 1997; Haney & Klein, 1993; Heath & Levin, 1991; McCarton, *et al.,* 1997; Ramey & Ramey, 1992; Rossetti, 1996; Smith & McKenna, 1994; Squires, *et al.,* 1996; Wasik, *et al*., 1990.

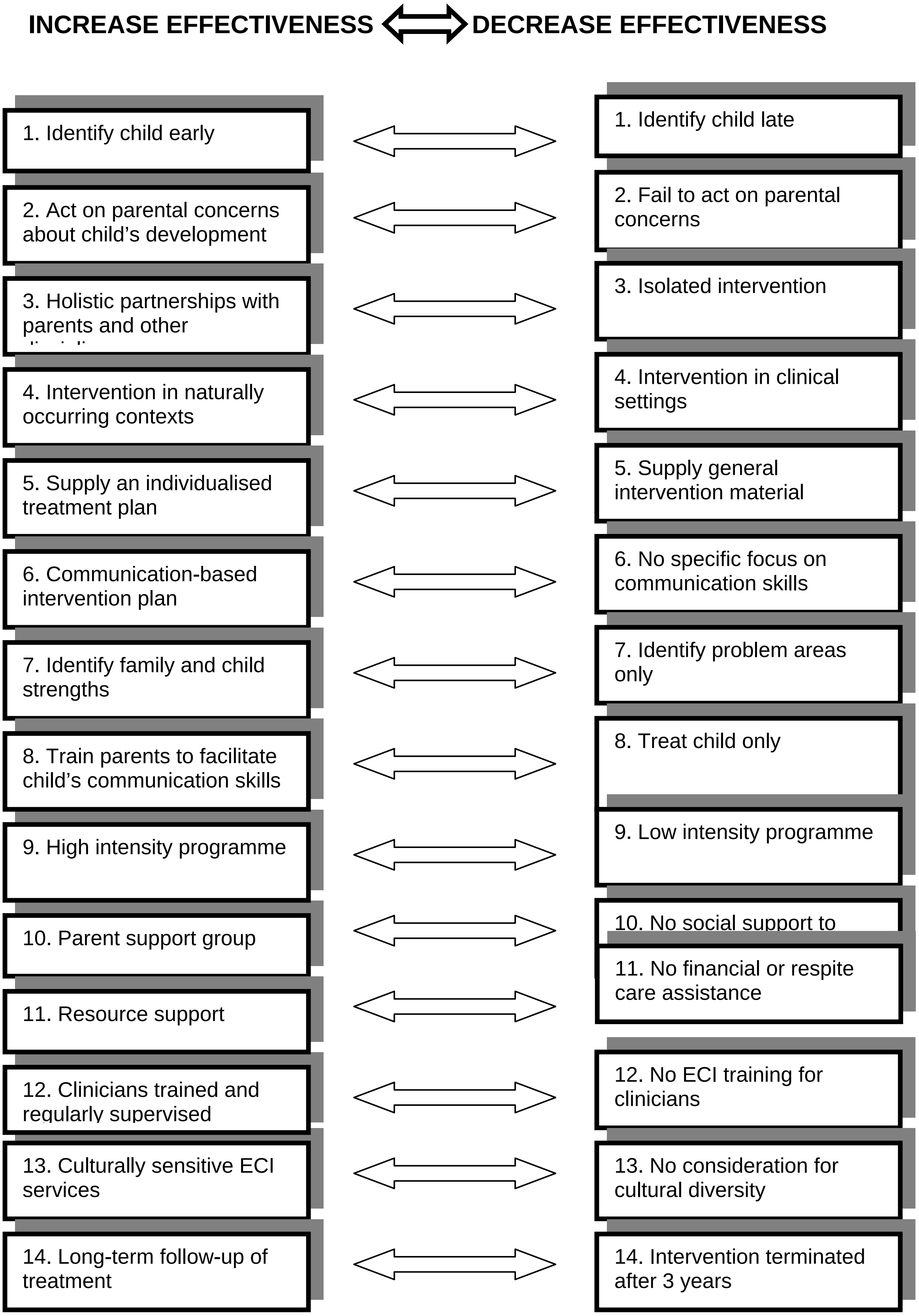

Figure II.IV Continuum of parameters for efficacy in ECI service delivery

2.5 SUMMARY

The chapter provides an overview of current research on best practice in ECI and indicates that the question regarding the effectiveness of services is characteristic of second generation research in ECI. Using the ECI process as a framework for best practice, the effectiveness of identification of infants at risk for communication disorders, assessment and the provision of ECI services is discussed. The new role of parents as the primary clients in ECI, the transdisciplinary team model, different assessment procedures and current EI programmes features are highlighted in order to provide guidelines for best practice in ECI. The chapter concludes with a set of parameters, presented on a continuum, to provide the underpinnings of a model of best practice in ECI.

CHAPTER 3

STRATEGIES TO DEVELOP EARLY COMMUNICATION INTERVENTION IN THE SOUTH AFRICAN CONTEXT

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Aim: The aim of the chapter is to discuss different strategies to enhance communication intervention services in the South African context and, based on a literature overview, present a profile of the subjects who require early communication intervention in order to provide the underpinnings for a computer database to be utilized in the empirical study.

3.1 INTRODUCTION

The profession of speech-language therapy and audiology in South Africa is currently undergoing a paradigm shift to improve imbalanced service delivery, redress teaching programmes and focus its research endeavors on the unique needs of the context (Hugo, 1998; Pickering, McAllister, Hagler, Whitehill, Penn, Robertson, McCready, 1998; Tuomi, 1994; Uys & Hugo, 1997). The paradigm shift has been stimulated by the South African Speech-Language-Hearing Association (SASLHA) since the early 1990’s (Lewis, 1994), international and national changes in health care, education for learners with special needs and views on people with disabilities.

Although the profession of speech-language therapy and audiology has a history of providing quality services to people with communication disorders, the focus of services were narrow and not aimed at the needs of the entire South African population (Louw, 1994). The need for transformation was clear as the professions’ relevance and effectiveness of training, research and service provision was in question (Lewis, 1994).

The far reaching political changes since 1994 in South Africa and the new government's policy to achieve a reduction in poverty and inequality (Savage, 1998; Woolard & Barberton, 1998) brought about changes in national health, education and welfare policy (ANC, 1994a). Reforms in the different public sectors of society touch the very core of speech-language therapy and audiology as a profession as it implies far-reaching changes in the market place (Hugo, 1998). The focus of planning and management of speech-language therapy and audiology services, including early communication intervention (ECI), is now to develop strategies for the prevention of communication disorders and to deliver services to the *whole* population of people with communication disorders and not only to those people and communities who can afford the services.

The challenge facing the slow but steady growing profession of 1198 registered speech-language therapists and audiologists and 42 community speech and hearing workers (Health Professions Council of South Africa, August 1999) is to effectively serve its clients drawn from the total population of South Africa estimated at 37 859 million people (Central Statistical Services, 1997b).

It is clear that the current South African situation poses great challenges to the profession of speech-language therapy and audiology and ECI as an essential component of the profession. According to Moodley (1999) the insufficient number of professionals to serve the increased population of persons with communication disorders necessitates the adoption of alternative strategies and service delivery models in South Africa. At the same point in time SASLHA (Louw, 1997) is fully aware of the importance of ECI and propagates a nationwide movement toward ECI by providing guidelines for the effective provision of these services by speech-language therapists and audiologists.

In order to develop alternative strategies for ECI service delivery there is an urgent need to systematically collect national and local data to support ECI planning to identify and predict which infants and toddlers are most likely to need the services of an early communication interventionist (Louw, 1997). The application of information technology to secure data in a database can significantly enhance the quality and quantity of the data (Lord-Larson & Steiner, 1989) to be used as ECI epidemiology in order to plan and prioritize service delivery.

The aim of the chapter is to indicate how current changes in South Africa regarding health care, education, and intervention for people with disabilities can be utilized to develop strategies for effective ECI service delivery in all communities. The identification of appropriate ECI strategies enhanced by a description of the profile of clients requiring ECI in South Africa will provide the underpinnings for a computer database to be utilized in the empirical study.

3.2 CHANGES IN HEALTH CARE IN SOUTH AFRICA

The implementation of ECI in the health care system in South Africa has been identified as a strategy to enhance services to infants and toddlers at risk for communication disorders by a number of authors (Delport, 1998; Fair & Louw, 1999; Louw, 1997; Moodley, 1999). The aim of the discussion is to indicate how changes in health care, such as the adoption and implementation of a primary health care approach, can enhance the collaboration between ECI and primary health care services.

3.2.1 Adopting a Primary Health Care Approach

International changes in health care came about when many countries adopted the Declaration of Alma-Ata (WHO, 1978) which recognized the attainment of the highest possible level of health for all as a most important world-wide social goal and proposing a primary health care approach as the key to reach that target (Alperstein & Bunyonyo, 1998). The *Global Strategy of Health for All by the Year*

2000 (WHO, 1981) which developed the proposals of the Declaration of Alma-Ata (WHO, 1978) and added specific targets and strategies to attain them, has become a guideline by which countries, such as South Africa, adapted their own health policies.

The goal of the South African health policy is to meet the health needs of the whole population by means of an intersectoral approach, with the emphasis on health care in stead of medical care and with special reference to the consensus that all have the same right to that care (ANC, 1994b; Bower, *et al.*, 1997). One of the means to reach this goal is the development of a comprehensive primary health care system to reach all the different communities in South Africa (ANC, 1994b).

Primary health care evolved from a uni-professional and fragmented community nursing service characterized by district nursing, occupational health nursing and school nursing (Bouwer, *et al*., 1997) to multi-professional services which are “Affordable, sustainable and essential health care for all individuals, families and communities in the district rendered in accordance with the people’s health needs– and with their full acceptance and participation”.
(Department of Health, Welfare and Gender Affairs, Mpumalanga, 1997, p 77).

Primary health care can offer a variety of services, both preventative and curative, in the form of:

- Prenatal care, childbirth classes and family planning
- Physical examinations for the diagnosis of common health problems
- Preventative services in the form of promotion of health, health counseling and immunizations against infectious diseases
- Treatment of common ailments and chronic diseases
- Early identification of sensory impairments and developmental disabilities
- Home visits and community outreach activities

- Referrals to secondary health care when appropriate

(ANC, 1994b; Bower, *et al*., 1997; Dunbar & Reed, 1999; Edwards, Kaplan, Barnett & Logan, 1998; Kaplan-Sanoff, *et al*., 1997).

In analyzing the different functions of the newly evolved primary health care approach, it is evident that pediatric health care and developmental services to young children at-risk and with disabilities can be integrated, resulting in holistic care to families and their children (Lequerica, 1997). It is furthermore possible to achieve primary, secondary and to some extent, tertiary levels of prevention of conditions associated with illness and disability by following this approach. The idea that primary health care can provide an infrastructure for communication-based intervention services in South Africa was already proposed by Aron (1991) a decade ago. Since infants and their caregivers in all communities in South Africa utilize primary health care facilities at the minimum for immunizations during the infant's first year, it is an invaluable opportunity to establish ECI in different communities, since the clients are already available at the primary health care clinic or centre.

3.2.2 Collaborative Services between Primary Health Care and ECI

Since mutual goals exist between the primary health care model and the ECI approach (Fair & Louw, 1999) collaboration between these two services appears feasible. An example of an integrated primary health care and early intervention (EI) programme consisting of regularly scheduled well-child visits; developmental surveillance and parent guidance at an urban paediatric primary health care centre in the USA is described by Kaplan-Sanoff, *et al.* (1997). The centre serves a diverse population living in poverty conditions with a high incidence of infants prenatally exposed to drugs and infants born prematurely. The poverty conditions in that particular context posed high risks for malnutrition and lead poisoning in children, as well as family dysfunction. The results of the programme indicate that the children who were enrolled in the health and developmental programme had significantly fewer emergency room visits at the local hospital, fewer hospitalizations, more regular participation in well-child care and more sick visits at the health care centre. The comparison group displayed the opposite figures, with more emergency room visits, hospitalizations and poor attendance of well-child care and less sick visits at the clinic.

The results imply that families who made use of the primary health care facility had healthier children as well-child care and developmental surveillance provide regular contact between families and health professionals. This resulted in the early identification and treatment of illness and developmental problems and more opportunities for families to receive support and information that promoted their children's health and development. As expected, the programme resulted in significant savings for the particular health system. A key professional on the team proved to be the Family Advocate who built close relationships with the families and explained the philosophy of regular visits to the centre even when the child is not sick (Kaplan-Sanoff, *et al*., 1997).

Although South Africa may not have the resources to establish similar comprehensive primary health care centres throughout the country, some inferences regarding the collaboration between ECI and primary health care can be drawn from the study (Kaplan-Sanoff, *et al*., 1997) and transferred to the local context. The inferences are mostly applicable to communities living in poverty, but do not exclude developed communities, and involve the following:

- Children living in poverty, in the first place, are more frequently exposed to medical illness, family stress, inadequate social support and parental depression. Secondly, they experience more serious consequences from these risks than do children from more advantaged circumstances. This implies that children living in poverty experience double risks from their environment, are at greater risk for developmental delays and disabilities

(Kaplan-Sanoff, Parker & Zuckerman, 1991; Lequerica, 1997) and represent a population in urgent need of ECI services.

- A primary health care facility can be effective in the early identification and treatment of illness and developmental delays in young children, resulting in effective preventative care.
- The concept of regular visits to a primary health care facility for health and developmental surveillance must be explained to parents. In the study by Kaplan-Sanoff, *et al.* (1997) this was effectively achieved by the role of the Family Advocate, a professional who could speak the clients' first language and who was able to build ongoing relationships with the families.
- The concept of the Family Advocate seemed to fulfil an essential role on the collaborative team, acting as a bridge between the family and the professionals, especially in a situation where language and cultural differences can act as barriers to effective communication and service delivery. This is of particular importance in the South African health care context where language and cultural barriers are known to influence communication between clients and professionals (Loening & Mbali, 1997).

It appears that these successful collaborative efforts of health and developmental services to young children and their families can provide valuable guidelines for a strategy to extend ECI services in primary health care facilities. As a result of the close association between illness and disability, especially where young children live in poverty (Lequerica, 1997), it appears that a collaborative approach of services to young children and their families can prevent or minimize some of the sequelae of disabilities. In this regard that ECI can make unique contributions to services offered to families at a primary health care facility.

3.2.3 Unique Contributions of ECI in a Primary Health Care Context

In order to develop a strategy for the successful collaboration between ECI and primary health care services it is important to indicate which unique features of ECI can enhance such collaborative services to families:

- EI has succeeded over the years to achieve very strong collaborative relationships with families and this has proven to be one of the two key factors affecting the success of EI (Rossetti, 1993). The family's potential has been utilized to play a variety of roles such as observing, describing, interpreting, evaluating and participating in the ECI process (Crais, 1993). The family-centered EI approach has proven to be effective in programmes for families from diverse backgrounds and positive short-term and long-term effects are possible with families living in poverty (Bryant & Maxwell, 1997). As maternal and child health receives principal health priority status in South Africa (ANC, 1994b), ECI can contribute to the development of all young children at risk and with disabilities, but especially the many newborns, infants and toddlers and their mothers living in poverty and whose only option of health care is the local clinic.
- EI has developed the unique team structure of transdisciplinary service provision (Foley, 1990) which can be employed as a strategy to transfer discipline specific knowledge and skills to the primary health care team, consisting of multidisciplinary health care professionals and community health workers (Moodley, 1999). This implies that ECI has already adopted an operational approach not only to transfer knowledge to fellow professionals, but also to train family members, primary level workers and volunteers from the community. The concept of training of all people involved has been identified by McConkey (1995a) as one of the core aims of EI in developing countries.
- As a result of the widespread development and implementation of neonatal hearing screening in developed countries (Rigo & Arehole, 1998), ECI is

uniquely equipped with appropriate strategies and methodologies to contribute to the early identification of hearing loss and other disabilities in the primary health care context. New knowledge allows the identification of infants with risk conditions and disabilities in the neonatal period already (Kuster, 1999) and thereby paving the way for effective services to infants at risk for communication disorders and their families.

- ECI not only provides effective identification strategies, but has developed an extensive collection of treatment programmes, meeting the needs of infants and toddlers with disabilities,

  - ranging from mild to severe,
  - belonging to families with adequate resources to families living in poverty,
  - living in communities providing appropriate social support to communities experiencing social dysfunction (Guralnick, 1997; See also Chapter 2, Table 2.2).

- As the timing of intervention is critical for the prevention of risk conditions and their sequelae, it is the ECI approach of promoting early communication development which can prevent these conditions from occurring or decrease the effects of disabilities (Rossetti, 1990a). In this regard information to promote normal communication development and identify risks for communication disorders can already be included in the antenatal education of pregnant mothers visiting primary health care facilities. ECI has the potential to alleviate the double risks associated with poverty, as enhanced communication skills early in life more adequately prepares a child for academic progress than any other developmental area (Capute, *et al*., 1987).

ECI therefore contributes unique and sophisticated approaches such as family-centered practices, transdisciplinary teamwork, numerous identification and treatment methodologies as well as the earliest intervention possible to a health care approach designed to be universally accessible to individuals and families in their communities. In order to successfully implement the strategy of collaboration between ECI and primary health care in South Africa epidemiological data is required to indicate the varying needs of the different communities. The database approach to research is particularly applicable for collecting epidemiological data required to plan collaborative ECI services.

The collaborative services of ECI in the health sector should be part of a systems approach to health care. According to the Alma Ata Conference on Primary Health Care (1978) developing countries in particular need to co-ordinate the different public sectors as economic development, anti-poverty measures, food production, water, sanitation, housing, environmental protection and education all contribute towards the same goal of human development. This approach is in accordance with the systems model as applied in early intervention where the child is considered part of an intricate system that encompasses individual, familial, community and even larger political factors (Blackwell, Gruber & vonAlmen, 1997; Briggs, 1997). In this regard ECI also has a vital role to play in the education sector of the country, which is discussed forthwith.

3.3 CHANGES IN EDUCATION FOR CHILDREN WITH SPECIAL NEEDS

Since one of the aims of ECI is to enhance a child’s communication development for school readiness and successful academic progress (Rossetti, 1996) it is important to take cognizance of changes in educational approaches for children with special needs. ECI, with its unique focus on communication skills, has a crucial contribution in preparing a child for academic success and should use the opportunity to develop strategies for effective service delivery in the changing education system in South Africa.

3.3.1 Inclusive Education for All

International trends in education for children with special needs and efforts coordinated by UNESCO (United Nations Educational, Scientific and Cultural Organization) have culminated in countries adopting *The Salamanca Framework for Action* (1994) which advocates equal opportunities for children with special needs in education and society (UNESCO, 1995). The South African Schools Act (RSA Government Gazette, 1996) adopted this approach embracing inclusive education for all learners and followed the world trend of special needs education reform as part of general education reform (Schoeman, 1998).

The implication is that the public school system now largely provides in the needs of learners with disabilities in stead of special schools allocated with a comprehensive team of professionals of which speech-language therapists and audiologists were part. Due to financial constraints public schools have reduced the already small number of available speech-language therapy and audiology posts in recent years (Tuomi, 1994). The loss of posts in public schools resulted in children with disabilities now entering these schools with limited speech-language therapy and audiology services and leaves teachers without this collaborative support to adapt curricula and design individual educational plans.

The implication of limited communication-based services in schools in South Africa is that ECI services to pre-school children are now more important than ever to prevent or reduce the impact of learning disabilities in school-age children. In this regard Hugo (1998) identified several important new tasks for speech-language therapists and audiologists in the education context and mentions “participation in early / pre-school programmes with specific focus on the development of communication” (Hugo, 1998, p 6) as the first new task.

ECI therefore has an important contribution to make in the present education system in South Africa. ECI professionals have to prove to be indispensable partners on transdisciplinary teams in schools and pre-school settings rather than working only in own areas of expertise as characterized by the multidisciplinary and interdisciplinary team models (Briggs, 1997). In this regard Hugo (1998) proposes a change in the primary role of clinicians offering communication–based services, i.e., not only to identify, screen, assess and treat children with communication disorders, but to be valuable and appreciated members of the education team as consultants and facilitators. An inclusive education approach also demands new collaborative models of assessment and treatment (Klein & Moses, 1994) in school and pre-school contexts which implies that ECI professionals are well equipped to fulfill these roles as a result of their experience in transdisciplinary teamwork.

3.3.2 The Role of ECI in the Education System

Since ECI is the starting point of services to young children at-risk for and with communication disorders it is important for early communication interventionists to participate in developing early childcare programmes and training the caregivers. The important role of ECI in early childcare programmes involving infants and young children, ranging from the informal settings provided by day mothers in their homes, to the formal structures of crèches and nursery schools, can be illustrated in the following arguments:

- As all children are currently eligible for inclusive education, the long-term ECI goal of school readiness as formulated by Rossetti (1998) is now more urgent than ever. This goal applies to children with disabilities as well as those who grow up in poverty environments resulting in a risk for developmental delays. In the past children with disabilities entered a special school environment very different from the academic and social challenges of schools for typically developing children (Schoeman, 1998). All children are now required to follow the same curriculum, although at a different pace and with adjustments. The success of school programmes therefore depends to a large extent on the readiness of learners when they enter the formal education system.

- School readiness implies that the learner is sufficiently equipped to cope with the academic and social demands of the school environment. As communicative competence is considered the basic academic skill (Billeaud, 1998), early communication-based programmes are of critical importance to equip children with effective communication skills and to sufficiently prepare them for the higher language functions of reading and writing. In this respect Rossetti (1996) states that ECI increases the possibility for a child to be included in the regular education system.
- Most studies on the effectiveness of preschool programmes for children living in poverty indicate short-term and long-term gains, some with positive effects continuing into adolescence. A critical factor determining outcome seems to be the duration of the programme, i.e. the longer the child is enrolled in a programme, the better the results for the child (Boocock, 1995; Bryant & Maxwell, 1997; See also Chapter 2, Figure II.IV). This fact strongly presents a case for preschool programmes to start as early as possible in a child’s life, again emphasizing the indispensable contribution of ECI to the education system facing the challenge to successfully include all learners both academically and socially.
- In an overview of various international research projects, Boocock (1995) concluded that preschool experience helps children living in poverty to narrow, but not close, the achievement gap separating them from more advantaged children. Research evidence also suggests that maternal employment and reliance on childcare do not harm children, even in very young ones, and may yield benefits if the childcare is of good quality (Boocock, 1995). The finding that there may always be an achievement gap between children living in poverty and their peers from advantaged environments, seem to be the strongest motivation for the development of good quality early childhood programmes. These programmes have the

potential to benefit children and if not for the programmes, the achievement gap may widen.

- EI has proven to be cost-effective to the educational system. Rossetti (1996) provides evidence from various studies that early preschool programmes result in long-term savings, as children who received EI require less remedial services. Studies in the USA indicated that every dollar spent on preschool intervention saves from $3 to $6 dollars later (Rossetti, 1996).
- In an international review of special needs education carried out by UNESCO (1995), participating countries identified early intervention as one of the main issues to consider for the future development of special education in their contexts. This implies that EI is worldwide being acknowledged as a starting point of the education system for children with special needs.

The inclusion of children with special education needs can therefore already be implemented before they enter formal education if they were exposed to early intervention programmes. The advantage is that inclusion into the mainstream of education and society can be achieved earlier and therefore more successfully than in the event of a child with disabilities only being included at the point of entrance to formal education (McConkey, 1995b; Saleh 1996). The successful implementation of these ECI strategies, depends on careful planning guided by valid data, generated by a research tool capable of complying with research needs. In order to support the different preschool programmes and children with disabilities entering the formal education system, the database approach to ECI research can offer epidemiological and other types of data required by the service provider.

If ECI is the starting point of educational services to infants with disabilities and those who are at risk for developmental delays, the ideal, as stated in USA legislation (Rossetti, 1996), of providing comprehensive, coordinated, multidisciplinary, family centered services throughout the child’s life, can be achieved (ASHA, 1989). Special needs education should therefore be seen in the broader perspective of preparing infants at-risk and those with disabilities to be fully integrated in society from as early in their lives as possible.

The role of ECI can therefore not only be limited to providing collaborative services in health and educational contexts. The long-term perspective of infants with disabilities needs to be considered as reforms in the social and vocational sectors of society which have opened new opportunities for people with disabilities to participate in community life. (WHO, 1994).

3.4 CURRENT VIEWS ON REHABILITATION OF PEOPLE WITH DISABILITIES

In order to develop strategies to enhance comprehensive ECI services in South Africa the current approaches regarding the rehabilitation of people with disabilities pose certain challenges and opportunities for ECI.

3.4.1 Abandoning the Medical Model of Disability

The concept of rehabilitation for people with disabilities has undergone major changes in recent years, internationally and in South Africa. There has been a move away from the medical model of disability with its emphasis on the nature of the impairment and the result that disability was mainly viewed as a medical and welfare concern (WHO, 1994). In the past people with disabilities received medical and rehabilitative care as well as welfare grants, but less attention was given to the fact that they were increasingly isolated from the mainstream of society, often from a very young age.

Long-term institution-based rehabilitation services, even though equipped with state of the art technologies and scientifically based rehabilitation and education programmes, resulted in isolating people with disabilities from their families, peers and society. The effect on the community was that people with disabilities were invisible, public awareness of disabilities were limited, negative attitudes towards people with disabilities were cultivated and false perceptions, such as that professionals only are responsible for people with disabilities, were created. When people with disabilities are not seen to participate in and contribute to community life, they are regarded as a burden on society (Mpofu, 1996; WHO, 1994).

The result of past views and practices was that people with disabilities were economically unproductive and largely excluded from active participation in decisions about themselves and policy formulation. Institution-based rehabilitation services remained exclusive and could never sufficiently provide in the needs of people in developing countries where the incidence of disability is on the increase as a result of social factors often overlooked by rehabilitation practices of the past.

The move away from institutionalized care and the subsequent isolation from society, the role of families in taking responsibility for the care of their young children with disabilities and the role of EI in recognizing the potential of infants with disabilities (Robinson, 1997), resulted in a new era of improved quality of life for people with disabilities and their families. EI provides the essential link of improved quality of life for people with disabilities from birth onwards. The early integration of infants with disabilities and their families into their local communities is now widely advocated as it is one of the predictors of successful integration later in life (McConkey, 1995b). The role of EI in the current approach to the rehabilitation of people with disabilities is therefore recognized and should now be applied to the South African context. One of the challenges for the development of ECI in South Africa is the increase of infants with disabilities and the causal factors.

3.4.2 Increase of Disability in Developing Countries

Apart from medical factors such as the HIV/AIDS epidemic in South Africa and increasing the number of infants, children and adults with diseases and disabilities (Bobat, *et al.,* 1999), there are also social factors that increase the prevalence of disability. Social factors responsible for the increase of disability in developing countries such as South Africa pertain to violence, war, crime, poverty, unhealthy lifestyles, natural disasters, accidents, especially transport related accidents and lack of public awareness on the prevention and treatment of disability (*White Paper on Integrated National Disability Strategy*, 1997).

The concept of double risk relating to people living in poverty as described by Kaplan-Sanoff, *et al.* (1991), Lequerica (1997), van der Merwe (1999) and described earlier in this chapter, can be useful in explaining the increase of disabilities in developing countries such as South Africa. The consequences of acquired disabilities are more severe for those with limited resources than for those with means to prevent trauma or acquired conditions from deteriorating into severe developmental delays and behaviour problems. As most of the factors relating to the social causes of disability apply to the South African context it directly impacts on the communication-based service provision to people with acquired communication disabilities.

The need for changes in rehabilitation practices is emphasized by the increase of disability in infants and children as a result of accidents, abuse and neglect, especially those from families living in poverty (Mowder, 1997). Among the population of individuals with acquired communication disabilities are infants who present with unique problems which can be distinguished from infants with developmental disabilities. Only recently has research and clinical interest been focused upon the youngest age group with traumatic brain injury (Sellars, Vegter & Ellerbusch, 1997). Studies have shown that the very young brain is to a certain extent adaptable to early focal injuries such as stroke or penetrating injuries.

More diffuse injuries, however, have a profound effect on later development and are described as a domino effect of the sequelae of the trauma. As the continuous development of skills depend upon earlier foundational skills their prognosis for rehabilitation is generally poor (Sellars, *et al.,* 1997). These young children grow up with severe disabilities, which have the potential to become handicaps if not managed by a comprehensive service delivery strategy.

The conditions surrounding neglect and abuse of children is thought to start already in infancy. Lester (1992) describes infant behaviour as part of a communication system within the caregiving environment. The ability of the infant to communicate effectively and the ability of the parents to interpret the infant's cues effectively and provide appropriate caregiving will determine the success of the system. Particular risk situations can arise when mothers fail to correctly interpret the stress signals and crying patterns of their infants. Infants who were prenatally exposed to cocaine are easily excitable as a result of the neurobehavioural effect of cocaine on brain functioning. These infants can be perceived by their mothers as difficult to care for and can be at greater risk for abuse. In contrast, infants with intra-uterine growth retardation and fetal malnutrition (also an effect of prenatal cocaine exposure and poor nutritional status of their mothers) tend to be passive as a result of depressed neurobehavioural functioning. Depressed infants therefore appear to be undemanding and not in need of attention, but may be at greater risk for neglect (Lester, 1992). As the abuse of cocaine is on the increase worldwide, the infants born from mothers using cocaine and at risk for the detrimental sequelae, will also increase.

The challenges of increased populations of infants, children and adults with disabilities, most of who could have been be prevented, are vast and new theoretical models and intervention approaches are necessary.

3.4.3 Adopting a Social Model of Disability

Currently there is a strong move towards a social model of disability with the emphasis on human rights and development, resulting in challenging rehabilitation practices of the past and long-term outcomes of treatment. The social model implies that medical and educational services for people with disabilities are not sufficient if vocational and social concerns are not addressed (*White Paper on an Integrated National Disability Strategy,* 1997).

In response to these challenges the strategy of community-based rehabilitation was developed, aiming to integrate rehabilitation endeavors with health and development activities at the community level. Community-based rehabilitation is characterized by the active role of people with disabilities, their families and the community in the rehabilitation process. In community-based rehabilitation, knowledge and skills for the basic training of people with disabilities are transferred to adults with disabilities themselves, to their families and to community members and professionals do not dominate the process (WHO, 1994).

Since the families of young children with disabilities often face isolation from their communities (McConkey, 1995b), the principle of community-based rehabilitation of greater involvement of the community in the family and increased participation of the family in community life, can have positive outcomes for ECI. Community-based rehabilitation services therefore offer strategies to provide ECI services to the increased population of young at-risk for communication disorders and their families living in developing contexts in South Africa (Fair & Louw, 1999).

3.4.4 Community-Based Rehabilitation

The process of community-based rehabilitation, driven by people living in the community, whether in rural, semi-urban or inner-city contexts, can include the following operational strategies:

- A community committee promotes the removal of physical and attitudinal barriers and ensures opportunities for people with disabilities to participate in school, work, leisure, social, and political activities within the community.
- A community rehabilitation worker engages people with disabilities (ranging from young to old) and their families in rehabilitation activities.
- Children with disabilities attend the local school.
- Community members provide local vocational training for adults with disabilities.
- Community support groups assist families in the care and respite care of their young children or adult members with disabilities.
- Community initiatives are supported by referral services within the health, education, labour and social sectors.

(Mpofu, 1997; Werner, 1988; WHO, 1990; WHO, 1994)

The aim of all the community-based rehabilitation strategies mentioned above is to achieve social integration and independence for people with disabilities. If social integration is the goal, the long-term outcomes envisaged by the various professional rehabilitation efforts should pursue the same objectives. The specific role of professionals, such as early communication interventionists, in community-based rehabilitation is multifaceted and extends far beyond the primary professional functions of assessment, treatment and counseling.

3.4.5 Expansion of the Role of the Early Communication Interventionist

Professionals operating in community-based rehabilitation services are seen as resourceful people who act as facilitators, collaborators, interventionists, provide training and support the community health workers (McConkey, 1995a; WHO, 1994). Although community work has already been described as a professional function in communication pathology, the social model now used in community-based rehabilitation demands adaptations to new theoretical frameworks and practices. The importance of research as a professional function to guide these efforts becomes evident. Participatory action research as a tool for sustainable social development is particularly relevant in community-based rehabilitation activities as one of the outcomes is to improve the quality of life for those who participate in the research (Schurink, 1998).

Figure III.I illustrates that the concept of community-based rehabilitation ensures that due attention is awarded to the whole spectrum of professional functions of the speech-language therapist and audiologist as described by Uys and Hugo (1990), which applies to the early communication interventionist as well.

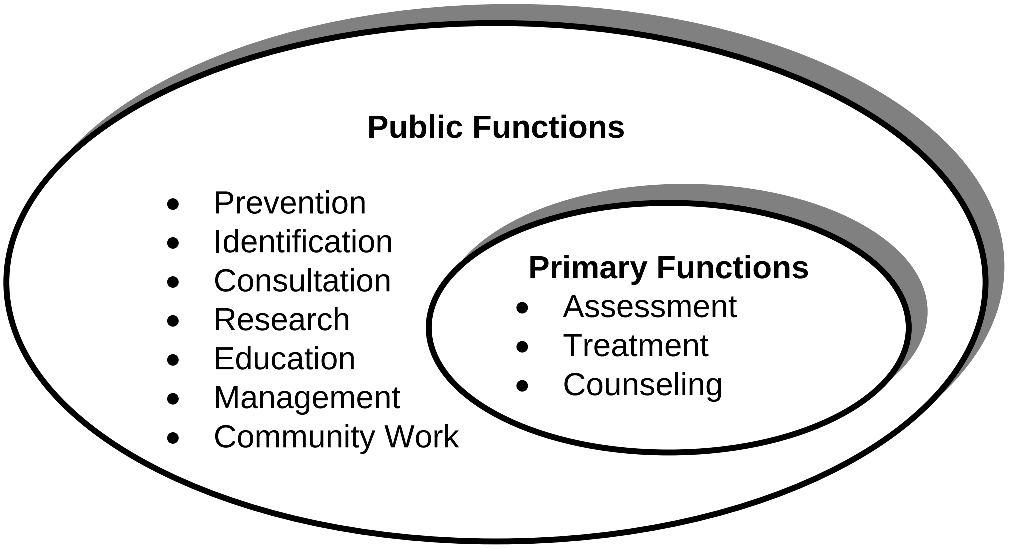


Figure III.I **ECI professional functions in relation to community-based rehabilitation**
Based on Uys & Hugo, 1990.

When analyzing the ten professional functions as depicted in Figure III.I, it appears that a distinction can be made between primary functions which relate to services aimed at specific clients and functions with a broader focus, hence public functions. Public functions relate to professional activities performed in collaboration with communities, the different public sectors and the multi-professional fraternity. It is the public functions of early communication interventionists that permit role expansion and release, the essence of transdisciplinary work.

An example of the application of the public professional functions is an operational strategy used by UNICEF which entails a three-phase process of assessment of the situation, analysis of the cause of the problem and action taken based on the analysis and available resources (Patel, 1993). Community work therefore implies collaborative and consultative research efforts to assess a situation and analyze the causes of problems. In order to improve the situation, effective action is taken in the collaborative and transdisciplinary management of programmes to prevent and identify problems, educate community health workers and families and eventually assess, treat and counsel individuals with disabilities.

Werner (1988), in a training manual for community health workers, rehabilitation workers and families, views the role of professionals as providers of information, explanations, suggestions, examples and ideas and not to tell communities and parents what to do. By means of explaining basic principles and motivating actions, the scientific underpinnings of rehabilitation can be conveyed to communities. The effectiveness of a rehabilitation programme will depend on a management approach, which allows continuity of the three-phase cycle, ensuring re-assessment and adjustments to the programme so that the needs of infants with disabilities and their families are adequately met.

It is therefore clear that community-based rehabilitation provides an opportunity for the whole range of ECI professional functions to be practiced, demonstrating the profession's potential to effectively adapt to the diverse demands of a community-based rehabilitation approach.

3.4.6 Challenges of Effective Community-Based Rehabilitation

Effective community-based rehabilitation is a complex process as the needs and stresses of families living in poverty usually exceed the developmental needs of their children with disabilities (Baxter & Kahn, 1996; Lequerica, 1997). A study by Baxter & Kahn (1996) illustrates the diverse demands exerted on rehabilitation professionals participating in an inner-city EI programme in the USA. The study also highlights the importance of research as a vital component of community-based rehabilitation since the notion to focus on strengths and needs of families in EI often leaves the specific needs of families and communities unqualified.

The results of the study (Baxter & Kahn, 1996) indicated that the needs identified by the families with infants at risk or with disabilities were very similar and in order of importance, related to food needs, housing, transportation, medical needs, needs for the child and caregiver's needs for personal time. The developmental needs of the infant with disabilities were therefore not the most important needs perceived by the families.

The families further indicated that their limited resources were the major cause of their stresses. There can, however, be different contributors of stress when dealing with families from various backgrounds. McDowell, *et al*. (1995) found in a study conducted in South Carolina that declines in financial status were the major stressors for black families. White families whose children had the same developmental delays as the black families experienced the slow developmental progress of their child as the major source of stress. Baxter and Kahn (1996) concluded that chronic life stressors, rather than discrete life events contribute to high levels of stress in families living in poverty. These findings also confirm Guralnick's conceptual model of early development and risk factors in which information needs, interpersonal and family distress, resource needs and confidence threats are identified as potential stressors for families with a child with a disability (Guralnick, 1997).

Another problem area that seems to be widespread in community-based intervention is the poor attendance of clients in intervention programmes. In a study conducted in Chicago the children's attendance of therapy was more consistent if the families received financial and social support. Another reason for consistent attendance in therapy related to the severity of the child's disability. If the parents perceived the child's problem as severe, attendance was more consistent. Other factors that influenced therapy attendance were the number of siblings in the family, which meant that the mother had additional childcare burdens. The last factor to significantly influence therapy attendance was the father's educational level. The higher the father's education, the better he recognized the importance of intervention and the stronger he supported the mother in attending therapy sessions (Kuchler-O'Shea, Kritikos & Kahn, 1999).

A similar study conducted in South Africa indicated that therapy attendance also relates to financial factors (Bulmer, 1999). The study was conducted at a clinic for children with cerebral palsy at the Chris Hani Baragwanath Hospital serving a large peri-urban community. The parents indicated that the main reason for terminating therapy was the lack of funds for transport to attend the clinic. The parents in the South African study did not receive financial assistance although the therapy sessions were fully subsidized. Once more, the first barrier in the intervention process was the financial status of the family and not external factors such as the availability of transport.

The examples from the different studies reviewed serve to illustrate the necessity of a comprehensive systems approach to ECI service delivery in community-based rehabilitation and in dealing with families living in poverty.

In conclusion, community-based rehabilitation provides a context for the development ECI services in developing communities and can be effective to achieve the following:

- The continuum between disability prevention and rehabilitation is seen as an attainable goal and not only as a theoretical ideal. Community-based rehabilitation strongly emphasizes the prevention of disability as a long-term vision and as a viable answer to the limited resources of developing countries. The promotion of development, health and safety as early as possible in a child's life and the earliest possible starting point of intervention for infants at risk and with disabilities are ECI strategies already proven to be effective to prevent disabilities or at least their sequelae (Rossetti, 1996). As prevention is regarded as the highest form of professionalism (Downs, 1991) its pursuit should be the focus of any rehabilitation programme.
- Community-based rehabilitation expands the narrow rehabilitation practices of the past to include all public sectors relating to people with disabilities. As the site of rehabilitation is the community itself, the co-ordination of medical, educational, vocational and social rehabilitation services to reach all people with disabilities is much more attainable than in the case of the isolation people experience in institution-based or hospital-based rehabilitation services.
- In a community-based rehabilitation approach people with disabilities are challenged to be active in their own rehabilitation and not to be passive recipients of services. The result is that greater participation of people with disabilities improves their motivation and ensures more effective rehabilitation. As people with disabilities are not removed from their communities, the effects of rehabilitation are highly visible and public

awareness is raised resulting in the community becoming educated about disability which, in turn, contributes to the development of communities.

As stated earlier, the long-term goals of service provision are the prevention of communication disorders and delivering of services to the *whole* population of people with communication disabilities. It is clear that the community-based rehabilitation approach offers basic principles and operational strategies which can be used to adapt ECI in the South African context.

The challenges to make ECI services available to all who need it in South Africa is great. The current changes in health care, education for children with disabilities and new approaches in the rehabilitation for people with disabilities provide strategies such as those offered by primary health care, preschool programmes for school readiness and community-based rehabilitation services to provide relevant ECI services to the different communities in South Africa. The expansion of ECI services to all the communities in South Africa, implies changes in the market place (Hugo, 1998). The dire need for national and local data to direct the planning of ECI services and policy development demands an investigation of available data to obtain a profile of clients requiring ECI services in order to provide guidelines for the empirical research of the current study.

3.5 PROFILE OF CLIENTS REQUIRING ECI IN SOUTH AFRICA

Although people with communication disorders have always been at least 10% of the total population of South Africa (Uys & Hugo, 1997) the caseload has now increased and the profile of clients have changed drastically in the past decade. As a result of poor recognition of the profession of speech-language therapy in general and ECI in specific, as well as limited service delivery, a detailed profile of the South African population of infants with communication disorders remains largely unknown and indicates the crucial need for empirical survey studies.

In an attempt to answer the question relating to the characteristics of clients requiring ECI, a literature survey was done to provide broad features of the population, which will serve as a basis for the essential components of a computer database for ECI to be developed in the empirical study.

In an overview of articles by Aron (1991), Hugo (1998), Pickering, *et al.* (1998), Tuomi (1994), Uys (1993), Uys and Hugo (1997) and data released by Central Statistical Services (1997a; 1997b; 1997c) the population of young children with communication disorders and their families in South Africa will be described in terms of their different home languages and cultures, the literacy rate and ages of their parents and the different risk conditions to be found in the infants.

3.5.1 Home languages and cultures of ECI clients

The client and the family requiring ECI in South Africa may speak one or more of the 11 official languages of the country, or depending on the region, may speak a minor language or a dialect of a language. Table 3.1 was compiled to provide the latest percentage distribution of home language in SA (Central Statistical Services, 1997b). According to Table 3.1, isiZulu (22,4%) is the most common home language in the country, while only 9,1% of South Africans speak English as their home language.

The distribution of home languages also provide a profile of the cultural diversity of families with young children requiring ECI services. Culture can be defined as mental programming which represents patterns of thinking, feeling and potential acting and learned throughout a person’s life and can be distinguished from a person’s personality and human nature which is universal and the shared inheritance of all people (Hofstede, 1997). Culture signifies a person’s adherence to a specific group of people or a category and manifest in shared symbols, heroes, rituals and values and ECI professionals not sharing the same culture as their clients, must adopt culturally sensitive practices (Hofstede, 1997; Jager,

Table 3.1 Percentage Distribution of Home Languages in South Africa

Language	% Speakers
1. isiZulu	22,4%
2. isiXhosa	17,5%
3. Afrikaans	15,1%
4. Sepedi	9,8%
5. English	9,1%
6. Setswana	7,2%
7. Sesotho	6,9%
8. Xitsonga	4,2%
9. siSwati	2,6%
10. Tshivenda	1,7%
11. isiNdebele	1,5%
12 Other	1,8%
13. Afrikaans and English	0,2%
14. Sign Language	Unknown

Source: Central Statistical Services, 1997b

1994; Seeff & Bortz, 1994). Since the manifestations of culture are visible in cultural practices, but the cultural meanings are invisible by outsiders (Hofstede, 1997), it is exactly in the interpretation of cultural practices or behaviours that miscommunications between clients and professionals of different cultural groups can arise. It depends on ECI clinicians to be knowledgeable regarding the views families hold about communication disorders and causes in their young children and the role of indigenous healers and their views on the causes and treatment of communication disorders in South Africa (Platsky & Girson, 1993). Insight in the culturally determined beliefs of the ECI clients and those of the communities they represent can enhance effective communication, mutual respect and contextual service delivery.

Schuck and Bucy (1997) provide an example of the utilization of family rituals in early intervention. Family rituals are repetitious, highly valued, meaningful family activities that transmit a family's cultural values and attitudes. The benefits of rituals for learning in young children are that they serve as powerful organizers of behaviour that provide children and their families with a sense of stability, identity and a means of learning about culture and socialization both within and outside the family. Early interventionists can use their understanding of a family's culture and rituals to assist families in creating and adapting functional rituals to include infants and toddlers with disabilities. These rituals act as meaningful and enjoyable routines, which are regarded as the basis for early learning (Ratner, Parker & Gardner, 1993). The clinician's cultural sensitivity to affirm a family's rituals can therefore greatly enhance ECI in South Africa, an approach that depends on family participation. It is, however, not only the cultural diversity of the different communities in South Africa which must be considered in ECI.

Although multi-lingualism is a sociolinguistic reality in South Africa (See Table 3.1), there is a tendency towards uni-lingualism, as English dominates the mass media and often seem to be the common denominator when people of different language groups interact. The implication is that the other languages can be marginalized, especially those languages with poorly developed written forms (Alexander, 1996). Although the *National Language Plan for South Africa* (Alexander, 1996) aims promote the view that multi-lingualism is a resource and not a problem, it poses certain challenges in ECI service provision:

- ECI clinicians belonging to a body of professionals of whom to date most have mastered only English and Afrikaans treat clients and their families from various linguistic backgrounds.
- Language incompatibility is a communication barrier shared by all health professions, but for the ECI clinician efficient use of language is both the medium of communication as well as the eventual goal of the intervention (Hugo, 1998). This implies that other health professionals may be able to render services with the help of an interpreter, but assessment and treatment of clients with language disorders is not possible when the clinician is not a proficient speaker of the client's language.

- Multi-lingualism occurs on the macro level as well as on the micro level. As a result of urbanization, it often occurs that various languages are spoken within the same family and within a particular community. The situation frequently appears where young children attend childcare facilities, preschools and schools where the medium of teaching is different from their home language (or home languages), which poses a risk for learning difficulties, especially for those already at risk as a result of environmental conditions such as poverty.

Cultural and linguistic diversity is characteristic of ECI clients and their families in South Africa. At the centre of the language debate in South Africa is the question of child and adult literacy (Alexander, 1996) which leads to the following characteristic which relates to the families of the young children requiring ECI services.

3.5.2 The literacy rate of families requiring ECI services

As a result of unequal education opportunities provided in the 11 official and other languages spoken in South Africa, many South Africans, especially those from the disadvantaged rural communities, are illiterate. According to figures provided by the Central Statistical Services (1997b) the literacy rate for people over 15 years and older is 82.16%. The literacy rate refers to the percentage of persons who are able to read, write and speak their home language. The mean years of schooling of persons 25 years and older for the total SA population are 6,86 years (Central Statistical Services, 1997b).

As a result of poverty, low education and literacy levels many families cannot provide the necessary support for emergent literacy skills of their children. The result is that these children’s language and literacy levels differ from their peers when they enter school, contributing to learning difficulties. The facilitation of emergent literacy skills in young children at risk for communication disorders and school failure while many of their parents have limited literacy skills themselves, poses great challenges for an effective parent-centered approach in ECI and holds implications for parent training and providing them with information.

Another important characteristic of ECI clients' families relates to the age of the parents.

3.5.3 Age of parents of young children requiring ECI

Since the emergence of ECI a direct relationship with the families of infants were formed and the involvement of families in ECI are now regarded as a determiner of successful services (Rossetti, 1996). A specific group of parents representing an age group, whose unique needs have been highlighted in recent years, are adolescent mothers. Adolescent mothers have an increased prevalence of infants born at risk and with disabilities, even in the event of adequate prenatal care (Rossetti, 1996). The group of mothers in the USA most at risk for poor outcomes of their infants are young, single, undereducated, poor, black mothers with a history of drug and/or alcohol abuse (Rossetti, 1998). Although the specific profile of mothers most at-risk in South Africa is not known, the prevalence of adolescent pregnancies is high (Department of Health, 1997), indicating that this age group should be targeted in ECI, on the levels of primary and secondary prevention. With the alarming spread of HIV/AIDS, now recognized as an epidemic in South Africa (SABC, 1999), this age group has already been targeted in the *National Adolescent Sexual Health Initiative* (NASHI) for sexual health education programmes (Strachan, 1999). World-wide collaborative research efforts are now directed at mother-to-child transmission of the AIDS virus and how to decrease the incidence of infants born with the virus (Stucky, 1999).

This implies that ECI should be involved in collaborative efforts to prevent adolescent pregnancies and harmful behaviours of the parents that can negatively impact on them as well as on the health and development of their children. In order to be effective, the age groups to be targeted are girls and boys in their pre-adolescent years and older.

The last characteristic of ECI clients in South Africa to be discussed relates to the different risk conditions for communication disorders to be expected.

3.5.4 Risks for communication disorders in ECI clients in South Africa

Knowledge about the nature and prevalence of communication disorders among young children from different communities serves to guide clinicians, policy makers and researchers, but also indicate how much research is still required in South Africa.

The illuminating concept proposed by Rossetti (1996) to utilize infant mortality rates (IMR) to determine who are ECI clients can be helpful to identify the nature and prevalence of different communication disorders of ECI clients in South Africa. According to Rossetti (1996) it is important for the ECI clinician to be familiar with IMR, its causes and contributing factors, since those infants who survive these conditions that cause death in some infants, are at risk for developmental delays.

Tables 3.2 and 3.3 provide information on the causes of death in infants in South Africa. Table 3.2 provides information about the causes of death in order of importance during the first year of life while Table 3.3 provides details of the leading cause of death, i.e. conditions originating in the perinatal period.

Table 3.2 Recorded causes of infant deaths, 0-12 months during 1994 in South Africa

Recorded Cause of Death	% Infant Deaths	# Infant Deaths
1. Conditions originating in the perinatal period, e.g. low birth weight	43.85%	7 600
2. Intestinal infectious diseases	14.74%	2 556
3. Symptoms, signs and ill-defined conditions	10.34%	1 792
4. Diseases of the lower respiratory system	9.38%	1 625
5. Congenital anomalies	5.64%	977
6. All unnatural causes	4.44%	769
7. Nutritional deficiencies, e.g. kwashiorkor and marasmus	2.72%	471
8. Endocrine and metabolic diseases (HIV/AIDS included)	2.09%	362
9. Other bacterial diseases	2.04%	354
10. Diseases of the nervous system, e.g. meningitis, cerebral palsy, epilepsy	1.59%	275
11. SIDS (Sudden infant death syndrome)	1%	173
12. Venereal diseases	0.78%	135
13. Tuberculosis	0.42%	73
14. Viral diseases	0.24%	42
15. Diseases of the upper respiratory tract	0.22%	38
16. Diseases of pulmonary circulation and other forms of heart disease	0.16%	28
17. Diseases of the urinary system	0.12%	20
18. Malignant and benign neoplasm	0.10%	18
19. Diseases of the digestive system	0.06%	11
20. Diseases of blood and blood-forming organs	0.03%	6
21. Disease of the ear and mastoid process	0.02%	4
22. Other infectious and parasitic diseases	0.02%	3
Total number of recorded deaths	**100%**	**17 332**

Source: Central Statistical Services, 1997c.

The statistical information of the two tables was extracted from the *Death Register Form* and *Medical Certificate* which are submitted to the Department of Home Affairs and the causes of death were classified according to the *ICD-10* (*International Statistical Classification of Diseases and Health Problems*) by the SA Central Statistical Service (1996; 1997c).

According to Table 3.2 the predominant cause of death in infants during their first year of life in South Africa is conditions originating in the perinatal period, of which prematurity and low birth weight are the most important causes (See also Table 3.3). The figure of 43.85% overshadows all the other 21 causes of identified infant death and confirms the well known fact that birth weight is the most important predictor of infant survival (Rossetti, 1996).

When applying Rossetti's argument (1996) to these statistics it follows that if so many infants die of perinatal conditions, those who survive these conditions are at risk for developmental delays and should form the majority of the ECI caseload in South Africa. It is clear that further research is necessary to determine who are the infants presently receiving ECI in South Africa and if the caseload mirror the conditions set out in Tables 3.2 and 3.3.

Upon closer inspection of Table 3.2 it appears that many of these conditions are preventable and if not, can be successfully treated and should not be the cause of death. An example of prevention through immunization is NR 14 where 42 infants died of viral diseases such as chicken pox, herpes simplex and measles. NR 21 also indicates a preventable cause of death as 4 infants died of suppurative otitis media. The IMR in South Africa is calculated at 52.8 per 1000 live births (WHO, 1996) which ranks low in comparison with Western countries who have figures of below 10 deaths per 1000 live births (Rossetti, 1998).

According to Table 3.2 intestinal infectious diseases and diseases of the lower respiratory system (such as bronchitis, bronchiolitis, pneumonia, broncho-pneumonia, influenza and asthma) both rank very high as causes of death. Some of these diseases relate to the first level of health care service, i.e. the provision of basic needs such as safe drinking water, basic housing and the provision of adequate food (See Chapter 1, 1.2.5). Evidence of the lack of basic needs is also indicated in the high ranking of nutritional deficiencies as a cause for infant death. This figure is alarming as the expectation is that breast feeding should be more successful during the first year of life as it provides an infant with adequate nutrition. These statistics imply that the South Africa infant population is extremely vulnerable for diseases that can be cured at primary health care level if treated in the beginning stages of the disease. If so many infants die of these diseases it indicates the heavy burden that secondary health care have to bear.

In terms of the ECI caseload in South Africa it appears that infants with low birth weight and prematurity should be the majority of clients. The next largest group of ECI clients should be those with infectious and lower respiratory system diseases as they are also at environmental risk and most likely to be hospitalized and living in poverty. The next largest group of ECI clients are infants with congenital anomalies, indicating established risk conditions. The following group are those exposed to trauma and accidents which could relate to neglect and abuse resulting in traumatic brain injury (Sellars, *et al.*, 1997).

Table 3.3 Perinatal conditions recorded as causes of death during 1994 in South Africa

Perinatal condition	% Deaths	# of Deaths
1. Short gestation and low birth weight	46.99%	3 571
2. Respiratory distress syndrome	13.46%	1 022
3. Other respiratory conditions of the fetus and newborn	9.87%	750
4. Intra-uterine hypoxia and birth asphyxia	7.03%	534
5. Ill-defined conditions	6.71 %	509
6. Infections specific to the perinatal period	5.47%	416
7. Placenta, cord and membrane complications	3.03%	230
8. Birth trauma	2.22%	169
9. Perinatal disorders of the digestive system	1.12%	85
10. Complications of labour	0.84%	63
11. Maternal conditions unrelated to present pregnancy	0.8%	61
12. Perinatal jaundice	0.7%	53
13. Fetal and neonatal haemorrhage	0.65%	49
14. Haemotological disorders	0.29%	22
15. Maternal complications of pregnancy	0.25%	19
16. Conditions involving integument and temperature regulation	0.2%	15
17. Endocrine and metabolic disturbances	0.17%	13
18. Haemolytic disease of the fetus or newborn	0.16%	12
19. Long gestation and high birth weight	0.04%	3
Total	**100%**	**7 600**

Source: Central Statistical Services, 1997c.

Tables 3.2 and 3.3 therefore provide guidelines for research and clinical purposes in the local context. Both tables contain entries reflecting inaccuracies in the recording system, i.e. NR 3 in Table 3.2 and NR 5 in Table 3.4 which accounts for 10,34% and 6,71% of causes of death that could not be classified. The poor quality of South African vital registration data is well recognized in the health professions and efforts are now geared to improvements in the system (Wood & Jewkes, 1998).

According to Table 3.3 the leading cause of death in infants with prematurity and low birth weight is respiratory distress syndrome. Rossetti (1990a) provides USA statistics also indicating respiratory distress syndrome as the most important disease causing death in this population. The subsequent causes of death indicate conditions relating to, but not exclusively to low birth weight and prematurity. The importance of these perinatal conditions for ECI are that they negatively impact on infant health as well as on development and the developmental sequelae can be minimized if intervention already starts in the perinatal period.

The answer to the question of which communication disorders occur in clients requiring ECI services can therefore be answered by referring to IMR. The causes of infant death provide the different conditions resulting in developmental delays and communication disorders these infants are at-risk for.

It is also clear that ECI services are inseparable from collaboration with the health system, in particular neonatal intensive care units and primary health care services. The majority of infants in the ECI caseload should be infants with low birth weight and prematurity, i.e. graduates from the neonatal intensive care unit. The second largest group of infants who are at risk for developmental delays, are those infants dying of infectious diseases and diseases of the lower respiratory system (See Numbers 2 and 4 in Table 3.2), who also live in poverty. They are the clients who will be identified at primary health care facilities and community-based rehabilitation services.

3.6 CONCLUSION

In order provide services to all the different communities in South Africa ECI can employ different strategies already utilized in the health system, education system and community-based services. The principles of primary health care, ECI programmes for preschoolers and community-based rehabilitation are compatible with ECI and provide strategies to serve the diverse populations of young children and their families requiring ECI services.

The discussion of the five aspects relating to the different characteristics of clients and their families requiring ECI services in South Africa served to present a profile indicating that clients represent:

- Diverse linguistic backgrounds and English is not a common language for all
- Diverse cultural traditions and the meaning of cultural practices are not always clear to outsiders
- Various levels of literacy and education, but a high prevalence of illiteracy
- Young parents in their teens who are of particular concern in ECI
- Different risks for communication disorders and the largest single group of clients requiring ECI are infants with low birth weight and prematurity, while the second largest group are represented in the population of infants who die of intestinal infectious diseases and diseases of the lower respiratory system and live in poverty.

The broad profile of the population at-risk for and with communication disorders indicates further identification of the population in order to reflect the unique needs of the diverse groups requiring ECI in South Africa. As stated by SASLHA

(Louw, 1997) further research is necessary to obtain recognition and to establish the field of ECI in South Africa.

The use of a computer database to store large amounts of information on infants and toddlers at risk for and with communication disorders and their families can contribute to a national data bank of those requiring ECI services.

The value of a national data bank can be demonstrated by Swedish long-term research projects employing large numbers of subjects. In a national survey, using data collected over the past 30 years Becker, Svensson & Källén (1998) found correlations between cleft palate and low birth weight in the subjects. The findings are valuable contributions to the field of cleft palate as these correlations were suspected for a period of time, but large numbers of subjects were required to obtain reliable data.

A computer database will not only provide data on large numbers of subjects, but can also contribute to a rich description of subjects if designed to collect comprehensive data. The use of a computer data base in research on infants and toddlers and their families requiring ECI in South Africa may therefore contribute to the dearth of detailed information on those who need services which can make a difference in the quality of their lives.

3.7 SUMMARY

The chapter describes the need for transformation of speech-language therapy and audiology services in South Africa and proposes the utilization of ECI as a key strategy to integrate the services into primary health care, inclusive education policies and community-based rehabilitation approaches. A broad profile of clients requiring ECI in South Africa revealed that the population displays characteristics of diverse linguistic, cultural and literacy backgrounds and that the majority of clients requiring ECI are infants with low birth weight and prematurity and those suffering from diseases associated with poverty.

CHAPTER 4

DATABASE SYSTEMS IN EARLY COMMUNICATION INTERVENTION

CHAPTER 4

DATABASE SYSTEMS IN EARLY COMMUNICATION INTERVENTION

Aim: The aim of the chapter is to discuss the research applications of information technology in early intervention in order to provide the underpinnings for a database system in second-generation research in early communication intervention.

4.1 INTRODUCTION

The developing field of early communication intervention (ECI) in South Africa requires research generating activities in order to accelerate the process of establishing the discipline in all contexts and demonstrate effective and relevant services. As research is the way to increase understanding about unresolved problems (Leedy, 1997), the need for data to guide the development of the field of ECI in South Africa is imperative. Rossetti (1996) urges not only researchers, but also early intervention (EI) professionals to become involved in the process of research in order to provide documentation, data, comparative information and empirical comparisons to demonstrate the effectiveness of early communication intervention (ECI).

Although ECI is still in its infancy in South Africa, it is well established in certain centres and developing nationwide (Louw, 1997; Haasbroek, 1999). However, ECI in South Africa is still facing first-generation research issues such as proving its effectiveness to health and education service providers and to reach consensus, as stated by Guralnick (1997), about society’s responsibility to provide ECI services. In the South African Speech Language and Hearing Association’s (SASLHA) Guidelines for Speech-Language Therapists and Audiologists regarding ECI, Louw (1997) indicates that the identification and prediction of which infants and toddlers are likely to need ECI is the starting point of the provision of effective services. ECI in South Africa is therefore still engaged in first-generation research issues, but needs to accelerate the development of the local field to participate in second-generation EI research activities. According to Guralnick (1997) second-generation research in EI must strive to provide empirical data about strategies and processes to design individualized programmes to meet the unique needs of young children and their families in all contexts. The application of information technology to stimulate research generating activities needs to be investigated as it offers certain benefits which exceeds those of conventional research methodologies. The greatest impact of information technology is demonstrated in the functions of data capturing, data structuring, analysis, reporting, retrieval and generating queries (Nieuwoudt, 2000).

Rapid advances in information technology have been proven to greatly benefit research activities across disciplinary fields. An example of the importance the field of education affords to information technology in the 21st century is the establishment of the Twenty-first Century Conceptual Tools Center at Purdue University (TCCT Center, 1999). Since the central mission of the TCCT Center is to identify the most important concepts and abilities necessary for success in the technology-based age of information, it is clear that information technology is envisaged as the driving force of advances in research and all its applications.

The application of information technology in ECI research appears a pertinent and logical collaborative effort to equip the field for the 21st century and specifically address the problem stated by Guralnick (1997) of collecting information to more effectively match programme features with child and family characteristics and desired ECI outcomes. It appears, however, that the collecting of client data in a database system and using it for research purposes is not widely applied in the field of speech-language pathology or ECI. The aim of the chapter is to investigate the application of information technology in EI in order to provide background knowledge for the design of a customized database system to be used in ECI research.

4.2 INFORMATION TECHNOLOGY IN SPEECH-LANGUAGE PATHOLOGY RESEARCH

The application of information technology in speech-language pathology research currently extends far beyond the use of computer packages for the statistical analysis of data. The use of information technology in speech-language pathology research is well-established and ranges from providing the researcher access to information retrieval systems via the Internet (Kuster & Poburka, 1998; Robinson, Cole & Kellum, 1996) to computerized language sample analysis tools such as the CHILDES project (MacWhinney, 1996) and the Language Sample Analysis (LSA) (Miller, Freiberg, Rolland & Reeves, 1992), various software programmes for speech and voice analysis and recognition, the extensive research based on computer technology in the field of augmentative communication (Curtis, 1987) and database systems to support longitudinal research (García-Sánchez, 1999; Mandeville, Raymond & Anderson, 1988).

The two editions of *Seminars in Speech and Language* (Volume 20, Numbers 2 & 3, 1999) devoted to technological applications for speech and language assessments and interventions indicate the extent of information technology–based research supporting clinicians in assessing and treating clients representing the whole spectrum of communication disorders. Despite the vast number of software programs available to enhance clinical interventions, it appears that information technology is underutilized in speech-language pathology (Nelson & Masterson, 1999). As indicated by a 1997 ASHA survey, clinicians appear to be reluctant to venture beyond the word processing functions of their computers and the use of information technology for clinical purposes is currently limited (Nelson & Masterson, 1999).

This situation is likely to change as information technology is rapidly developing and becoming more accessible to the user and the user becoming more accessible for information technology. Current reasons for the limited use of information technology in speech-language pathology appear to be twofold.

According to Nelson and Masterson (1999) the potential benefits of information technology in speech-language pathology service delivery must still be demonstrated in research. There is a dearth of evidence indicating that clients make greater gains and progress more rapidly when computer technology is used. Although research demonstrating the advantages of information technology is still limited, the same authors indicate that there is already evidence that the use of information technology in speech-language intervention is consistent with the criteria for effective intervention as it allows for improved collecting, maintaining and reporting of client data (Nelson & Masterson, 1999).

Secondly, Robinson, *et al.* (1996) point out that the application of information technology is curtailed by the fact that undergraduate courses teach computerized information seeking skills and literature retrieval strategies only to a limited extent. It appears that clinicians in the field of speech-language pathology do not yet fully realize that conventional information retrieval methods and the exclusive use of low-technical procedures and techniques in assessment and treatment are no longer sufficient in clinical practice.

It is clear that a large variety of clinical and research tools based on information technology is available, but professional training programmes, planning, a change of mind and further research is necessary to increase the use of information technology in speech-language pathology. One such a tool is database systems which contain vast possibilities for speech-language pathology and can bridge the gap between clinicians and researchers and enhance information technology utilization in the field. Clinical data entered in a personal computer equipped with a database can be linked to a wide network of databases nationally and internationally and may greatly enhance research and clinical applications in speech-language pathology and specifically in ECI (Niewoudt, 1999).

A brief explanation of the concept of database systems will serve to illustrate its importance to a profession facing the challenges of the information technology age.

4.3 FEATURES OF RELATIONAL DATABASE SYSTEMS

In its most basic form, a database is a computerized record-keeping system with the purpose of maintaining information and making that information available on demand (Aitken, *et al.,* 1997; Curtis, 1987; Date, 1990). A relational database is a collection of relations and supports a fixed collection of data types (Ramakrishnan, 1998). The most common relational database system for limited use is *Microsoft® Access.*

A computerized relational database has certain advantages over a conventional paper-based filing system, as it stores sets of data in database files which can be manipulated by sorting it, changing it or finding items within it. The most salient advantages of a computer database relate to the ability to manage large volumes of data and to manipulate the data at a high operating speed. A database is also efficient as there is no need for voluminous paper files, the tedious task of maintaining files by hand is eliminated and, if regularly updated, accurate information is available on demand at any given time (Date, 1990). A relational database system can create baselines, chronological sets and provide time slices of development (Nieuwoudt, 2000). The features of a computer database therefore demonstrate its suitability for data processing for research purposes as the systematization and categorization of data are the first steps in the process of research (De Vos, 1998).

Rapid advances in the field of database systems research have resulted in the wide spread application of databases in all disciplines, linked via the Internet (Connolly, *et al.,* 1996; http://hera.eecs.berkeley.edu/Research/Summaries/1995-99). According to Connolly, *et al.* (1996) and Bowers (1993) the exceptional productivity in database research over the past thirty years has led database systems to be viewed as the most important development in the field of software engineering. The database provides the underlying framework of the entire global information system and has radically changed the way organizations operate and research is conducted.

As databases became more powerful and flexible to use, their apparent simplicity conceals the highly complex and sophisticated structure of the system which created a whole new way of thinking about data processing (Bowers, 1993). The approach taken with relational database systems is to separate the definition of data from the application programs. This approach, known as data abstraction, results in an internal and external definition of objects so that the user only sees the external definition and is unaware of how the object is defined and how it functions (Connolly, *et al*., 1996). As a result of the complex structure of a database system, it has numerous advantages.

4.3.1 Advantages of Relational Database Systems

In contrast with spreadsheets, database systems are much faster to operate and data manipulation is more flexible. According to Date (1990) the centralized control of data in a database system is the overriding advantage to the user or institution. Based on a literature review the benefits of centralized control in relational databases are as follows:

- *Redundancy can be reduced*. When non-database systems are used, such as spreadsheets or electronic file-based storage systems, there tends to be redundancy and waste of storage space as data are stored in separate files which are difficult to integrate.
- *Inconsistency can be avoided to some extent*. Centralized control implies that inconsistent data can be identified, therefore avoiding the supply of incorrect or contradictory information to database users.
- *The data can be shared*. The fact that the database is integrated and relational-based implies that different users can share the same information concurrently or for different purposes. Existing applications can share the data in the database, but new applications can also be developed to operate against the same stored data without having to create any additional stored data. It is the sharing of data, linked via information networks, that distinguishes database systems from traditional filing systems and spreadsheets.
- *Standards can be enforced*. As the database is centrally controlled desirable standards can be observed, thereby increasing the value of data and making it more suitable for research and for national and international data exchange.
- *Security restrictions can be applied*. Central control requires a security system and ensures that access to the database is through proper channels and that sensitive data is protected. Anonymity of subjects participating in a research project can therefore be guaranteed.
- *Integrity of data*, i.e. ensuring that data in the database is accurate, *can be maintained.* Even if redundancy is controlled, data can still be inaccurate if integrity checks are not controlled centrally. Integrity controls are most important when data is shared and utilized for research purposes.
- *Conflicting requirements can be balanced*. The database can be designed and operated to serve the best interests of an institution rather than the requirements of individuals.

(Benyon, 1990; Bowers, 1993; Connolly, *et al*., 1996; Date, 1990).

As a database is a shared collection of logically related data, which also provides a description of this data, it can be designed to meet the information needs of a particular organization (Connolly, *et al*., 1996). Databases can therefore be customized to be used in diverse contexts, from production companies to research laboratories. The seven benefits of centralized control of databases can be used as guidelines and operating criteria when designing a database system for the specific research needs of the present study.

In order to demonstrate the diverse application possibilities of database systems and provide guidelines for the requirements and features of the intended database system of the current study, some selected examples of existing databases in EI will be discussed.

4.4 DATABASE SYSTEMS AS MANAGEMENT TOOLS IN EI

An overview of literature revealed that database systems are used extensively in EI in the USA, but since the databases are mostly used as management information systems and not as research tools, it appears that descriptive articles about them are not published. The USA law mandating EI to all infants and toddlers with disabilities, Part H of the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476), prescribes 14 components of an EI system to be implemented in each State. The last of these components is an information management database system (Hebbeler, 1993; Stayton & Karnes, 1994).

In order to fulfill the requirements of the Program for Infants and Toddlers with Disabilities, Part H of IDEA (1990), the data system of each state must at least be able to provide information regarding the numbers of all who require EI, the numbers of clients served and the types of EI services provided by the particular State. Apart from these basic requirements of an EI data system, States are encouraged to design a useful tool to build and improve their EI programmes and to benefit the EI service provision by creating an information culture. The result is that no two data systems are alike as they are designed to meet the needs of a particular State and make provision for different approaches to data collection. In the beginning stages of the implementation of the data system, States were encouraged to maintain a balanced perspective on the degree of error that will be involved in such multi-user data systems. The establishment of a data system was to be viewed as a process which must be improved over time. The importance of data collection from the initiation of a programme was stressed as uniform record keeping is the only way to effectively monitor and evaluate the programmes in a State (Hebbeler, 1993).

In paying so much attention to the establishment of data management systems for EI, the USA legislators demonstrated their understanding of the long-term and short-term advantages of database systems for the implementation of the act. It is clear that the operational needs of any programme, whether designed for management or research purposes, require that information must be recorded, analyzed and interpreted and database systems are the most effective and accurate tools with which to do it.

In a survey of the different management information systems of the various States, Hebbeler (1993) found that all the States implemented data systems which vary greatly, but has the core function of overseeing the local programmes. The State data system therefore provides a means of bridging the gap between the State and the local level of EI service provision in the USA. According to Hebbeler (1993) the S*tate level* client-based data systems are able to perform comprehensive functions to answer questions concerning local services and assist in:

- *Describing the population* being served in the State, how it changes over time and the kind of services individuals are receiving. The information on clients is used to generate annual reports, plan services, determine staff requirements and estimate budgets.

- *Identifying weaknesses* in the State service delivery system so that targeted assistance can be provided to local programmes. For example, data on referrals and referral sources revealed that mass screening clinics conducted at the local level were not an efficient way of using resources, as few children requiring EI were detected this way. Other useful data revealing weak points were the number of children on waiting lists.
- *Monitoring of the Federal regulations* for specified timelines for certain events in the service delivery process, such as the review of Individual Family Plans.
- *Planning for the future*. If data has been collected over several years, valuable information regarding programme changes over time is revealed. Projections about the nature and size of the population to be served can be made.
- *Facilitating linkages* between agencies and institutions and ensure the immediate follow-up of infants requiring further EI after they have been discharged from the NICU.
- *Compiling reports* to be used to convince the State’s legislators and sponsors about the importance and need for EI (Hebbeler, 1993).

It is clear that a large number of questions can be answered by the State database systems as the information output is only limited by the type and quality of the data which was entered. As data systems are able to link data sets the different States also use their databases to operate an automatic process of payment for EI services (Hebbeler, 1993).

The local EI programmes of the different States also benefit from the same information the State management data systems releases, but according to Hebbeler (1993) these local programmes face greater information management challenges than the State level databases. The local level information systems must be able to track information on hundreds of children while the State manages information of 25 to 75 programmes only. In order to demonstrate the capabilities and flexibility of the database approach to information management, the following functions of the local EI databases in the USA are presented (Hebbeler, 1993). In utilizing their data systems, the clinicians in local EI programmes can do the following:

- Generate statistical reports on clients for evaluation and intervention planning purposes.
- Review data and produce various lists or sub-sets of children.
- Monitor the status of EI services to individual children and their families and remind the clinicians about upcoming appointments.
- Produce legible and complete copies of a child's record to share with the family and interdisciplinary team.
- Access information about other resources available in the community.
- Generate individual transition reports for school districts when children continue with intervention after three of years age.
- Easily and quickly transmit required data to the state level database.
- Although not a function of databases, word processing and producing of labels for mailing or file folders are possible as the data is derived from the database.

(Hebbeler, 1993)

The overview of the varied and innovative functions of a database management system for the local EI programmes in the USA points to the careful planning necessary before designing such a data system. Another necessity is the high level of technical expertise required from clinicians to realize the full potential of their information system. Since it is *people* who convert data to information and *not machines* (Hebbeler, 1993), a lack of training and resistance against the use of computer technology can therefore negatively impact on the vast possibilities of database systems.

The description of the State and local data management systems portrays them as powerful tools to enhance EI programmes and identifies EI as a leader in the application of database management systems in the field of speech-language pathology. One of the greatest advantages of longitudinal databases in EI is the unique opportunity of tracking individual infants with disabilities and those at risk for developmental delays from birth onwards throughout their lives. When using such an EI database the advantage is that the data is recorded prospectively and the inaccuracies and omissions in information created by retrospective data recording can be avoided. These benefits constitute the most important motivations for the implementation of information management and research database systems in the field of EI which in turn directs the attention to the foremost reason for data collecting. As stated aptly and clearly by Rossetti (1996), effective EI services can only be delivered if we have the data to guide our actions.

Even though the data systems for EI described previously were not designed for research purposes, it is clear that large management databases can be used to identify subjects for research projects, provided that families have given their consent before any data is entered into the system. The *South African Constitution* has a clause in the *Bill of Rights* to protect a person's privacy and states that "everyone has the right to privacy which includes the rights not to have the privacy of their communications infringed" (http://www.polity.org.za.govdocs/constitution/saconst 01.html.). This clause relates directly to research conducted in South Africa and must be adhered to in pursuit of ethical standards in research.

In contrast with management databases it is, however, the customized research databases recently being described in the literature that promise exiting new applications in EI.

4.5 DATABASE SYSTEMS AS RESEARCH TOOLS IN EI

Currently, limited articles are available on the use of databases as research tools in EI. These articles were located in different sources, indicating that research databases, just as data management systems, are utilised and reported in EI, but are not always published. The resources that provided access to reports on databases, were the Internet, where the ISEI (International Society on Early Intervention) (1999) announced a short description of a database by García-Sánchez (1999) on their web site, the ERIC (Educational Resources Information Centre) database, an information network designed to provide access to non-journal resources where unpublished articles were located by Bezruczko and Zell (1993), Bornstein and Casella (1993) Hebbeler (1993) and in professional journals where articles were identified (MacWhinney,1996; Mandeville, *et al*., 1988; Miller, *et al*., 1992). In order to investigate the use of database systems in EI research each of these databases will be described briefly.

4.5.1 The Individual Following Record to Early Intervention (García-Sánchez, 1999)

The announcement on the ISEI web site on the Internet described a Spanish database system designed to be used as an individual following record of infants with cerebral palsy and as an epidemiological research tool in EI. *The Individual Following Record to Early Intervention* (García-Sánchez, 1999) was designed with the purpose to systematize the recording of large amounts of data of children, birth to six years old, with cerebral palsy attending different EI centres of the Región de Murcia, in Spain. The database is able to record data on 185 variables which include information regarding the diagnosis and characteristics of the child's disability, history of the pregnancy, birth and perinatal period, information about the sociocultural and socioeconomic characteristics of the family and information about the EI programme such as treatment modalities and the child's integrative experiences in the kindergarten and primary school. The *Individual Following Record to Early Intervention* (García-Sánchez, 1999) is capable of recording successive assessment data of 53 different sub-scales of assessment instruments, registering the results according to different age intervals.

The database is intended for use by a team of professionals from different EI centres and is coordinated from a university-based research centre. An operating manual is available in Spanish to ensure effective participation of the different users of the database system.

The description of the database demonstrates that it can be used to track the development of individual children for the monitoring of their EI programmes and for longitudinal studies contributing to the epidemiological data on the population of children and their families participating in the research. The detail in which the author (García-Sánchez, 1999) describes the database provides useful information about the structure of the data system which can be replicated or adapted when designing other databases. Unfortunately this database is currently only available in Spanish which restricts the linking of the data with other databases. The database, however, demonstrates how data can be shared among different EI programmes and assist the transition of subjects from one programme to another. This way data about subjects is not lost and a more comprehensive description of the population can be obtained.

No information about the results of the intended use of the database for epidemiological research was supplied. In order to demonstrate that database systems can be successfully applied in research, the following reports referring to database systems employed for research purposes will be discussed.

4.5.2 Relational Database System to Integrate Early Childhood Assessment Data across Pre-kindergarten, Kindergarten and Grade 1 (Bezruczko & Zell, 1993)

The relational database system described by Bezruczko and Zell (1993), as well as the database described by García-Sánchez (1999), is also a tool designed for longitudinal data collection. This research tool (Bezruczko & Zell, 1993) aims to integrate the continuous assessments of a large group of urban disadvantaged children enrolled in EI programmes in Chicago. In a conference paper the authors describe how a large centralized database stores the data of 22,000 individual clients which can be accessed by teachers via tabletop computers in the local schools. The database was designed to address the data management problem caused by the large numbers of children requiring EI and large volumes of data which increases with each year a child is enrolled in the EI programme.

The structure of this database (Bezruczko & Zell, 1993) was designed to accommodate and systemize multiple assessment resources such as interviews with parents, naturalistic field observations of the child, survey responses and child performance examples without causing redundancy or duplication of the data.

Apart from the obvious data management advantages gained by the utilization of this database system, the research component of the database also proved to be successful. Instead of employing standardized norm-referenced tests, the recording and analysis of authentic samples of child performance resulted in the identification of a developmental sequence of language related skills. The results indicated patterns of continuity across the annual assessments of the children’s language skills and proved to be of clinical value in providing direct guidelines for treatment (Bezruczko & Zell, 1993).

The database described by Bezruczko and Zell (1993) demonstrates the large capacity of databases for data storage as large volumes of text data containing actual samples of children’s performances can be entered into the database. This important feature of a database was not evident in the description of the database system described by García-Sánchez (1999) as it appears that children’s performances are mostly described in terms of age intervals on different assessment instruments which is then entered into the database as numerical data. Whereas the use of numerical data is a time-saving method for data entry, text data can provide valuable data for qualitative analysis, thereby demonstrating the flexibility of database systems to accommodate different research methodologies, depending on the database design.

The most important feature of the database design described by Bezruczko and Zell (1993) is therefore its applicability for longitudinal research on a group of subjects since their enrollment in EI programmes. This feature is also demonstrated in the following database system to be described.

4.5.3 Developmental Assessment and Instruction for Success in Early Years (DAISEY) Data System (Mandeville, *et al*., 1988)

Another example which proves that databases are immanently suitable for longitudinal research is the DAISEY Data System (Mandeville, *et al*., 1988). This database was developed twelve years ago to support a longitudinal research project tracking the academic performance of disadvantaged students from one and a half years to five years of age as they progress through the South Carolina public school system. The design of the database appears to be similar to the systems described by Bezruczko and Zell (1993) and García-Sánchez (1999), but the research applications are different. The research project initially started without database technology, but a database system was later implemented to manage the large amounts of data required for the project. A data system was designed to collect test scores and other data about the subjects and eventually link the different data sets to track the children’s school progress and describe their long-term development. The authors (Mandeville, *et al*., 1988) concluded that the DAISEY Data System proved to be capable of managing the large amounts of data, that the linking of the different data sets were carried out accurately and that the use of database technology was cost effective. As longitudinal research projects are known to be costly, cost savings as a result of the application of database systems can stimulate longitudinal research.

The description of the DAISEY Data System (Mandeville, *et al*., 1988) emphasizes once more the advantages of database systems as flexible research tools, capable of handling large volumes of data over continuous years of research with cost saving benefits.

4.5.4 A Computerized Classroom Language Management and Recording System for Deaf and Hard of Hearing Children (Bornstein & Casella, 1993)

Cost-effectiveness is also one of the advantages reported by Bornstein and Casella (1993) of the database system used in their report on “A Computerized Classroom Language Management and Recording System for Deaf and Hard of Hearing Children”. According to the authors the database is a cost-effective resource to the education system and for research. As data sets can be divided in smaller sets or combined into larger units, a database system can provide data for large research projects as well as smaller studies such as student research projects. Although the database system described by Bornstein and Casella (1993) allows for applications in EI it is used mostly for school aged children with hearing loss. The aim of the database system is to assist class teachers to manage large amounts of information required to teach children with a hearing loss effectively. The functions of the database permits the class teacher to use the electronic mail system to contact other teachers and consult experts, to update data regarding the child and to view and print the data. The database was designed to store information on 13 different clusters of variables such as the child's hearing loss, additional disabilities, family background, language skills, auditory skills, speech reading, speech, manual communication, reading, writing, instructional strategies, the instructional environment and test scores.

When comparing the database of Bornstein and Casella (1993) with the database described by García-Sánchez (1999) it is clear that both databases are designed for their specific contexts of services to children with communication disorders relating to cerebral palsy and hearing loss respectively. The comparison of the two database systems also emphasizes the differences between the EI approach and school-based services later in a child's life. The clusters of variables of the database for classroom information management (Bornstein & Casella, 1993) concentrate on comprehensive information of the child's communication skills and academic needs, whereas the EI database of García-Sánchez (1999) is clearly based on EI principles as advocated by Guralnick (1997) and Rossetti (1996). The emphasis on the prenatal and perinatal history of the child provides information about biological risk factors impacting on the child's development and the extended information on the family and family characteristics reflects the importance of the family in the EI process.

4.5.5 Child Language Data Exchange System (CHILDES) (MacWhinney, 1996)

MacWhinney (1996) describes the CHILDES Project of which one component consists of a large internationally recognized database of language transcripts, containing normal and disordered language samples, mainly in English, but 20 other languages are now accommodated. The system involves a worldwide network of researchers from a variety of disciplines involved in the study of language. According to MacWhinney (1996) the study of child language has progressed through five phases, from naïve speculation, to diaries and biographies, to transcripts, to computers and now to the current phase of connectivity. Through the Internet researchers and clinicians can now access the CHILDES database and use it as a resource for language analysis. The emergent connectivity of the Internet holds the potential of establishing the Glossome Database, much like the Human Genome Database (MacWhinney, 1996). The CHILDES database emphasizes research and only recently have some clinical applications been included.

The next database is both a research tool and a clinical tool for the analysis of child language performance.

4.5.6 Language Sample Analysis (LSA) (Miller, *et al*., 1992)

Miller, *et al*. (1992) describes a reference database of language samples of typically developing children used in public schools in Wisconsin. An earlier version of the LSA as it is currently known, was already published in 1982 as the SALT (Systematic Analysis of Language Transcripts) which indicates that researchers in the field of speech-language pathology realized the value of database systems long before the current popularity and technological advances of the database as described by Connolly, *et al*. (1996).

The LSA (Miller, *et al*., 1992) more so than the CHILDES (MacWhinney, 1996), is a clinical tool designed to be used by speech-language therapists to transcribe, analyze and interpret language samples of children with language disorders. The reference database contains 27 to 30 normal language samples, representing narrative and conversational contexts, for each age interval, from three to 13 years of age.

The advantages of the LSA data system are that the tedious language sampling and analysis of the past is now a much easier process. Miller, *et al*. (1992), however, differ from Mandeville, *et al.* (1988) in stating that the use of database system did not result in time and cost savings, as the use of information technology involves more processes. The cost-savings come into effect as better quality of data, better interpretations and better programmes result in more effective interventions which results in cost savings only in the long run.

The main achievement of the LSA (Miller, *et al*., 1992) is the contribution to a changed view of language impairment. According to Miller, *et al*. (1992) traditional language tests do not reveal the specific aspects of expressive language difficulties, such as vocabulary diversity which can only be determined through the use of computer technology. The researchers' opinion is that the LSA is crucial to the identification and description of disordered language performance.

It is clear that the use of database technology in the study of child language has brought about much more sophisticated and accurate techniques which resulted in new developments and clinical applications in speech-language pathology. The description of the two database applications also demonstrate that the type of research undertaken is impossible without database technology.

The last two databases which were discussed relate to the very successful application of database technology to research in language analysis and interpretation. These two databases have limited application in EI as the study of child language usually start on the syntax level, implying that the subjects have already reached that developmental level. The aim of the discussion was, however, to indicate how advances in database technology and developments in the study of language mutually stimulate one another.

The discussion on the six databases as research tools with applications in EI has certain implications for further research as well as for the present study.

4.6 APPLICATIONS OF THE USE OF DATABASE SYSTEMS FOR ECI

The use of database systems in ECI research can become a most useful source to describe populations requiring ECI services and guide programme planning. Although limited resources on the applications of database systems in EI are currently available, a literature overview provided useful information and the following implications became clear for applications in ECI:

- Data management systems can be utilized for research purposes as the organization and systemization of data is the first step of the research process (MacWhinney, 1996). Immediate access to data is one of the most valuable advantages to enhance the research process.
- Database systems assist the researcher as well as the clinician to produce better quality observations, recordings, analyses and interpretations (MacWhinney, 1996). These gains will eventually result in more effective interventions.
- Database systems have already made significant contributions in the study of child language (MacWhinney, 1996; Miller, *et al.*, 1992).
- Database systems can successfully manage large amounts of data, link different data sets and can accommodate many users (Bezruczko & Zell, 1993).
- The use of database systems do not necessarily result in cost and time saving benefits (Miller, *et al*., 1992), but gives immediate access to information which would otherwise not be possible.
- The effective way to carry out longitudinal research is to use database technology (García-Sánchez, 1999).
- The effective way to manage an EI programme is to utilize a customized database system (García-Sánchez, 1999) as EI permits the unique opportunity to follow individual children prospectively from birth onwards.

Database systems undoubtedly hold many advantages for ECI research which can subsequently be applied to improve ECI service provision. As advances in database technology are considered one of the most acclaimed achievements of software engineering (Connoly, *et al.,* 1993; Bowers, 1993) data management by means of a customized database system is the way to fully exploit the most valuable resource for research, namely data (Benyon, 1990).

In order to establish a database system complying with the needs of the developing field of ECI in South Africa it is important to determine which information about infants and toddlers requiring ECI is already available. An analysis of the local context regarding ECI research is one of the most important underpinnings for further context relevant research.

4.7 ECI RESEARCH RELATING TO RISK POPULATIONS IN SOUTH AFRICA

A review of the literature revealed that a substantial amount of research regarding various aspects of EI in the field of Communication Pathology has already been carried out. In order to analyze the achievements and areas of needs in local ECI epidemiology, a sample of studies describing different subgroups of children younger than three years old and at risk for communication delays were selected from the general pool of EI research in South Africa. Although an integrated approach to the collection of epidemiological data on the communication profiles of infants and toddlers at risk for delays and their families in South Africa is not available, an overview of the individual descriptive research projects revealed a significant amount of data on different subgroups of the population qualifying for ECI services and presented in Table 4.1. None of these studies employed database technology to obtain data.

Table 4.1 (See following pages) provides a summary of studies conducted at the Centre for Early Intervention in Communication Pathology describing young children less than 3 years old requiring ECI. It appears that a steady flow of

Table 4.1 South African studies describing young children mainly under three years old requiring ECI

Author(s)	Population	Subjects	Nature of Study
A. Established risk conditions: Cleft lip and palate, Pierre Robin Sequence, Down syndrome, Sensorineural hearing loss			
1. Louw, 1986	Black infants with cleft lip and palate in the Ga-Rankuwa Hospital	25 subjects; 7-11m old; 9 different African language groups	The proposal of a holistic assessment protocol based on a morpho-functional description of the subjects regarding: - Oro-facial morphology - General development - Mother-child interaction - Communication development
2. Kritzinger, Louw & Hugo, 1996	Young children with cleft lip and palate at the Facial Deformities Clinic, University of Pretoria	44 subjects; 3-31m old; Afrikaans and English	A developmental description of the subjects regarding: - General development - Communication development
3. Fair & Louw, 1998	Young children with Pierre Robin Sequence at the Facial Deformities Clinic, University of Pretoria	4 subjects; 5-28m old; Afrikaans and English	Determined the subjects' progress in ECI in the following areas: - General development - Communication development
4. Louw & Kritzinger, 1991	Infants with Down syndrome receiving ECI at CHRIB	3 subjects; 10-11m old; Afrikaans	Determined the subjects' progress in ECI in the following areas: - General development - Communication development
5. De Freitas, 1997	Young children with Down syndrome at CHRIB	34 subjects; 1-47m old; Afrikaans, English, Tswana, Zulu, German	A description of the subjects regarding: - Pre- and perinatal history - Associated abnormalities - Oro-facial abnormalities - General development - Communication development
6. Swanepoel, 1997	Young children with Down syndrome	5 subjects; 5-24m old; Afrikaans and English	A description of the subjects' communication interaction regarding: - Mother-child communication interaction - Communication functions
7. Roodt, 1994	Young children with sensorineural hearing loss	5 subjects; 10-24m old; Afrikaans and English	A description of the subjects regarding: - Communication skills - Hearing loss - Phonology
B. Biological Risk: Low birth weight and prematurity, chronic otitis media, twins			
8. Smit, Louw & Uys, 1987	Young children who were premature	6 subjects; 30-37m old; Afrikaans	A description of the subjects' expressive language skills regarding: - Mother-child communication interaction - Communication development
9. Kritzinger, 1994	Infants at biological risk, living in Pretoria	19 subjects; Neonates–12m old; Afrikaans and English	A longitudinal study to identify predictors of the subjects' communication development based on: - Mother-child communication interaction - General development - Communication development

Table 4.1 continued

Author(s)	Population	Subjects	Nature of the study
10. Du Preez, 1995	Toddlers at biological risk, living in Pretoria	17 subjects; 18m old; Afrikaans & English	A description of the subjects' communication development at 18m regarding: - General development - Communication development
11. Hugo, Louw & Kritzinger, 2000	Infants and toddlers with various risk conditions at CHRIB	56 subjects; 5-34m old; Mainly Afrikaans and English	The development of a scale for listening behaviour of the subjects
12. Kritzinger & Louw, 1997	Infants at biological risk	25 subjects; 2-26m old; Afrikaans, English Tswana, Zulu	A description of joint book reading practices of the subjects and their mothers
13. Dedekind, 1997.	High risk infants	40 subjects; 1-35m old; Afrikaans and English	A description of the mother-child communication interaction
14. Coetzee, 1991	Twins	3 sets of twins; 24-30m old; Afrikaans	A description of the subjects regarding: - Mother-child-communication interaction - General development - Communication development
C. Environmental Risk			
15. Pieterse, 1998	Infants in a disadvantaged community (Eersterust)	71 subjects; 6-16m old; Afrikaans and English	A description of joint book reading practices of the subjects and their mothers, living in a poor community
16. Van der Merwe, 1999	Infants in a disadvantaged community (Eersterust)	100 subjects; 0-18m old; Afrikaans, English, Zulu, Ndebele, Sotho	A description of the risk factors present in the subjects, living in a poor community

studies was produced the past 15 years, an initiative from this particular centre which is considered as leader in the field of ECI in South Africa (Rossetti, 1998).

The studies described in Table 4.1 are categorized according to the different risk conditions occurring in the subjects and not according to chronology. This way the different populations of high risk infants on which some data is available are emphasized and guidelines for further data collection are provided. The high risk population groups investigated in the studies represented three groups of young children with *established risk conditions*, i.e. cleft lip and palate and the sub-group Pierre Robin Sequence (Studies 1-3), Down syndrome (Studies 4-6) and sensorineural hearing loss (Study 7), young children at *biological risk* (Studies 8-14) and young children at *environmental risk* (Studies 15 and 16). The choice of these risk categories is contextually relevant as all of these conditions have an increased prevalence in certain South African communities (See Table 1.4, Chapter 1).

The variation in age groups of the subjects employed in the studies indicate that the entire EI age range have been studied, from the neonatal period, through infancy to the toddler period. The subjects were drawn from a wide variety of language groups, indicating that infants and toddlers representing different South African languages were included in the studies (See Chapter 3, Table 3.1). This also indicates the unique opportunity of EI to investigate subjects from different language groups characterizing South Africa, as the different aspects of early communication behaviours, such as vocalizations, non-verbal communication skills, communication functions and mother-infant communication interactions are less dependent on language-specific knowledge and can be described by a researcher not sharing the same language as the subjects. The study by Louw (1986) clearly illustrates that a holistic assessment protocol could be successfully applied to a group of infants representing nine different languages.

The 16 different studies were mostly descriptive surveys, but two studies employed an *ex post facto* design to determine treatment progress (Studies 3 and 4), one study was a longitudinal survey to describe the subjects' development and determine predictors of their development (Study 9) and the aim of one study was to develop an assessment scale to describe the subjects' listening skills. According to Table 4.1 it appears that the descriptive studies succeeded in providing comprehensive profiles of the subjects' communication functioning, mother-infant communication interaction patterns and general developmental functioning, but limited descriptions about the characteristics of the families are provided. The studies of Smit, *et al*. (1987), Pieterse (1998) and Van der Merwe (1999), however, provide extensive detail about the families, such as parental educational levels, their ages, employment and qualifications. It appears that only two of the studies described the subjects' socio-economic status namely Pieterse (1998) and Van der Merwe (1999) mentioning that the research was conducted in a disadvantaged community. This can be attributed to the fact that these populations were not always easily accessible and the emergence of studies such as these reflects the new efforts in providing ECI services to all.

Pieterse (1998) and Van der Merwe (1999) both conducted their research in the mainly disadvantaged community of Eersterust outside Pretoria and succeeded in describing some of the important environmental risk factors negatively impacting on the communication development and school readiness of the subjects. Both studies utilized large samples, i. e. 71 and 100 subjects respectively and can be regarded as valuable contributions to the field of ECI as limited research has been conducted in disadvantaged communities to date. Pieterse (1998) found limited book reading practices in the families investigated and Van der Merwe (1999) found a high prevalence of both biological and environmental risk factors in the subjects. The combination of biological and environmental risk factors evidenced in the subjects corresponds with the leading causes of infant deaths in South Africa (See Chapter 3, Tables 3.2 and 3.3). The results therefore confirm that infants with low birth weight and prematurity and living in poverty constitute the major population requiring ECI services in South Africa.

The two studies cited also demonstrate not only the need for further data collection, but also for a more integrated approach to data collection. The advantages of database technology imply that contributions of various researchers can be entered into a national database, data can be shared and more comprehensive epidemiological data of the different groups of young children requiring ECI can be obtained.

The discussion of the different studies in Table 4.1 also served to illustrate that most important local research has already been initiated and that further development of the field of ECI depends on the continuation of this research.

4.8 CONCLUSION

In order to stimulate ECI research-generating activities and continue with research to accelerate the process of effective service delivery to all young children and their families requiring ECI, a database system can be utilized as a unique research tool to address the needs arising from the local South African context. Based on a research overview and recent technological developments in the field of database design and application for research, the following conclusions are made regarding the relevancy to ECI:

- As families play such a pivotal role in EI (Rossetti, 1993) there is a need to provide comprehensive descriptions of the families representing the different and diverse communities in South Africa. As proposed by Guralnick (1997) in his conceptual model of early development and risk factors, family characteristics to be described must include the personal characteristics of the parents as well as the characteristics not related to the child’s risk status, such as social support, marital relationship and financial resources. This information will assist in the identification of the potential stressors for families, such as information needs, resource needs, confidence threats and interpersonal and family distress created by the child’s risk condition.
- There is a need for epidemiological studies employing large numbers of subjects in order to provide clear profiles of the different populations requiring ECI and to design treatment programmes matching these profiles. This will

contribute to second-generation research issues as the improvement of information gathering can facilitate a process to allow improved individualized interventions for children and families. The ideal is to best match ECI programme features to child and family characteristics and treatment outcomes (Guralnick, 1997).

- The large numbers of subjects required for epidemiological research and the voluminous amounts of data of longitudinal projects necessitate the use of a database system with features similar to those described by García-Sánchez (1999). A database system contributing to the national databank on infants and toddlers at risk for communication delays requires to provide a structure with specific features as described by Sokolov & Snow (1994). These features should provide sufficient flexibility to describe individual clients, yet uniform enough to reveal the unique patterns of characteristics of the different populations of young children and their families requiring ECI in South Africa.

The underpinnings and rationale for a uniquely designed database system as a contemporary ECI research tool meeting the needs of the local South African context have now been provided. The next step is to design such as tool and demonstrate its applicability for data management and research purposes in a specific ECI service delivery context.

4.9 SUMMARY

The chapter’s vantage point relates to the needs of second-generation research in ECI while first-generation research challenges still prevail in South Africa. The use of database technology is proposed as a way to stimulate research generating activities to improve the gathering of information for epidemiological data to better match programme features with child and family characteristics. The features of database systems and their applications as management and research tools in EI are discussed. Examples of database systems in EI research and needs in ECI research in South Africa provide the underpinnings for the development of a database system for the present study.

CHAPTER 5

METHODOLOGY

CHAPTER 5

METHODOLOGY

Aim: The aim of the chapter is to specify and describe the methodology used to design and demonstrate the application of a computer database system as a research tool in an Early Communication Intervention programme.

5.1 INTRODUCTION

The research process, as a structured inquiry aiming to solve problems and creating new knowledge which is generally acceptable (Grinnell, in De Vos, 1998), is supported by well planned scientific methodology to reflect the particular characteristics of the whole research project undertaken (Leedy, 1997). Furthermore, the use of appropriate research methodology is critical to the research process as the quality of research findings is directly dependent on the accountability of the research methodology followed (Mouton & Marais, 1990). The development of discipline specific research methods and theories for the advancement of a scientific field is most important as a discipline may borrow theories and methods from other fields but those materials may not be appropriate to study its subject matter (Hegde, 1987).

The purpose of establishing a customized database system is to develop a unique ECI research tool to store and manipulate data and to extract meaning from it (Leedy, 1997) in order to contribute to the development of appropriate research methodologies in the emerging scientific field of early communication intervention (ECI) in South Africa.

Advances in database systems have opened vast possibilities of database application in different scientific fields, indicating its adaptability as a contemporary research tool suitable to meet the unique requirements of a developing field such as ECI in South Africa. Although the storing and processing of data is not unique to the database approach (Bowers, 1993), technological developments have resulted in improved management of data and greater productivity for the database user (Connolly, *et al*., 1996), which displays the relevancy of the database system approach as a 21st century scientific tool.

In utilizing the advantages of the latest developments in information technology, the current empirical study proposes the use of a research tool which can contribute with increased effectiveness to local ECI research needs. South Africa not only presents with an increased prevalence of infants at biological and environmental risk (CCS, 1997c), but also with a growing population of infants and their families requiring ECI services. One of the recently identified reasons for the growing population of infants at-risk is the rapid spreading of the AIDS epidemic, with increasing numbers of infants born who are HIV positive and often orphaned early in life (Strachan, 1999). It is clear that an urgent need for ECI exists in South Africa as services must be provided to diverse populations of infants and their families.

A description of the unique patterns of characteristics of the different populations of infants and their families requiring ECI services in South Africa can therefore provide valuable information regarding the planning of service provision to the diverse populations to be included in a comprehensive service delivery plan. Although ECI is established and practiced in the private sector (Haasbroek, 1999) and ECI services are emerging in the public sector (Moodley, 1999), these services are fragmented and not yet sufficient to provide in the needs of the growing population of infants and families requiring ECI services. Despite the lack of a national policy on ECI, it is, however, an opportune time to promote the development of ECI services in South Africa as the government already recognizes maternal and child health, women's health and primary health care as priority issues in the implementation of its national health policy (Department of Health, 1997). The identification of vulnerable groups in society is therefore already an important step towards the promotion of ECI services as part of the comprehensive *National Health Plan for South Africa* (ANC, 1994b).

Although ECI is still an emerging scientific field in South Africa and service delivery must yet be established in all contexts, it is clear that recent ECI research in South Africa is exploring new directions in the development of field specific scientific methods and theories. Recent ECI research projects already offer creative and innovative solutions to extend appropriate ECI services to more infants and their families and provide valuable insights into second generation early intervention (EI) research issues (Guralnick, 1997).

Delport (1998) and Moodley (1999) found that collaborative team efforts and transdisciplinary training programmes with nurses in primary health care provide a model for raising awareness about risk conditions in infants and for the earlier identification of infants at risk for communication delays. Hansen (1999) provides guidelines for developing a culturally sensitive ECI programme which proved to be effective in rendering services to a Xhosa speaking toddler with a hearing loss and his caregiver.

These three studies explored some of the issues proposed by Guralnick (1997) as second-generation EI research concerns. According to Guralnick (1997) the exploration of three elements, namely EI programme features, child and family characteristics and the nature of the outcomes can be used as a model of current research issues in EI. Figure V.I provides a schematic representation of the EI research model proposed by Guralnick (1997) which will be used as a framework for the present study.

Using the three dimensional model (Guralnick, 1997) as a guideline for investigating an ECI programme and as depicted in Figure V.I, research results can be obtained on two different levels. Firstly, as represented by the plus sign (+) in Figure V.I, the relevant features of each of the three elements of ECI can be identified and described. Secondly, interactions which are possible between the different elements can be determined as represented by the arrows in Figure V.I. Although the arrows in Figure V.I appear to indicate only uni-directional relationships, there are different possibilities for determining relationships between the different ECI elements as positive and negative relationships can be determined (De Vos, 1998). The value of an investigation into an existing ECI programme in South Africa, is to provide a critical review of the programme features, the characteristics of the clients and the nature of the outcomes when longitudinal research is conducted, and to indicate how the different elements of the programme relate to one another. The results of the investigation can be applied to provide guidelines for improved service delivery of the specific ECI programme and appropriate service delivery in other contexts.

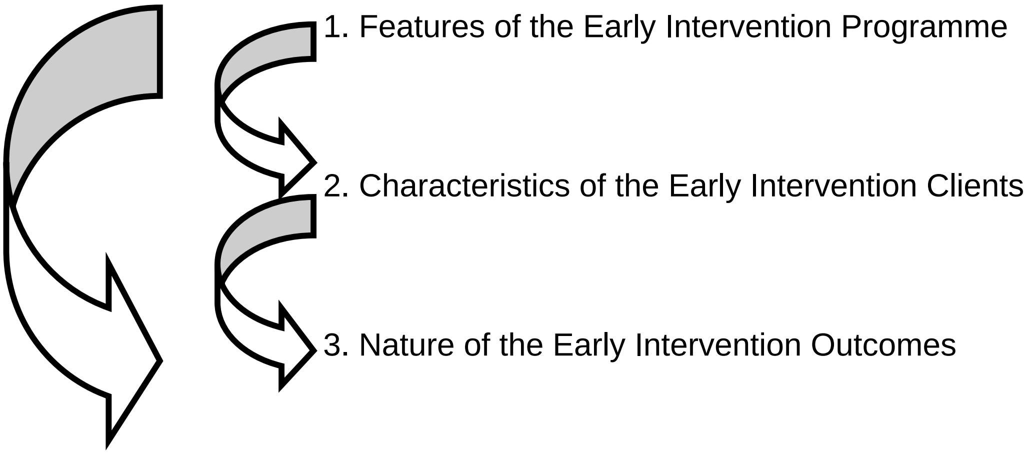


Figure V.I Schematic representation of the research methodology of the present study (Based on Guralnick, 1997)

All three elements of the EI research model (Guralnick, 1997), but in particular the characteristics of ECI clients, are highly relevant research questions in South Africa. Since there is a dearth of epidemiological data on the specific characteristics of families and their infants and toddlers requiring ECI in South Africa, a specially designed research tool is required to accommodate the large numbers of subjects required for an epidemiological study. Such a research tool must also be comprehensive enough not only to describe client characteristics, but also to identify the features of the programme and determine the programme outcomes when utilized in longitudinal research. Lastly, the research tool must be sophisticated enough not only to present results as isolated characteristics, but to collect data in such a way that relationships between the different elements of the programme can be indicated by performing statistical analysis tests.

The present study proposes to use the EI research model of Guralnick (1997) as a framework to develop a research tool uniquely designed to describe the features, clients and outcomes of a specific ECI programme and indicate the interactions among the different elements. The intended research tool must be able store large volumes of data prospectively in order to provide a comprehensive profile of the clients receiving services in a specific ECI programme and thereby establishing the same research tool for further and longitudinal research purposes in order to determine the outcomes of the ECI programme.

As database systems have been established as effective data management tools with research applications in the field of EI (Hebbeler, 1993), the utilization of a custom-designed research database is considered to be an appropriate scientific tool to be used in the methodology of the present study.

The aim of the chapter is therefore to describe the methodology employed to design and utilize a database system for the data management and research requirements of a specific ECI programme in South Africa.

5.2 AIMS OF THE STUDY

The overall *objective* of the study is to establish a database approach to collect comprehensive data on a group of infants and toddlers with communication disorders and at risk for communication delays and their families participating in an university-based ECI programme in order to describe the features of the programme, the characteristics of the clients, indicate possible interactions between the different ECI elements and to determine the nature of the ECI programme outcomes when future research is conducted.

In order to realize this objective, two main aims were formulated.

5.2.1 First Main Aim

The first main aim of the study is to *design a relational database system* which complies with the data management and research needs of a specific ECI programme in order to describe the features of the programme, the characteristics of the infants and toddlers with communication disorders and at risk for communication delays and their families participating in the programme and the nature of the programme outcomes.

In order to achieve the first aim the following sub-aims were formulated:

- To determine the essential components and functions of the proposed database system by describing the features of a specific ECI programme, namely the Clinic for High Risk Babies (CHRIB). In order to identify the specific needs for an electronic storage medium to be used for research purposes, the assessment approach, procedures and the existing conventional CHRIB filing system will be analyzed.
- To design and construct a relational database system by enlisting the help of a database system developer.
- To develop proficiency in operating the database system for the accurate entry of data, manipulation of data such as creating queries and reports and utilizing a reliable backup system to ensure the security of the data collected.

5.2.2 Second Main Aim

The second main aim is *to demonstrate the use the database system* as a research tool by presenting a multifaceted profile of a group of infants and toddlers at risk for communication delays and their families who participate in an ECI programme at the university-based CHRIB. The results of the application of the research tool will be used to determine the ECI clients' service delivery needs and propose a conceptual framework for effective service delivery approaches and further ECI research in South Africa.

In order to achieve the second main aim the following sub-aims were formulated:

- To collect and enter the data of a group of clients participating in the CHRIB ECI programme into the database system to provide quantitative and qualitative data regarding their biographical details, family circumstances, prenatal, perinatal and later developmental histories and diagnoses and/or risk conditions for communication delay.
- To utilize the database data as a front end for the *SAS*® (1999) (Statistical Analysis System) computer package to perform a scenario analysis of the data to provide descriptive statistics of the incidence, frequency and distributions of certain characteristics of the subjects, their families, risk conditions and developmental histories.
- To interpret the results of the study within the framework of available epidemiological and descriptive data on infant populations at risk for communication delays in South Africa and to provide a conceptual framework for appropriate local service delivery.
- To determine the viability of the CHRIB database system for future epidemiological research involving larger numbers of subjects.

5.3 RESEARCH DESIGN

According to Mouton and Marais (1990) the research design of a given study provides the plan of how the research problem was executed. The research design assists the researcher in adopting a critical orientation to the systematic planning of the empirical study and the rational decision making of the research process. The aim of the research design is therefore to “plan, structure and execute the project concerned in such a way that the validity of the findings are maximized” (Mouton & Marais, 1990:193).

The research design selected for the present study is a quantitative descriptive survey which represents one of the categories of non-experimental research (Leedy, 1997). The nature of a quantitative descriptive survey is to observe and systematically record behaviours essentially in the form of discrete data and to study group differences, developmental trends and relationships among variables (Leedy, 1997; Pannbacker & Middleton, 1994). Since the aim of the empirical research of the present study is to conduct a structured and an in depth inquiry into the characteristics of the clients enrolled in a particular ECI programme, the descriptive survey design appears to be the most suitable scientific approach to explore and demonstrate the research possibilities of the relational database system which were utilized as a research tool.

The suitability of the descriptive design approach selected for the present study is further elucidated by the methodology employed for collecting and entering the data into the database system. The method of data recording in the present study was largely dependent on systematic and structured observations derived from four sources, namely:

- A questionnaire completed by the parents prior to the assessment
- An interview with the parents
- The assessment of the infant
- Medical reports on the client, when available

While some data was obtained by way of information provided by the subjects' parents and medical reports, the other data such as assessment results were derived by means of direct elicitations and observations of communication behaviours of the subjects without any attempt to control or manipulate the events or variables. Since no variables were manipulated to test cause and effect hypotheses as in true experimental designs, the ultimate research question to be answered in a descriptive study is a relationship question.

To determine possible relationships between variables, such as relationships between the different characteristics of the subjects was, however, beyond the scope of the present study. Using Figure V.I as a guideline, results were analyzed and interpreted on the first level of descriptive research methodology only, as both an in-depth and a broad description of ECI client characteristics was presented. The descriptive research design therefore provided the researcher with an accountable methodology to move closer toward a “thick description” of infants and their families (Hammer, 1998) requiring services in a particular ECI programme. The further advantage of a descriptive survey design for the present study is that the same data can later be used to present the results on a second level of analysis by determining degrees and direction of relationships between the different variables (See Figure V.I). Such an analysis of the data implies that the measuring of one variable predicts the measuring of a second variable, either in a positive or a negative way. A descriptive survey research design therefore allows the description and prediction of phenomena but no causal explanations can be constructed (De Vos, 1998; Leedy, 1997; Maxwell & Satake, 1997).

According to Leedy (1997) the data in a descriptive survey is particularly susceptible to distortion due to bias. Bias relates to any influence that may have disturbed the randomness by which the selection of a sample population has been determined. This implies that careful consideration should be given to the type, methods and procedures of sampling. Since the present study employed subjects from a particular ECI programme and no random selection procedures were adhered to, the results cannot be generalized and applied to a wider population of infants and families requiring ECI in South Africa.

The use of a descriptive design therefore provided an appropriate research plan for rational decision-making to execute the present study, which aimed to employ database methodology to develop a discipline-specific contemporary ECI research tool.

5.4 SUBJECTS

The subjects employed in the study were infants and toddlers and their families referred to and assessed at CHRIB, an ECI service delivery and student training facility. CHRIB has been operating at the Department of Communication Pathology, University of Pretoria, as a formal assessment and treatment clinic since 1990 (Annual Report 1990, Department of Speech Pathology and Audiology) and now forms part of the Centre for Early Intervention in Communication Pathology. The clinic was established to accommodate referrals of infants and toddlers at risk for communication delays and to provide a basis for undergraduate training in ECI as well as research, an initiative started by individual members of staff since the late 1970's.

The client population of infants and toddlers assessed at CHRIB is varied and depends on the referral sources. Families with infants and toddlers at risk for communication delays are referred to CHRIB by one of the following referral sources, i.e., the Facial Deformities Clinic (Department of Oral Facial Maxillo Surgery, University of Pretoria), The Down Syndrome Association, speech-language therapists referring clients to CHRIB for consultative services, occupational therapists, physiotherapists, paediatricians, child psychiatrists, nurses, other parents who previously had their young children assessed at CHRIB and self referrals (Annual Reports, Department of Communication Pathology, 1996-1999).

Since no attempt was made to include each subgroup of the population of high risk infants and toddlers in South Africa in the selection of subjects, the method of nonprobability convenience sampling was utilized (Leedy, 1997). Bias could therefore not be controlled in sampling and the subjects will not be representative of the population requiring ECI services in South Africa. The subject characteristics in the present study will indicate a bias toward families who can afford to pay for services as CHRIB is university-based and not supported by the public health system as in the case of EI clinics based at public hospitals and primary health care clinics.

5.4.1 Selection Criteria of Subjects

In order to operationalize the second main aim of the study, i.e. to demonstrate the use of the database system as an appropriate tool for continued research in ECI, the following two criteria for the selection of the subjects were applied:

- The subjects had to be assessed in CHRIB and had to have undergone the complete CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) as described in under heading 5.5 of this chapter.
- Each subject had to be assessed by at least three of the four data collectors described in Table 5.5 in order to ensure consistent data collection and recording procedures.

By applying the least restrictive subject selection criteria, it could be ensured that the largest possible number of subjects could be recruited within the time constraints of the empirical study. Since it is one of the main features of database systems to store large volumes of data on large numbers of subjects, the real value of this feature of the CHRIB database will only become apparent in the future. By utilizing the largest possible number of subjects in the present empirical study, some of the benefits of the capacity of the database could already be demonstrated.

Therefore, all infants and toddlers, together with their families, who were assessed at CHRIB between March 1996 (the starting date of the CHRIB database) and October 1999 were recruited as subjects for the empirical study.

5.4.2 Selection Procedures of Subjects

The following procedures were followed in the selection of the subjects:

Since the CHRIB database was designed to serve a dual purpose, i.e. to be used as an information management system as well as a tool for research, data on all clients assessed at CHRIB was entered into the database.

Permission to use the data for research purposes was obtained prior to the assessment. As all families with infants or toddlers referred to and assessed at CHRIB received a letter to request that the data be used for research purposes (See Appendix A), all clients were regarded as potential subjects in the empirical study.

5.4.3 Description of Subjects

As the aim of the study is to demonstrate the value of the CHRIB database system in providing a comprehensive profile of the subjects and their families, a description of their characteristics is an integral part of the results of the study and will be discussed in the following chapter. An abbreviated description of the characteristics of the subjects is presented in Table 5.1 (See following page for clarification).

As indicated in Table 5.1 a total number of 153 subjects were utilized in the empirical study, the product of a three and a half year old database system.

According to Table 5.1 the ages of the subjects at their first assessment at CHRIB indicate a broad age spectrum, ranging from the neonatal period to 6 years 5 months. The average age of 18 months indicates that the majority of subjects were assessed at CHRIB at an early age, thereby confirming its function as an ECI service provider. The high upper margin of subjects’ ages suggests that CHRIB received late referrals, which should be expected in a context such as South Africa where ECI is still a largely unknown field (See Figure I.I, Chapter 1). The phenomena of late identification and late referrals of children at risk for developmental delays are some of the reasons why early interventionists in South Africa are beginning to view the entire period of the preschool years as the responsibility of EI (Centre for Augmentative and Alternative Communication, 2000).

Table 5.1 Summarized description of subject characteristics (N=153)

Characteristic	Category	# Subjects or value	%
1. Age at the time of CHRIB assessment and data collection	-Range -Average age	3 weeks – 77months 18.04 months	- -
2. Main diagnostic categories of the subjects	-Cleft lip and palate	79	51%
	-Down syndrome	23	15%
	-Other established risk conditions*	8	5%
	-Autism/Pervasive developmental disorder	4	3%
	-Subjects from multiple pregnancies	15	10%
	-Low birth weight and prematurity	10	7%
	-Delayed speech and language development only	11	7%
	-Tongue tie only	1	1%
	-Hyperactivity	2	1%
3. Gender	-Female	71	46%
	-Male	82	53%
4. First language	-Afrikaans	101	66%
	-English	41	26%
	-Portuguese	4	2%
	-Northern Sotho	3	2%
	-Zulu	1	1%
	-Swazi	1	1%
	-Urdu	1	1%
	-Turkish	1	1%
5. Geographical location	-Pretoria Region	86	56%
	-Gauteng excluding Pretoria	40	26%
	-Northern Province & Mpumalanga	9	6%
	-North West Province	5	4%
	-KwaZulu Natal	4	3%
	-Free State	4	3%
	-Zimbabwe	1	1%
	-Turkey	1	1%
6. Population group	-White	135	88%
	-Coloured	7	5%
	-Indian	6	4%
	-African	5	3%

* See Chapter 6 for details

The main diagnostic categories of the subjects depicted in Table 5.1 indicate that slightly more than half of the subjects (51%) presented with cleft lip and palate, an established risk condition for communication delay. The large number of subjects with cleft lip and palate can be explained by referrals received from another university-based clinic, the Facial Deformities Clinic at the Department of Oral Facial Maxillo Surgery.

The following three diagnostic categories listed in Table 5.1 also relate to subjects with established risk conditions, namely Down syndrome, autism/pervasive developmental disorder (PDD) and other categories of established risk conditions for communication delay as described by Rossetti (1996). A total of 74% subjects therefore displayed *established risk* conditions for communication delay. The remainder of the subjects represents *biological risk* categories, such as children with low birth weight and prematurity and children from multiple pregnancies and children with diagnostic categories associated with communication delay in the absence of the established and biological risk categories already mentioned. The distribution of the risk categories of the subjects indicates that most of the subjects were selected from the population of infants and toddlers with confirmed risk conditions which will always result in some form of communication delay. Since established risk conditions are easier to identify as a result of the visibility of the disorder (Rossetti, 1996), it offers an explanation to the increased referral of subjects from this risk category to CHRIB. The diagnostic categories of the subjects utilized in the empirical study therefore represent a different sample as statistics suggest most of the young children requiring ECI in South Africa present with low birth weight and prematurity and are from families living in poverty (CSS, 1997c).

According to Table 5.1 the subjects' gender distribution of more males than females is a phenomenon also reported in the literature. According to Lahey (1988) studies found that there is a larger proportion of boys in comparison with girls displaying communication delay.

As depicted in Table 5.1 the subjects represent a wide spectrum of eight different languages. The majority, i.e., two thirds of the subjects' first language was Afrikaans, 26% of the subjects were English speaking and the remainder of the subjects (8%) represented the other six languages listed in Table 5.1. The increased number of subjects from Afrikaans speaking families can be attributed to the fact that 56% of the subjects were from the Pretoria region, an area where the majority of people speak Afrikaans as a first language. According to Ngwezi (1999) statistics released by Statistics South Africa indicate that 4.2 million people speak Afrikaans as a first language, followed by 2.6 million Sepedi and 1.1 million English speakers in the greater Pretoria region. Another factor explaining the Afrikaans language bias in the subjects is the fact that the University of Pretoria is mainly an Afrikaans institution. Even though the subjects spoke different first languages, most of them could communicate effectively in either Afrikaans or English and only in certain instances an interpreter was utilized to communicate with the family.

As stated earlier and indicated in Table 5.1 slightly more than half of the subjects (56%) live in the Pretoria region and that the remainder of the subjects came from Gauteng province, of which Pretoria is part, and five other provinces in South Africa. Two of the subjects are from countries with no ECI facilities at this stage, i.e. the neighbouring Zimbabwe, and Turkey, on another continent. It is clear that CHRIB provides much needed ECI services to families as the subjects reside in Pretoria and various parts in South Africa as well as from other countries. Since a substantial proportion of the subjects (44%) resides in areas outside the Pretoria region, it appears that the subjects' families had sufficient transport available to them to attend the ECI facility.

Lastly, the characteristics of the subjects utilized in the empirical study are described according to the different population groups as used by the Central Statistical Services (CSS, 1997b) and depicted in Table 5.1. By far the majority the subjects are from white families (88%) and 12% of the subjects are from coloured, Indian and African families. Since the majority of subjects are from white families, it is clear that the specific ECI service delivery programme described in the empirical study meets the needs of a specific culture not representative of the South African population.

In summary the subjects of the empirical study represent a unique sample of young children requiring ECI in South Africa. The characteristics of the sample indicate a wide spectrum of different ages, languages and geographical localities, but with more consistent features relating to the diagnostic categories and the population group they represent.

5.5 MATERIALS AND APPARATUS

The materials used in the empirical study were the CHRIB Case History Form (Louw & Kritzinger, 1995a) (See Appendix B), the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) (See Appendix C) and the CHRIB database system, modelled on these assessment materials.

5.5.1 Assessment Materials

A comprehensive assessment protocol for infants and toddlers at risk for communication delays was developed in CHRIB to meet the needs of the clients and their families. Principles of best practice regarding the assessment approach, assessment materials, parental involvement and teamwork as described in ECI literature were considered (Billeaud, 1998; Rossetti, 1996; Prizant & Wetherby, 1995).

Different sources were used to obtain reliable examples of communicative behaviours to evaluate the infant or toddler's development (Rossetti, 1990a; Ballard, 1991). The first source was the CHRIB Case History Form (Louw & Kritzinger, 1995a), a questionnaire sent to the parents and completed prior to the assessment.

5.5.1.1 CHRIB Case History Form (Louw & Kritzinger, 1995a)

The CHRIB Case History Form (Louw & Kritzinger, 1995a) (See Appendix B) consists of 5 sections with open-ended questions, requiring short descriptive responses, closed questions and dichotomous questions requiring Yes/No answers.

Careful consideration was taken to ensure that the questions were formulated clearly and not open to misinterpretation (Nichols, 1991). Different types of questions were used as different types of information were collected from the subjects' parents. Factual information was collected in the form of discrete data by posing closed questions which offers a few response choices from a list of options and dichotomous questions with only two response possibilities (Leedy, 1997; Nichols, 1991). Closed questions are preferable in questionnaires as the responses are suitable for data entry into a database and statistical processing by computer (De Vos, 1998). In contrast with closed questions, open questions have to be processed manually, but were necessary as some data collected from the subjects' parents had too many response options to classify meaningfully. Open questions were therefore used to a limited extent as many open questions lengthen the time of completion and the parents may be tempted to omit some questions which will decrease the value of the data obtained from the questionnaire (De Vos, 1998).

The features CHRIB Case History Form (Louw & Kritzinger, 1995a) can be described as follows:

The questionnaire starts with a section on general biographical information and parents are requested to supply the child's name, date of birth, the family's address and contact numbers. Thereafter details about the referring person and other professionals who have been consulted regarding the child's condition, are requested. The following questions relate to the family and personal information about the parents. The last part of Section 1 requires short descriptive responses on when the child's problem was first noticed, the child's medical diagnosis if applicable, the course of treatment to date, related problems and hereditary conditions in the family, the child's daycare and the family's home language.

The next section, Section 2, contains 19 factual questions regarding the pregnancy and birth history. Brief descriptive responses are requested in order to identify prenatal risk factors which could have contributed to perinatal conditions experienced by the infant, which in turn, could have contributed to the child's current condition. In this way the cumulative nature of the different risk conditions can be identified, resulting in determining unique patterns of risks for each child. This can lead to a better understanding of the reciprocal influences between the particular infant and the environment over time as described by Samerhoff (1975, in Rossetti, 1990a) when proposing the transactional model of causation in developmental disorders. The CHRIB Case History Form (Louw & Kritzinger, 1995a) was therefore constructed to include the concept of continuum of risk which implies that the origins of school failure can begin very early in a child's life (Rossetti, 1996).

Section 3 relates to the child's postnatal medical history and obtains information regarding illnesses, surgeries, hospitalizations and medications.

The remainder of the questionnaire, Section 4, relates to the child's developmental history. Parents are requested to provide age levels for the attainment of developmental milestones, closed choice questions are asked about feeding skills and hearing abilities and a descriptive response is required regarding middle ear problems experienced by the child. A list of dichotomous questions, requiring Yes/No responses, were compiled to obtain the parents' views regarding the child's interaction skills, communication development, language comprehension, speech and expressive language development.

The last four questions in the questionnaire deviate from the factual nature of the previous questions. Parents are requested to express their concerns about the child's speech-language development and hearing abilities, to describe their efforts to help the child thus far and state their expectations of the assessment.

The nature of the information obtained from the parents in the questionnaire is therefore factual data as well as perceptions, providing the assessment team with information regarding the parents' knowledge of and attitudes regarding their child's condition. According to Girolametto, Weitzman & Clements-Baartman (1998) and Rossetti (1998), it is now generally accepted that parents are reliable sources of information about their children, although they may lack the specialized knowledge to interpret the information correctly. By obtaining parents' opinions about their children's conditions, a family-centered approach to data collection could be achieved.

It is clear that the CHRIB assessment does not only involve parents as providers of information regarding their child, but also values their opinions. During the interview on the day of the assessment the parents are afforded a further opportunity to express their views, enabling the ECI team members to identify family strengths and needs and involve them in decision making about their child.

The next source utilized to obtain examples of the child's communicative behaviour is the CHRIB assessment itself.

5.5.1.2 CHRIB Assessment Protocol (Louw & Kritzinger, 1995b)

The CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) (See Appendix C) was developed to provide the child with opportunities to display a variety of spontaneous and elicited communicative behaviours which were interpreted by utilizing developmental criteria, a variety of developmental scales and three norm-referenced measurements. The CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) is based on the Stage Process Model of Early Development and adapted from the Holistic Assessment Model for Infants with Cleft Lip and Palate developed by Louw (1986).

Certain principles regarding infant-toddler assessment as outlined by Prizant and Wetherby (1995) were adhered to. Table 5.2 was compiled to provide the complete list of developmental areas with related assessment materials and measurement criteria used in CHRIB and upon which the CHRIB database system was modeled.

According to Table 5.2 a comprehensive communication assessment protocol, covering all developmental areas is utilized in CHRIB. The underlying principle to this integrative approach is that communication development is closely related to all other aspects of development and an assessment protocol should address these relationships (Louw, 1986; Prizant & Wetherby, 1995).

Table 5.2 Communicative Assessment Materials used in CHRIB

Developmental Area	Assessment Material	Measurement Criteria
1. Behaviour, attention, emotional independence and cooperation during the assessment	- Behaviour observation throughout assessment	- Developmental criteria according to age levels (Williamson & Zeitlin, 1990)
2. Hearing sensitivity	- Behaviour Observation Audiometry or - Visual Reinforcement Audiometry or - Play audiometry according to child's developmental age	- Standardized norms according to child's age (Northern & Downs, 1991)
3. Middle ear functioning	- Otoscopic examination - Basic immittance measurements	- Assessment guidelines according to Stach (1998) - Standardized norms established according to age (Silman & Silverman, 1991)
4. Listening skills	- *CHRIB Listening Scale* (Hugo, Louw, Kritzinger & Smit, 2000) - Clinical observations	- Description of listening skills according to a Likert-type Scale - Recording of behaviours
5. General development	- *Developmental Assessment Schema* (*DAS*) (Anderson, Nelson & Fowler, 1978) - *Developmental Activities Screening Inventory* (*DASI II*) (Fewell & Langley, 1984) - Clinical observations	- Developmental criteria according to 3 month age intervals - Standardized norms and computed developmental quotient - Recording of behaviours
6. Play Behaviour	- *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) - Clinical observations	- Developmental criteria according to 3 month age intervals - Recording of behaviours
7. Communication skills (means, turntaking and function)	- *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) - *Expression of Communicative Intent* (Wetherby & Prizant, 1989) - Clinical observations	- Developmental criteria according to 3 month age intervals - Description of communicative behaviours - Recording of behaviours
8. Oral-motor functioning and feeding skills	- *Oral-Motor/Feeding Rating Scale* (Jelm, 1990) - *Developmental Pre-Feeding Checklist* (Morris & Klein, 1987) - Clinical Observations	- Description according to a Likert-type Scale - Developmental criteria according to age levels - Recording of behaviours
9. Genetic anomalies	- *Genetic Screening Checklist* (Kritzinger & Louw, 1998) - Clinical observations	- Listing and description of anomalies - Recording of behaviours
10. Expressive language skills	- Phonetic Inventory - Phonology - Word Type and Syntactical Analysis (Manolson, 1992) - Pragmatics - *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) - *DAS* (Anderson, *et al.,* 1978) - Clinical observations	- Listing of phonemes - Analysis of phonological processes - Categorization of words and analysis of sentences - Recording of pragmatic behaviours - Developmental criteria according to 3 month age intervals - The same as above - Recording of behaviours

Table 5.2 continued

Developmental Area	Assessment Material	Measurement Criteria
11. Receptive language skills	- *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) - *DAS* (Anderson, *et al.,* 1978) - Clinical observations	- Developmental criteria according to 3 month age intervals - The same as above - Recording of behaviours
12. Parent-infant-communication interaction	- *Mother/Infant Communication Screening* (Raack, 1989) - *Observation of Communicative Interaction* (Klein & Briggs, 1987) - Clinical observations	- Description of interaction according to a Likert-type Scale (Both instruments) - Recording of behaviours

Another principle stressed by Prizant and Wetherby (1995) is the notion that communication is a social activity and occurs in almost all situations the infant or toddler encounters and that assessment information must be collected over time. The different developmental areas listed in Table 5.2 allow the assessment of communicative behaviours in at least three different contexts, i.e. two play-based situations, one with the data collector and one with the parents, as well as the hearing-testing situation conducted in a different room.

The CHRIB assessment is considered as the first of regular serial assessments carried out during the period the infant or toddler receives ECI (Rossetti, 1996). The CHRIB database system was specifically designed to allow multiple entries of data for one client in order to accommodate the periodic serial assessments and provide the opportunity for longitudinal research. This implies that data can be recorded from subjects at numerous times over several years (Leedy, 1997) as the research tool developed by García-Sánchez as the *Individual Following Record to Early Intervention* (García-Sánchez, 1998).

When studying Table 5.2 it is clear that the different assessment materials require a number of assessment strategies to be used for collecting the data. According to Prizant and Wetherby (1995) reliability of assessment findings can be increased when similar patterns of communication are observed across different contexts and when different assessment strategies are employed.

The guidelines for the administration of *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) require that samples of communicative behaviours are collected using three strategies, namely parental report, direct observation and elicitation of behaviour in a play-based context. As this specific instrument is widely used in ECI research (Rossetti, 1998) these guidelines were followed in collecting all the data on the subjects' communication behaviours. Careful consideration was given not to compromise the integrity of the research process and to ensure the reliability and validity of the different measuring instruments used in the data collection (De Vos, 1998). Research conducted by Calhoon (1997) indicates that the play-based assessment procedures recommended by *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) provide a broader picture of the child's emerging communication skills than when norm-referenced standardized measuring instruments are used. Calhoon (1997) concluded that preliminary results indicated that *The Rossetti Infant-Toddler Language Scale* (Rossetti, 1990b) has face validity as it accurately measures the communication skills under consideration and that it appears to be a relevant measure of these particular communication skills.

As infant and toddler communicative behaviours are often subtle non-verbal signals, short in duration and often not repeated (Owens, 1989), a video recording is used as a strategy to ensure that important data are not missed and to validate observed behaviours.

Guidelines proposed by most leading authorities on infant-toddler assessment and followed in CHRIB, recommend the measurement of the child's communication functioning in terms of developmental criteria instead of measuring the child against the norms set by typically developing children (Billeaud, 1998; Rossetti, 1998). Table 5.2 indicates that criterion-referenced assessment instruments are mostly used as part of the CHRIB assessment protocol as these instruments provide the most useful intervention guidelines.

The use of norm-referenced instruments is limited to the *DASI II* (Fewell & Langley, 1984) and the two hearing tests. The results of the hearing tests were interpreted according to the norms for auditory stimuli and levels of response as described in the Auditory Behaviour Index for Infants (Northern & Downs, 1991).

According to Table 5.2 most assessment instruments are domain-specific, with the *DAS* (Anderson, *et al*., 1978) as the only global assessment scale. This implies that unnecessary repetition of test items is prevented as domain-specific instruments allow in-depth assessment of all the different facets of infant-toddler communication development and reflects the synergistic nature of early development (Louw, 1986; Owens, 1989).

In order to obtain the relevant assessment information a team of four early interventionists is involved in the CHRIB assessment. Two of the team members are specialists in early communication intervention and the other two members are specialized in pediatric audiology. Apart from the professionals eliciting communication behaviours from the infant or toddler, parents are also requested to elicit communicative behaviours from their child.

As indicated in Table 5.12 two scales are used to rate the parents' interaction with their child. This feature of the CHRIB assessment both adds to the parent's active involvement and provides a more familiar context for the child to express communicative behaviours (Prizant & Wetherby, 1995).

The CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) provides an in depth description of a wide range of developmental areas related to early communication development which can immediately be translated into intervention goals and strategies as components of an individualized ECI programme. The information obtained from the CHRIB Case History Form (Louw & Kritzinger, 1995a) and the subsequent information gained from the parent interview and the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b), provide shared information between the professionals and the family to jointly decide on courses of action to be taken.

All information obtained from the CHRIB assessment is documented and stored in separate files for each client and becomes part of the departmental filing system kept in a filing room which can be accessed by members of staff and students. The format of the CHRIB information storage system is therefore as efficient and as secure as a conventional filing system will permit, but does not afford the clinic with the advantages which database technology can offer (Bowers, 1993).

According to Connolly, *et al.* (1996) the disadvantages of laborious data retrieval from a conventional paper-based information storage system can be overcome by a computer database system which can efficiently manage large volumes of information for the benefit of administration and research purposes (Connolly, *et al*., 1996). While paper-based record systems will always be necessary, a clinic such as CHRIB can become competitive in research output as the data, additionally stored in a computer database system, can be retrieved and manipulated at a greater speed and with much more sophistication. The links already established between the different files in a database system are an inherent feature of a relational based database which demonstrates its indisputable advantage over a paper-based filing system (Bowers, 1993).

The preceding analysis and discussion of the CHRIB assessment and filing system provides a framework of the special features required by a customized CHRIB database system to be used in the current study.

5.5.2 Features of the CHRIB Database System

The database designed for the current study is a *Microsoft® Access* (Aitken, *et al.*, 1997) relational database management system, structured according to the fifth normal form, then denormalized according to practical needs.

According to Connolly, *et al*. (1996) the relational model is based on the mathematical concept of a relation, which is physically represented as a table with columns and rows. This implies that data is structured in certain relationships and accurate representation of the data, its relationships and constraints, is required when a database is designed for a relational system. The technique used to produce a suitable set of relations for a specific database system is known as normalization. Normalization is performed as a series of tests on a relation to determine whether it satisfies or violates the requirements of a given normal form. Three normal forms were originally proposed and two higher forms, the fourth (4NF) and fifth (5NF) normal forms, are now used to deal with practical situations relating to the specific nature of a database to be designed (Connolly, *et al*., 1996).

The relational based data management system is based on an advanced data structure design and has the additional benefit of allowing logical and mathematical operations to be done on an entire file and can create new sets of data out of combinations of existing records (Aitken, *et al*., 1997; Schrodt, 1987).

The CHRIB database is Windows® based, i.e., a graphical user interface system which is client centered, function orientated and allows uncomplicated implementation. *Microsoft® Access* is a relational database programme which meets the requirements of the current study and was employed to design the customized database.

The special operating features of the customized CHRIB database system are in logical order described by Aitken, *et al*. (1997) as follows:

- The data entering level is completely mouse-driven and does not require program coding.
- A special feature of the database is the dynamic look-up tables, which implies that categories to be added to pick lists do not first need editing.
- The database files contain all information created for the database, i.e. the data, customized forms, reports and indexes.
- All data is entered into the database by means of special on-screen forms and stored in tables. A single form can be used to enter data into several tables concurrently.

Tables are the central focus of a database and the CHRIB database consists of 16 different tables as described in Table 5.3.

Table 5. 3 List of tables, their descriptions and types of data entered in the CHRIB Database

Table	Description	Types of Data (Maxwell & Satake, 1997)
1. Client	ID number, biographical data, antenatal and perinatal history, postnatal development	- Numerical and text data
2. Parentship	Data on mother, father and family	- Numerical and text data
3. Persons involved	Professionals consulted relating to the child's problem	- Text data
4. Referring persons	Data on person or professional who referred the family to CHRIB	- Text data
5. Persons	Name, address and contact numbers of persons involved in Nr3 and Nr4	- Numerical and text data
6. Diagnosis	Client's diagnosed condition according to the *ICD-10 International Statistical Classification of Diseases and related Health Problems* (CSS, 1996)	- Numerical and text data
7. Language	Family's home language	- Text data
8. General illnesses	History of client's past illnesses and hospitalizations	- Text data
9. Surgery	History of surgeries performed on client	- Numerical and text data
10. Medication	List of medications used by client, especially ototoxic medications	- Text data
11. Viral infections	List of viral infections contracted by mother during her pregnancy with client	- Text data
12. Perinatal	List of perinatal conditions of the client	- Text data
13. Assessments Main	Assessment data relating to client's hearing abilities, general development, cognitive development, play behaviour, receptive and expressive language development	- Text and interval data (age intervals)
14. Assessment Main 2	Assessment data relating to the client's language use, genetic anomalies and feeding skills	- Text and interval data (age intervals)
15. Parent-child-interaction	Assessment data on parent-child-communication interaction	- Numerical data
16. Memos	Descriptive data on each of the assessment areas	- Text data (longer descriptions)

- Table 5.3 describes each table and indicates which types of data were entered in the CHRIB database. The tables were labeled in abbreviated format on the Main Form as Client, Parentship, Persons involved, Referring persons, Persons, Diagnosis, Language, General illnesses, Surgery, Medication, Viral infections, Perinatal, Assessments, Assessment on the Main Form 2, Parent-child-interaction and Memos. The contents of the CHRIB Database were based on the main features of the CHRIB Case History Form (Louw & Kritzinger, 1995a) and the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b), but do not contain all the detailed information from the two sources as it would have become too time consuming and impractical to enter each subject's data. The structure of each table of the CHRIB database is outlined in Appendix D.

- The CHRIB database allows damage control in the form of automatic corrections and question and answer possibilities.
- Links were created to indicate the relationships between the 16 different tables. Figure IV.II represents the printed format of the CHRIB database illustrating the relationships between the different tables.
- Each of the tables has rows and columns, containing all the data in the database, but excluding the rules, relationships and programming.
- Each database entry is stored in its own row and is referred to as a record. This implies that each client's data is stored in a different row and the number of rows therefore represents the total number of clients in the Main Table of the database.
- The columns are the collections of all discrete values of each *field*, representing all the different categories of data collected, e.g. the client's name is contained in one field and the client's address in another. All the client addresses in the entire table are collectively known as the client address field. At the intersection of a field and a row is the individual bit of data for that particular record, known as a *cell*.
- Forms are used to enable end-users to enter data in an intuitive way, while guiding the data entry and validating the values entered. Reports are designed to be printed. Reports are therefore specially formatted collections of data, organized according to the user's specifications. The ability to extract and present data in coherent report format depends on the type of queries the database operator is able to generate.

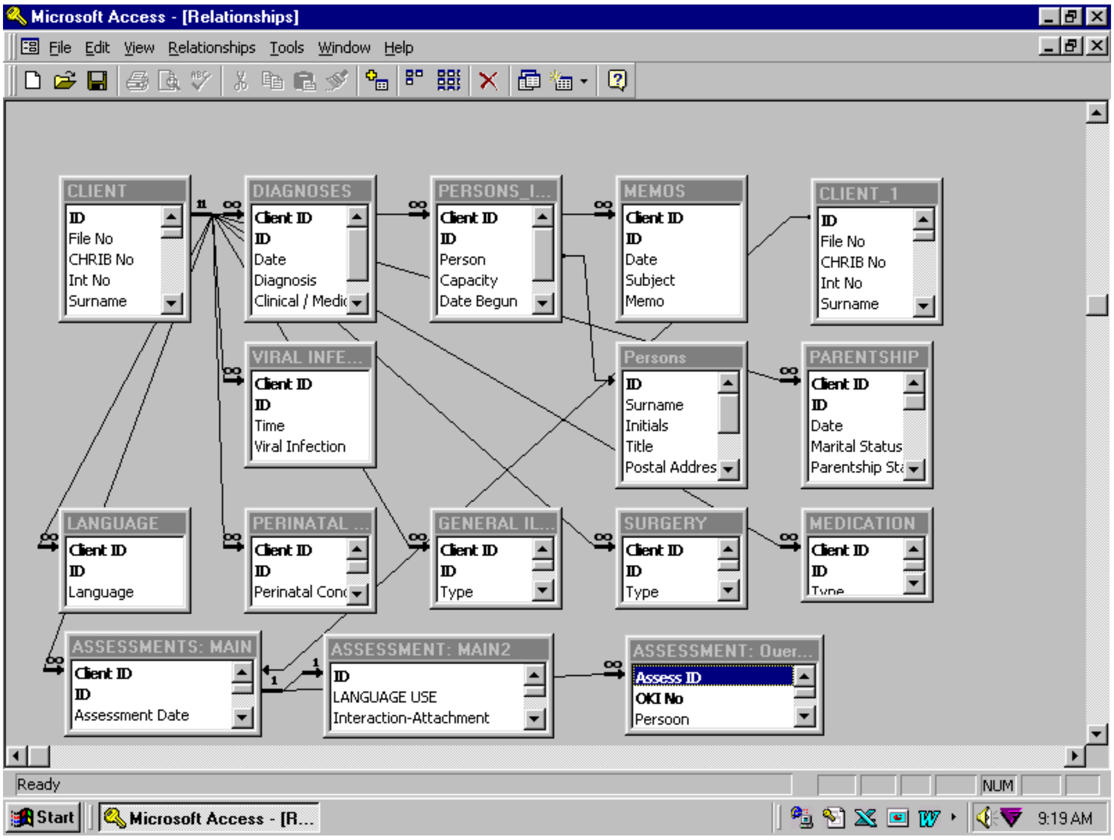
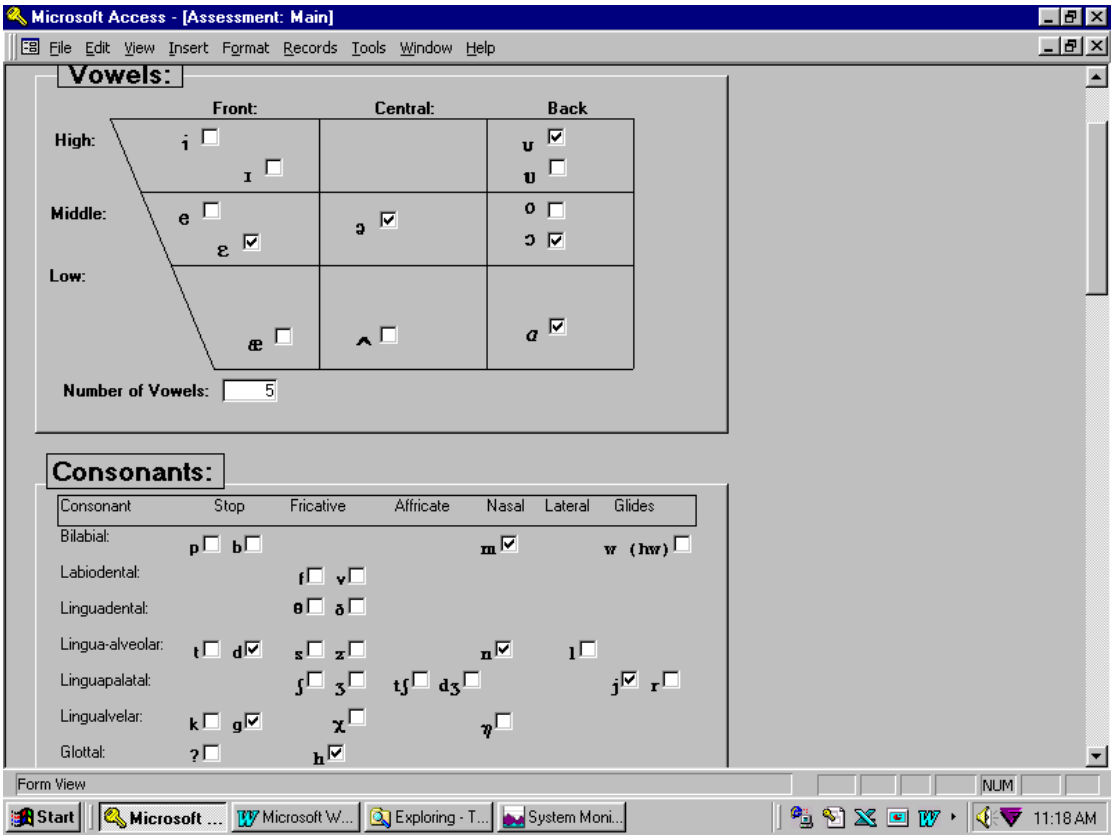


Figure V.II **Print out of relationships between the tables of the CHRIB Database**

- Queries are formal ways to sort and filter the data and enable the operator to specify the fields, their order, the filter criteria for each field and the order in which each field has to be sorted and appear in a report, unique or summarized. Simple as well as advanced data reporting are functions of sorting and filtering.
- Hyperlinks can be assigned between objects on forms or reports. (An object represents any control such as a field name or title). This implies that a report in *Microsoft® Access* format can be saved in *Microsoft® Word* format and hyperlinks will be activated when the document is opened in *Microsoft® Word.* By means of embedding a copy of an object can be inserted into another file while maintaining a link to the source file.
- By means of corresponding fields two database tables can be linked to one another, releasing large amounts of data for research purposes within a very short time.



Vowels:

	Front:	Central:	Back
High:	i ☐ ɪ ☐		u ☑ ʊ ☐
Middle:	e ☐ ɛ ☑	ə ☑	o ☐ ɔ ☑
Low:	æ ☐	ʌ ☐	ɑ ☑

Number of Vowels: 5

Consonants:

Consonant	Stop	Fricative	Affricate	Nasal	Lateral	Glides
Bilabial:	p ☐ b ☐			m ☑		w (hw) ☐
Labiodental:		f ☐ v ☐				
Linguadental:		θ ☐ ð ☐				
Lingua-alveolar:	t ☐ d ☑	s ☐ z ☐		n ☑	l ☐	
Linguapalatal:		ʃ ☐ ʒ ☐	tʃ ☐ dʒ ☐			j ☑ r ☐
Lingualvelar:	k ☐ g ☑	χ ☐		ŋ ☐		
Glottal:	ʔ ☐	h ☑				

Figure V.III Print out of a CHRIB Database form for phonetic inventories of vowels and consonants

- Different front ends can be applied to the same data, opening vast possibilities for data processing and further statistical analysis. The CHRIB *Microsoft® Access* database has data exchange interfaces for software programs such as *Microsoft® Word, Microsoft® Excel, Oracle, SQL Server* and the *SAS®* (1999) computer package and allows data to be accessed in these programs.
- *Microsoft® Access* is a software program with applications on the Internet, a vast collection of connected computer networks. This implies that visitors to a website via an Internet host can read data in the CHRIB database when the data is presented in hypertext markup language (HTML). This application is, however, not yet implemented. In order to be accessible to national and international links, an international alphanumeric code classification system for client diagnoses, the *ICD-10 International*

Statistical Classification of Diseases and related Health Problems (CSS, 1996) was selected in designing the CHRIB database. As the database is centrally controlled, measures can be taken to protect sensitive information such as client names and addresses when linking with the Internet is considered in the future.

The preceding discussion on the structural and operational features of the CHRIB database system served to illustrate its sophisticated design and dynamic potential to store and process data for clinical use and extensive short-term and longitudinal research projects. In order to operate the *Microsoft® Access* database certain conditions for computer hardware and software are required.

5.5.3 Apparatus Requirements

The empirical study required the use apparatus for the design and utilization of the computer database system, recording and processing of the CHRIB assessment and conducting of the hearing testing.

5.5.3.1 Apparatus Requirements for the CHRIB Database System

- The CHRIB database system was installed in an *Intel Pentium Windows®* based system and the following hardware specifications were sufficient to support the software of the CHRIB database system:

  - Intel Pentium II 333 MMX CPU with cooling device, 512 kb Cache
  - PII motherboard, AGP, PCI, ISA, ECP EPP, 2x 16C550, PCI IDE 16 Bit sound
  - 64MB SDRAM 168 pin 8 ns 100 MHz
  - 4.3 GB UDMA 33 hard drive
  - 4 MB AGP Matrox Millenium VGA card, Y2K compliant
  - 36X CD ROM Drive, 160W speakers
  - AT mini tower case

The software package is *Microsoft® Office Professional 97*, made available by the University of Pretoria and operating on *Microsoft® Windows 98*. Authorization to use the *Microsoft® Office Professional 97* software was obtained by purchasing a *Microsoft® Open License* (Licensee reference: BN: 130108).

5.5.3.2 Apparatus Requirements of the CHRIB Assessment Recordings

- A video camera with the following specifications was used to record the CHRIB assessments: *Panasonic R33 VHSc Movie Camera NV* with a *Hi-Fi Stereo* microphone, a 10x wide lens with a power zoom.
- The assessment was recorded through a one-way mirror and an additional public address stereo amplifier (*Weltec Solid-State*) was used to enhance the quality of the sound.
- To ensure that no data is lost an additional audio recording of the interview with the parents was made using a *National Slimline Audio Recorder* Model RQ-2102.

5.5.3.3 Apparatus Requirements for Hearing Testing

- The hearing testing was conducted in a soundproof booth, using a *Welch Allyn GSI 61 Clinical Audiometer* equipped with a Visual Reinforcement Audiometry system. Visual Reinforcement Audiometry was used with children between six months and two years developmental age and the procedures of this technique were followed as described by Northern and Downs (1991).
- The Hear-Kit (Northern & Downs, 1991) with preselected and premeasured toys was used for Behavioural Observation Audiometry with neonates and infants under six months developmental age. The guidelines provided by Northern & Downs (1991) were adhered to when this procedure was carried out.

- A *Grason-Stadler GSI 28A Auto Tymp* was used in the clinical assessment of the middle ear function. The guidelines for basic immittance measurements as described by Stach (1998) were followed.
- A hand-held otoscope was used to for the visual inspection of the ear canal and tympanic membrane prior to the hearing testing procedures (Stach, 1998).

5.6 PROCEDURES

The procedures followed to conduct the empirical research included the design of the CHRIB database system, gaining proficiency in data entry into the database, collecting and analyzing the data.

5.6.1 Design of the CHRIB Database System

In association with a computer system developer specializing in research database designing and programming, the CHRIB database system was designed over a period of 9 months. The process entailed preliminary discussions to establish common ground regarding the rationale, the functions and requirements of the database system. Examples of existing databases designed by the programmer, such as the Paediatric Oncology Database at Kalafong Hospital, were reviewed to orientate the researcher to the application of database systems in research.

A total number of 112.5 hours were spent in developing the CHRIB database system and the computer system developer and researcher spent 38 hours in joint consultation sessions (Personal records of B. Nieuwoudt, database programmer, 1995-1996).

The operational strategy employed during the developing phase of the database involved a continuous process of assessment, analysis and action (Patel, 1993). The *assessment* involved critical thinking regarding requirements for research, training and service delivery at CHRIB in order to *analyze* the CHRIB Case History Form (Louw & Kritzinger, 1995a) and the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) so that *action* could be taken by way of designing the database system. A continuous process of assessment and analysis therefore preceded every step of the programming phase in order to best represent the comprehensive CHRIB assessment protocol and procedures in the database system. The operational framework of assessment, analysis and action ensured that changes and corrections could be implemented on a continuous basis which made a separate pilot study superfluous. According to Nieuwoudt (1999) a research database system requires continuous changes to suit the aims of the research whereas a production database system can operate with intermittent adjustments once programmed. Rapid application development, i.e. prototyping and production, is unique to a research database (Nieuwoudt, 1999).

The last step in the design of the database system involved the independent entering of data in the database system by the researcher. Four working sessions under supervision of the computer system developer took place so that the researcher could develop proficiency in the process of data entering and in using the back-up system to secure that data that had been entered (Nieuwoudt, 1991). Thereafter independent use of the database system was maintained but regular contact with the computer system developer was kept in order to ensure that problems could be discussed and minor adjustments could be made to the database.

5.6.2 Data Collection

The general and specific procedures regarding the data collection can be described as follows:

- Parents with infants and toddlers at risk for communication delays contact CHRIB when they have been referred and the CHRIB Case History Form (Louw & Kritzinger, 1995a) is sent to them. When the completed form is received back by CHRIB, an assessment date is arranged with the parents.

- A letter, sent out together with the CHRIB Case History Form (Louw & Kritzinger, 1995a), obtained the parents' or caregivers' consent to utilize information gained from the assessment for research and student training purposes. In the letter the assessment procedures were explained to the parents and they are requested to bring the child's favourite toys and a snack for the feeding evaluation (See Appendix A).
- The following step is the CHRIB assessment itself and entails the parent interview, assessment of the child's communication skills, hearing testing, opportunity for parent-child interaction while the data collectors observe from the behind the one-way mirror for the duration of the observation of the parent-child interaction, and feedback to the parents. The communicative assessment materials and procedures for data recording and interpretation as described in Table 5.2 were used. Table 5.4 describes the specific sequence of assessment procedures, participants and measures undertaken to ensure reliability and accuracy of data collection.

Table 5.4 Sequence of data collection procedures during CHRIB assessment, participants and recording measures to ensure reliability and accuracy

Sequence of Data Collection Procedures	Participants	Recording Measures to Ensure Reliability and Accuracy
1. Interview*	Parents, or caregivers when parents do not come, members of the extended family if present and a data collector	- Audio-recording of interview - Case History Form completed by parents - Reports from other professionals - Data collector's notes
1.Assessment of communication skills*	Child and first or second data collector	- Video recording - Record forms of assessment instruments - Data collector's notes
2. Hearing testing	Child, parents and third or fourth data collector	- Record forms of assessment instruments - Data collector's notes
3. Parent-child communication interaction	Child and parents play on their own	- Video recording - Record forms of assessment instruments - Data collectors' notes
4. Feedback session	Parents and data collectors	- Video recording - Summary form completed by data collectors

Key*

- Interview with parents and assessment of child's communication skills occur simultaneously in the same room

- As indicated earlier, CHRIB is also used as an undergraduate and postgraduate training facility and students observing the assessment were employed to carry out the video recordings from behind a one-way mirror.
- According to Table 5.4 four data collectors are involved in the CHRIB assessment. The data collectors are all qualified professionals specializing in EI as indicated in Table 5.5. Turns to conduct the assessment of the subject's communication skills were equally shared by the first two data collectors, while the interview was carried out by either of the four professionals involved. The third and fourth data collectors who specialize in pediatric audiology always conducted the hearing test. As all data collectors were experienced and familiar with the materials used as well as the data collecting procedures, consistency and accuracy in data collection could be ensured (Mouton & Marais, 1990).

Table 5.5 Qualifications and experience of data collectors

Data Collector	Qualifications	Years of Experience in ECI
First data collector	D Phil	20 years
Second data collector	M Log	13 years
Third data collector (audiologist)	M Log	3 years
Fourth data collector (audiologist)	B Log	1 year

- After an assessment the results of each subject was recorded and entered into the CHRIB database in the form of text data, numerical data and age interval data as indicated in Table 5.2. In order to control the accuracy of information in the databasis, the data entering was done by the researcher only. The data entering process took approximately 45 minutes per subject, totaling approximately 114.75 hours for the 153 subjects. The utilization of a database system in the current study allows the systematic recording of data related to the characteristics of the subjects which is immediately accessible for statistical analysis, resulting in economic time management.

5.6.3 Validity and Reliability

In order to ensure that the empirical study has generated accurate and valid findings of the characteristics of the subjects which have been studied, careful consideration was given to the internal validity of the study and the performance reliability of the measuring instruments used (Leedy, 1997; Mouton & Marais, 1990).

The theoretical validity of the materials and apparatus used were demonstrated by the fact that the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) was based on theoretical models of early development and assessment developed by Louw (1986). The Stage Process Model of Early Development and the Holistic Assessment Model for Infants with Cleft Lip and Palate (Louw, 1986) were developed mainly for research purposes and were therefore considered as a valid theoretical framework for the assessment protocol and the structure of the CHRIB database in the current empirical study. Careful consideration was given to the selection of assessment materials in order to ensure their reliability as instruments yielding the same results under comparable conditions (De Vos, 1998). Guidelines for the administration of the different assessment materials listed in Table 5.2 were adhered to in order to ensure consistent data collection procedures by all the data collectors.

In order to obtain accurate and reliable data the same assessment materials and procedures were used to collect data from each subject. The same data collectors were utilized consistently and they were all familiar with the data collecting procedures. Data entering into the CHRIB database was done by the researcher only so that consistency and accuracy could be maintained. Before the process of data analysis began, the researcher and the database application programmer reviewed the data in Microsoft® Excel files format so that inaccuracies could be detected and corrected. Data from the CHRIB database was manipulated by using the different functions of the software and different tables were created. The quantitative and qualitative data in the tables was examined more than once to ensure accurate presentation. A statistician was consulted in order to ensure relevant analyses for the particular type of data. The last step employed to demonstrate the internal validity of the empirical study was to ensure that the final conclusions of the research were adequately supported by the data (Mouton & Marais, 1990).

In order to increase the quality and the value of the data, validity and reliability considerations were therefore regarded as central to the integrity of the research process undertaken.

5.6.4 Data Analysis and Interpretation

In order to perform statistical analyses the data in the CHRIB database system was converted to a flat-file structure in *Excel* (*Microsoft® Office 1997*) so that the data could be processed and analyzed by the *SAS®* (1999) computer package. Table 5.6 provides the two sub-aims of the empirical study which required statistical analysis. As indicated in Table 5.6 the different fields or data categories were analyzed by calculating frequency distributions, means and two-way frequencies in some circumstances. Text data was analyzed and described qualitatively.

Table 5.6 Sub-aims of the empirical study and statistical procedures

Sub-aims	Statistical Procedures
To manipulate the data using the various functions of the software to: - Create new tables in the datasheet view - Edit the data in a table - Sorting and filtering data - Creating queries	No statistical procedures
To utilize the database system as a front end for the *SAS®* (1999) computer package to perform a scenario analysis of the data	Descriptive statistics to calculate the means and frequency of variables describing selected characteristics of the subjects

5.7 CONCLUSION

The research problem to be investigated by the empirical study pertains to the development of a contemporary ECI research tool in South Africa for future utilization in an information age driven by rapid technological advances. Using the framework of second-generation EI research (Guralnick, 1997) the application of such a research tool will contribute to the exploration of three elements, namely a specific ECI programme's features, the characteristics of the subjects participating in the research and the nature of the outcomes. The methodology employed in the empirical study stipulates that a uniquely designed database system will be used to provide a comprehensive description of the subjects so that valid and accurate inferences can be drawn from the results. A description of the CHRIB database indicated that the data generated by this customized research tool can be used to identify specific assets and needs of the ECI programme which will lead to the development of a conceptual framework for improved service delivery in CHRIB, thereby contributing to the developing field of ECI in South Africa.

5.8 SUMMARY

The chapter described the planning and implementation of the empirical study. The first main aim of the study was to design a database system as an ECI research tool and a detailed description of the database structure and features was provided. The database system was modeled on the assessment materials and procedures employed at CHRIB, an ECI service delivery facility. A quantitative survey methodology was selected to conduct the second main aim of the empirical study. Data of 153 subjects assessed at CHRIB was collected and entered into the database system over a period of three and a half years. The data analysis procedures were described so that use of the database as a research tool may be demonstrated when the specific population of infants and toddlers receiving ECI services at CHRIB is described.

CHAPTER 6

RESULTS AND DISCUSSION

CHAPTER 6
RESULTS AND DISCUSSION

Aim: The aim of the chapter is to describe and interpret the results of the empirical study which was conducted to demonstrate the applicability of the CHRIB (Clinic for High Risk Babies) database system for early communication intervention research.

6.1 INTRODUCTION

The scientific process guiding an empirical study involves the systematic collection, processing and interpretation of data in order to resolve the research problem (Leedy, 1997). The research problem in the present study involved the establishment and application of an early communication intervention (ECI) database in order to provide both a source of immediate available data for short term research projects and a source of large amounts of data for ongoing research and longitudinal studies by a specific ECI service provider.

The main aim of the empirical study was to demonstrate the use of the database system as a specially designed contemporary ECI research tool by providing a multifaceted profile of a group of infants and toddlers at risk for communication delays and their families. The comprehensive profile of the subjects' characteristics will serve as a basis to describe the population served by the particular university-based ECI programme and present a conceptual framework of an approach to service delivery in a tertiary level setting and the continued use of the CHRIB (Clinic for High Risk Babies) database system as an ECI research tool.

The data of the empirical study was collected, processed and stored in the CHRIB database system. Using the various functions of the *Microsoft® Office*

97 software and the *SAS®* (1999) software package and interactions between these programmes, the data was retrieved, organized, analyzed and systematically presented and discussed according to the sub-aims formulated.

The advantages of data retrieval by means of an electronic database are that voluminous amounts of data are readily available and the researcher is intimately involved with the process of data generation. Effective data management therefore poses a significant challenge to the researcher but can be viewed as a highly creative process in order to analyze, present and discuss the results in a systematic and coherent manner (De Vos, 1998).

Since large amounts of data are already stored in the three and a half year old CHRIB database, selected data from the 16 tables of the database was used and presented as results. Data from 11 tables labeled as Client, Parentship, Persons involved, Referring persons, Persons, Diagnosis, Language, General illnesses, Surgery, Viral infections and Perinatal, originally derived from the CHRIB Case History Form (Louw & Kritzinger, 1995b) and medical reports, was selected and described. The results will mainly be presented in the form of descriptive statistics, revealing the full detail and richness of the large amounts of data stored in the database. The descriptive method of data presentation and interpretation was selected as it leaves the researcher in greater control of the process of data management to emphasize detail and detect patterns emerging from the results. The calculation of means and use of inferential statistics, indicating possible interactions between variables, can still be carried out as a second step in data analysis, but these methodologies tend to mask emerging detail and patterns in the initial stages of analysis of results (Kruger, 2000a). Since the aim of the study is to develop a database system as a new research tool for a specific ECI programme, new and appropriate methodologies for data manipulation must also be explored. The aim of the chapter is therefore to provide a rich description of the results, which is both innovative and accountable, resulting in a better understanding of the subjects and their families investigated. An overview of the order in which the *results is presented in the chapter* is provided in Figure VI.I.

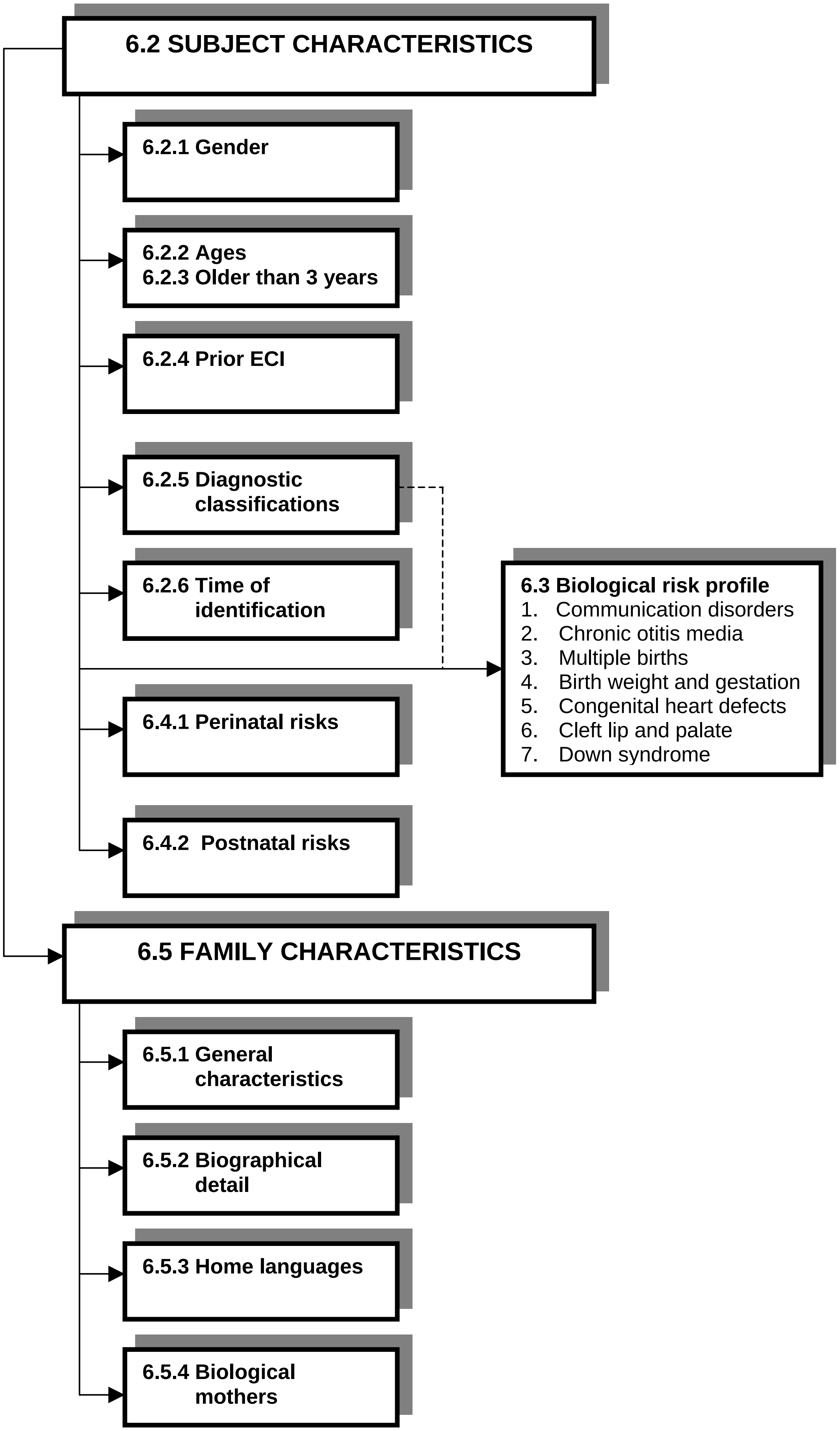


Figure VI.I Overview of results presented in the chapter

6.2 DESCRIPTION OF THE SUBJECTS' CHARACTERISTICS

A general description of the characteristics of the 153 subjects regarding age, gender, diagnostic categories, home language, geographical location and population group was presented in Table 5.1 (See Chapter 5) and is now expanded in Table 6.1.

The subject characteristics presented in Chapter 5 revealed a markedly heterogeneous group of children, representing many of the young children from diverse backgrounds requiring ECI in South Africa. In contrast, the similarities among the subjects' characteristics disclosed that the majority are boys of about 18 months old, presenting with cleft lip and palate, living in the Pretoria region, are from white families and speak Afrikaans as a home language.

Using the CHRIB database system to access the data, Table 6.1 was compiled to provide additional details of the characteristics displayed by the 153 subjects. Figure VI.II provides an outline of the chronological order in which the *characteristics of the subjects* were presented.

6.2.1 Gender of the subjects

The first characteristic of the subjects to be illustrated in Table 6.1 relates to the gender bias displayed by the subjects. While it is generally accepted that boys present with a higher prevalence of communication disorders than girls (Lahey, 1988), it is a surprising result since no attempt was made to select a representative sample of subjects with communication disorders. It appears that the results confirm the proven prevalence of boys presenting with communication disorders, thereby indicating that it is a universal phenomenon.

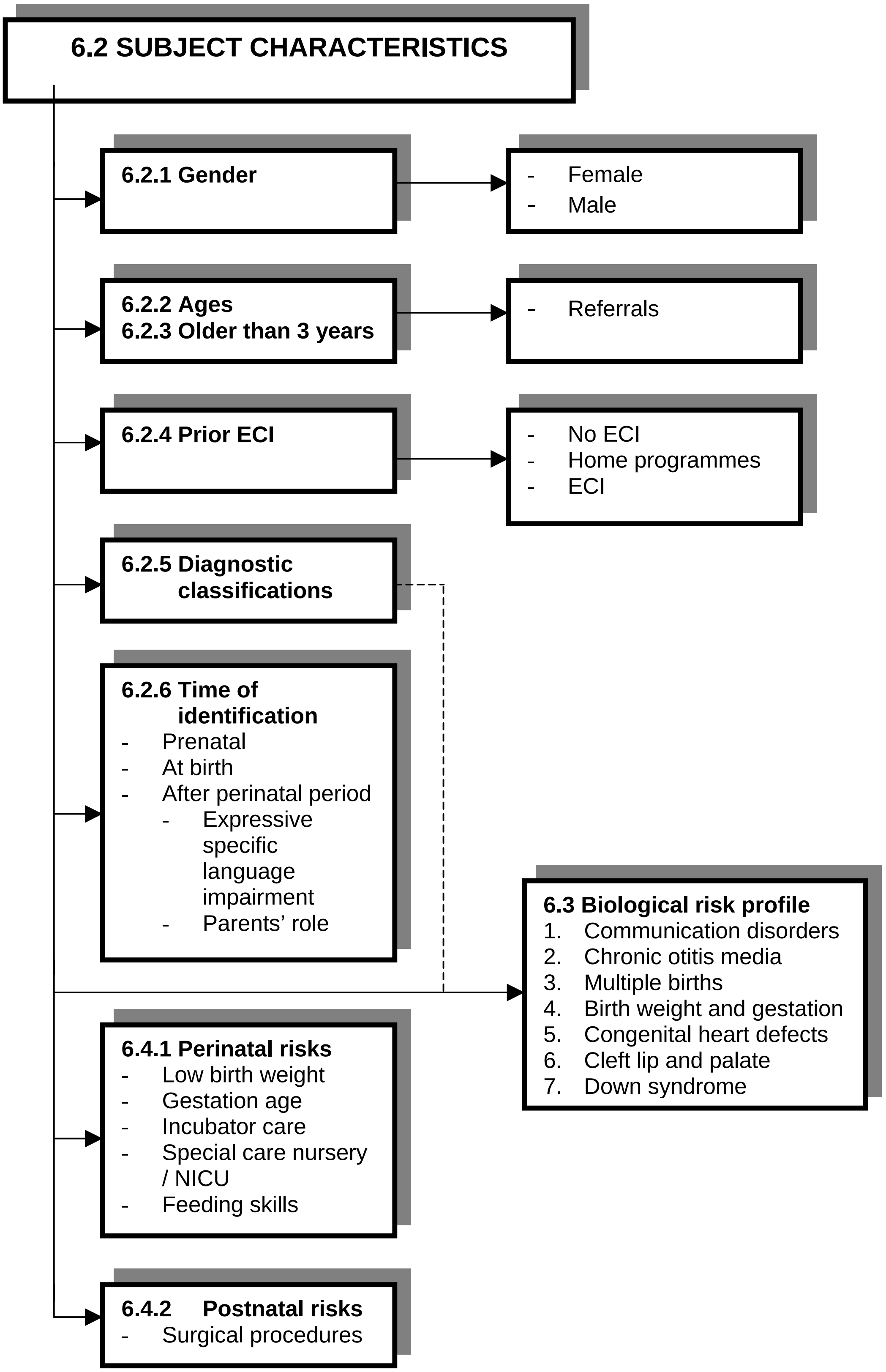


Figure VI.II Outline of results pertaining to the characteristics of the subjects

Table 6.1 Characteristics of subjects (N=153)

Characteristic	Category	# Subjects or value	%
1. Gender	-Female -Male	71 82	46% 53%
2. Age at the time of CHRIB assessment and data collection	-Range -Average age	3 weeks – 77months 18,04 months	- -
3. Subjects assessed at CHRIB after 3 years of age	–	11	7%
4. Subjects enrolled in ECI programmes before assessment at CHRIB	-No prior contact with ECI -ECI home programmes only -Already receiving ECI	62 75 16	41% 49% 10%
5. Main diagnostic categories of the subjects	-Cleft lip and palate -Down syndrome -Autism/PDD -Other established risk conditions -Low birth weight and premature birth only -Multiple pregnancies -Delayed speech and language development only -Tongue tie -Hyperactivity	79 23 4 8 10 15 11 1 2	51% 15% 3% 5% 7% 10% 7% 1% 1%
6. Time when subjects' risk conditions were first identified	-On sonar before birth -At birth -During the perinatal period -After perinatal period	8 90 8 47	5% 59% 5% 31%

6.2.2 Age of subjects

According to Table 6.1 the subjects presented with a broad spectrum of ages, from three weeks to 77 months, with an average age of 18 months. Figure VI.III provides a scatter graph distribution of the subjects' ages, which permits closer inspection of the results. As the data from the CHRIB database was already converted to *Microsoft® Excel* workbook files, further manipulation of the data was possible by means of the calculation and chart functions the software. The density of the dots in Figure VI.III reveals that most of the subjects were younger than 36 months at the time of data collection and only a few were older than three years. The lower margin of the subject ages indicates that CHRIB succeeds in recruiting clients from the earliest possible stage, i.e. the neonatal stage, which is considered as one of the indicators for effective ECI services (Rossetti, 1993).

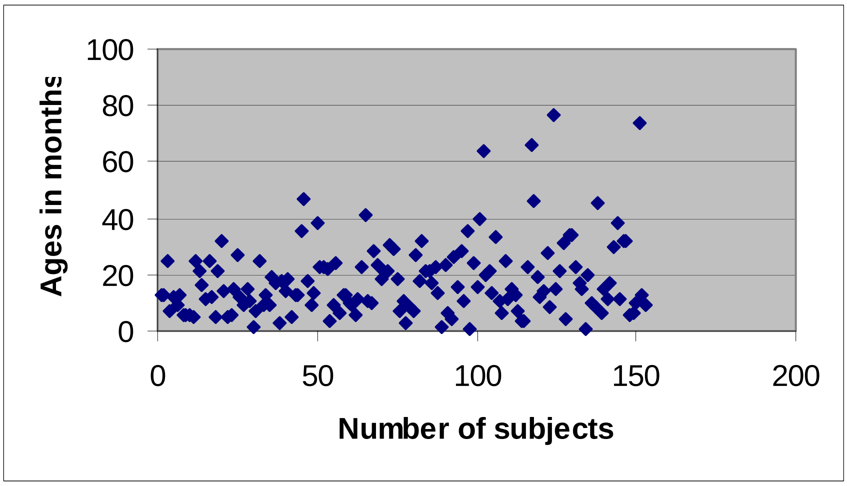


Figure VI.III Scatter graph distribution of subjects' ages (N=153)

The importance of the analysis of the subjects' ages pertains to the fact that CHRIB was established to serve the population of infants and toddlers at risk for communication delays under three years of age. Since sufficient intervention facilities existed for children older than three years, the specific age range for services at CHRIB was chosen to be in accordance with the ASHA (1991b) definition of EI.

6.2.3 Subjects older than three years

In contrast with the majority of the subjects and as indicated in Figure VI.III and Table 6.1 eleven of the 153 subjects were assessed at CHRIB after the age of three, which is beyond the generally accepted age range for *commencing* with ECI services (Rossetti, 1996). Upon closer analysis of the data in the CHRIB database and by creating a query (See Table 6.2), a process by which unnecessary information is eliminated, the reasons for the eleven late referrals to CHRIB involved the following circumstances:

- Two subjects came into contact with ECI services for the first time at the CHRIB assessment and they were subsequently diagnosed with established risk conditions. One subject (CHRIB ID 62) was diagnosed with a moderate hearing loss at the assessment and was referred to CHRIB by the parents themselves while the other subject (CHRIB ID 171) was diagnosed with a developmental delay associated with microcephaly and was referred to CHRIB by the Down Syndrome Association. As these two subjects had no prior contact with any ECI services and their conditions were identified late, it is of great concern that subjects with conditions which can be identified at birth or early in life, went unnoted.

Table 6.2 Print out of CHRIB Database Query of subjects older than 3 years (N=11)

Nr	ID*	Date of Birth	Assessment	Diagnosis*	Explanation
1	143	06/10/1992	10/03/1999	Q37.4	Bilateral cleft lip and palate
2	120	29/03/1993	05/08/1998	Q35.5.1	Pierre Robin Sequence
3	57	06/04/1993	12/03/1997	F84.01	PDD
4	171	29/07/1993	22/09/1999	Q02	Microcephaly
5	136	13/08/1993	10/02/1999	Q37.7.1	Right-sided cleft lip and palate
6	62	15/02/1994	23/04/1997	H91.2	Sensorineural hearing loss
7	78	19/02/1994	06/08/1997	F84.01	PDD
8	137	27/03/1995	03/02/1999	Q35.5.1	Pierre Robin Sequence
9	119	12/04/1995	29/07/1998	F80	Speech and language delay
10	157	29/09/1995	07/07/1999	F84.01	PDD
11	164	29/05/1996	04/08/1999	Q37.4	Bilateral cleft lip and palate

Key to table headings

- ID refers to the subject's CHRIB database identification number
- Diagnosis: Comprehensive key to the diagnostic classifications of *ICD-10* (CSS, 1996) is later supplied in Table 6.11

- Four subjects (CHRIB ID 57, 78, 119 & 157) were already receiving speech-language therapy and were referred to CHRIB by their speech-language therapists for consultation with the CHRIB team, as these therapists requested specialist assessment and treatment guidelines. Three of the four subjects were found to present with autism/pervasive developmental disorder (PDD) when assessed at CHRIB and the fourth subject was found to have delayed speech and language development associated with recurrent otitis media.
- The remaining five subjects had various types of cleft lip and palate and were diagnosed as such at birth, but were referred to CHRIB as their speech-language therapists requested a consultation with the CHRIB team or as a result of the parents' late response to an earlier referral to ECI services.

One of the conclusions to be drawn concerning the high upper margin of the age range of the subjects is that there were only two identifications of risk conditions after three years of age from the total of 153 subjects. This indicates that late identifications and referrals, i.e. after three years of age, occurred very rarely among the subjects. It appears that CHRIB is succeeding in fulfilling its goal to serve the population of infants and toddlers at risk for communication delays under three years of age. The results emphasize the very essence of ECI, which implies that intervention efforts must start as early as possible in a child's life as the time factor is one of the predictors of effective service delivery.

The critical importance of time in ECI is emphasized in the following example pertaining to the subjects with autism/PDD. The second inference to be drawn from the reasons for late referrals relates to the late diagnosis of autism/PDD in children, a concern also described by Squires, *et al.* (1996) and Wetherby, *et al.* (1998). According to these authors the diagnosis of autism/PDD is usually not confirmed until between two and a half and three years of age at best, which indicates that this population of infants presenting with a serious communication disorder is currently underserved by ECI. The late diagnosis of subjects with autism/PDD assessed at CHRIB therefore corresponds with findings of late diagnosis in clinical practice elsewhere. As the first evident symptoms of autism/PDD are a delay in speech development and very little is known about these children's early functioning to accurately diagnose them at an early age (Wetherby, *et al*., 1998), it appears that ECI can contribute to identify these children earlier.

The results concerning the relatively high ages of certain subjects also indicate that CHRIB, as a university-based ECI service provider, is recognized by other speech-language therapists and audiologists to provide specialist consultative services in cases of difficult-to-diagnose children or children demonstrating unsatisfactory progress in a treatment programme. Table 6.3 was compiled from the datasheet view of the CHRIB database in *Microsoft® Excel* by applying a filter procedure in order to reveal all the speech-language therapists and audiologists who referred clients to CHRIB for consultative services. (The CHRIB database table "Persons involved" contains the names of all the professional persons involved in a particular client. See Chapter 5, Table 5.2). The subject's ages were added to the table in a separate column.

According to Table 6.3, 16 subjects (10%), were referred to CHRIB by speech-language therapists and audiologists utilizing the consultative services offered by CHRIB. Six of the 16 subjects were referred to CHRIB when they were over three years of age, indicating that CHRIB's availability for consultative services, especially in the case of difficult-to-diagnose children, depends on the application of less strict rules for the upper age margin for assessments. In order to maintain to provide a consultative function, it will be necessary to continue to include assessments of children over three years of age in the ECI programme provided by CHRIB. In view of the expanding field of ECI in South Africa it is important to have a specialist referral base, so that services are not only provided to young children and their families, but also to ECI practitioners.

Table 6.3 Print out of the datasheet view of the CHRIB Database Table "Persons involved" (N=16)

Nr	LINK File*	Subject age*	Person*	Capacity
1	15	6.8m	132	SLT*
2	31	31.6	73	SLT
3	57	**47.1m**	120	SLT
4	58	17.6m	127	Audiologist
5	78	**41.4m**	145	SLT
6	96	6.8m	156	SLT
7	98	17.5m	159	SLT
8	100	21.4m	163	SLT
9	101	21.4m	163	SLT
10	109	6.6m	127	Audiologist
11	115	35.3m	170	SLT
12	119	**39.5m**	172	SLT
13	136	**65.8m**	188	SLT
14	143	**76.9m**	195	SLT
15	151	16.9m	206	SLT/Audiologist
16	157	**45.1m**	206	SLT/Audiologist

Key to table headings and abbreviations

- Link File: Subject's CHRIB database identity number
- Subject ages: Over 3 years of age are typed in bold
- Person: CHRIB database number allocated to professional person
- SLT: Speech-language therapist

6.2.4 Subjects enrolled in ECI programmes prior to CHRIB assessment

Further analysis of Table 6.1 (Nr 4) reveals that 91 (59%) of the subjects had been in contact with ECI services before their assessment at CHRIB. Apart from the 16 subjects who were already receiving ECI at the time of their assessment at CHRIB and referred for consultative services, a further 75 subjects and their parents received ECI home programmes and relevant information at another service delivery facility, the Facial Deformities Clinic, Department of Oral, Facial and Maxillo Surgery, University of Pretoria, which they had been attending from birth onwards. ECI services are rendered at the Facial Deformities Clinic as members of the CHRIB team consult at the clinic, provide parent guidance and training and perform a comprehensive assessment on the subject, i.e. the CHRIB assessment, once the primary surgery has been completed.

The high percentage of subjects (59%) in Table 6.1 whose risk conditions were identified early in life and received some form of ECI services indicates that the services rendered by CHRIB at the Facial Deformities Clinic succeed in lessening the gap between the early identification of a risk condition and the actual age at which a child starts receiving ECI services. As a delay in the actual commencement of ECI services after the identification and referral of the child undercuts the efficacy of ECI (Downs, 1994), the results indicate that CHRIB's involvement in a medical interdisciplinary team at another location, i.e. the Facial Deformities Clinic, resulted in improving the age of entry into an ECI programme for a substantial number of the subjects.

The results relating to ECI services which the subjects received prior to the CHRIB assessment, revealed an important professional function carried out by the CHRIB team. The role of CHRIB in providing consultative services at the Facial Deformities Clinic and to other speech-language therapists who refer clients, resulted in improved services to clients requiring ECI and extending the field of ECI. If CHRIB does not provide these consultative services, the clinic would be less effective in performing the various professional functions of service delivery, especially those functions involving teamwork and consultation.

Rendering specialist services implies that CHRIB's client base is expanding to include not only families with young children at risk for communication delays, but also speech-language therapists, audiologists and other professionals working in the field of EI. It appears that collaboration, whether in an interdisciplinary team at the Facial Deformities Clinic or in consultation with individual professionals is an important function of CHRIB and should be included in its management plan. Teamwork and collaboration are not only integral to the EI service delivery approach (Briggs, 1997) but should also be seen as enriching experiences to continue to enhance expertise and as excellent opportunities for student training in CHRIB.

Table 6.1 also indicates that CHRIB provided ECI services to 62 (41%) of subjects and their families who came into contact with ECI for the first time at CHRIB. Although CHRIB is not hospital-based or situated at a community health clinic where the continuous presence of CHRIB staff can facilitate referrals, the clinic succeeds in providing a substantial number of families with their first contact with ECI. The results emphasize the multifaceted role of CHRIB as an ECI service provider in a tertiary setting. Services ranging from the specialist level of consultative services to the basic functions of a primary care setting, such as the identification of risk conditions in children and the promotion of normal communication development, must be rendered.

6.2.5 Main diagnostic classifications of subjects

The next characteristic of the subjects depicted in Table 6.1 (See also Figure VI.II) relates to their main diagnostic classifications according to the *ICD-10 Manual* (CSS, 1996), an international classification system of diseases and related health problems, which was utilized in the CHRIB database. The *International Classification of Impairment, Disability and Handicap* (*ICIDH-2*) (WHO, 1999), a considerably more appropriate classification system for recording developmental disabilities which the subjects displayed, was not yet available at the time the data was recorded.

Appendix E was compiled to provide a complete record of all the different diagnostic classifications occurring in each subject. Selected information contained in Appendix E was compiled in tables and discussed in the ensuing text.

As presented in Table 6.1 Nr 5, 74% of the subjects displayed e*stablished risk conditions,* i.e. various types of cleft lip and palate, Down syndrome, autism/PDD and other established risk categories which, according to Rossetti (1996), are associated with communication disorders. The other established risk conditions displayed by the subjects included sensorineural hearing loss, microcephaly, agenesis of the corpus callosum, fetal alcohol syndrome, fetal *Roaccutane*® syndrome, subarachnoid haemorrhage after surgery to remove a cyst and a suspected genetic disorder in one subject which was unconfirmed at the time of data collection.

The high number of subjects with *established risk conditions* associated with communication disorders relates to referrals from the Facial Deformities Clinic. Another reason could relate to the fact that subjects with established risk conditions are easier to identify as requiring ECI, due to the visibility of some of the disorders.

In contrast, the limited number of subjects with *biological risk conditions*, such as low birth weight, premature birth and multiple pregnancies, could indicate that these subjects are not yet widely identified as candidates for ECI in South Africa. It appears that the low identification rate of infants with biological risk conditions still happen even though research proves that they have long term problems and require ECI. It could be that infants and toddlers with biological risk conditions are seen as requiring EI for services with a focus on developmental areas such as health and motor development only, thereby overlooking their risk for delayed communication development. Since ECI is still an unknown service in many of the different communities in South Africa

(Delport, 1998; Moodley, 1999), one of the reasons for disregarding ECI could be as a result of unfamiliarity with the service.

According to Table 6.1 Nr 5 only 17% of the subjects presented with main risk conditions relating to a *biological risk status*, i.e. low birth weight and premature birth and multiple pregnancy. The remaining 9% of the subjects were categorized according to the main developmental problem they presented with and could not be classified under the established or biological risk conditions already mentioned. These subjects presented with delayed communication development (11 subjects), a tongue-tie (one subject) and hyperactivity (2 subjects).

The numbers pertaining to the risk categories of the subjects in Table 6.1 Nr 5, however, do not provide the complete risk profile found in the subjects. The different categories, especially the biological risk conditions and speech and language delay, were found not to be mutually exclusive and more than one risk condition occurred in each subject (See Appendix E). In order to provide a description of combined risks found in the subjects, further analysis of the risk profiles is presented in 6.3.

The different diagnostic classifications of the subjects in Table 6.1 Nr 5 also indicate the broad variety of conditions associated with communication disorders which the data collector had to accommodate. The results have important implications for continued ECI programme planning in CHRIB and reiterate Rossetti's viewpoint that "no clinical activity is more challenging to the early interventionist than that of providing reliable and accurate assessment results" (Rossetti, 1991:11). The high occurrence of cleft lip and palate among the subjects (51%) demands specialized knowledge of the field, but the same level of knowledge is also required in the other diagnostic categories represented in the subjects in order to provide equally effective ECI services to the families involved. Children representing all the diagnostic classifications listed in Table 6.1 (Also see Table 6.11) had to be assessed with equal expertise, from a child with a single risk condition of a tongue tie and providing the surgeon with data and recommendations to enable him to make a decision regarding the necessity of surgery, to determining the devastating effects of agenesis of the corpus callosum on a child's development.

The broad spectrum of the subjects' ages (Table 6.1), from the neonatal stage, through infancy, the toddler years and older, further emphasize the high level of expertise and scientifically based approach and methodologies required to assess young children in order to provide effective ECI services.

6.2.6 Time of identification of subjects' risk conditions

The next characteristic of the subjects to be discussed relates to the ages at which their risk conditions were first noticed, either by the parents or by professionals (See Table 6.1 Nr 6). The information was supplied by the parents when completing the CHRIB Case History Form (Louw & Kritzinger, 1995a) and entered into the CHRIB database. Since the age of identification of risk conditions in the subjects does not necessarily coincide with the time of diagnosis by a professional and commencement with ECI, the results were considered as important information to CHRIB as an ECI service provider. Best practice in ECI aims to provide services to families as early as possible without a time lapse between the identification of a risk condition in a child and the actual time of commencement of treatment (Rossetti, 1996). When analyzing epidemiological data in the literature this ideal practice appears to be elusive as only a small percentage of children with disabilities are identified during the infant/toddler period. According to Kochanek and Buka (1995) epidemiological data reveal exceedingly low identification rates of children with developmental disabilities from birth to three. According to these authors the absence of effective screening and early identification models can be attributable to the situation where only a small proportion of the population of children with disabilities in schools were identified early (Kochanek & Buka, 1995).

According to Table 6.1 eight (5%) of the subjects' risk conditions were identified prenatally and Table 6.4 provides selected details of these subjects from the CHRIB database.

Table 6.4 Prenatal diagnosis of the subjects' risk conditions (N=8)

Nr	Client ID*	Diagnosis	Gender	Time of prenatal diagnosis as reported by the parents
1	19	Triplets	Male	During pregnancy with sonar
2	20	Triplets	Male	During pregnancy with sonar
3	21	Triplets	Female	During pregnancy with sonar
4	55	Down syndrome	Female	At 2 months of pregnancy
5	56	Cleft lip and palate	Male	Before birth, seen on sonar
6	102	Cleft lip and palate	Male	At 6 months of pregnancy on sonar
7	134	Cleft lip and palate	Female	At 28 weeks of pregnancy on sonar
8	169	Cleft lip and palate	Male	Before birth, seen on sonar

Key

- Client ID refers to the subject's CHRIB database identification number

As indicated in Table 6.4 the prenatal diagnosis was made by means of Real Time Ultrasonography in the case of the triplets and subjects with cleft lip and palate, a sound wave imaging technique now used routinely if available, to determine gestational age, fetal viability and major malformations (Batshaw, 1997). In the subject with Down syndrome additional Chorionic Villus Sampling was presumably carried out as the diagnosis was confirmed at two months of gestation (Louw & Kritzinger, 1998). It is possible that the other multiple births occurring in the subjects were also identified prenatally (See Table 6.1 Nr 6), since Real Time Ultrasonograhpy is now routinely carried out, but that the parents did not report the prenatal diagnosis of a multiple pregnancy in the CHRIB Case History Form (Louw & Kritzinger, 1995a).

These results not only indicate the high technological prenatal care which resulted in the earliest possible diagnosis in some of the subjects, but also reveal a new role for speech-language therapists (Louw & Kritzinger, 1998), specifically in CHRIB. This role involves the prenatal counseling of families in order to make informed decisions and to be adequately prepared about the developmental risks of the diagnosed conditions in their unborn children and the importance of commencing with ECI after birth. The advantage is that parents can be prepared prior to the time of active parenting of a child with a risk condition (Louw & Kritzinger, 1998). The results reported in Table 6.4 indicate that prenatal informative counselling (Thomson, 1995) and promoting increased public awareness of ECI services should be seen as important functions in CHRIB. Potential parents' increased knowledge of risk conditions for communication delays can lead to the earlier identification of infants at-risk and eventually to a higher success rate in the prevention of disabilities (Gerber, 1990; Kochanek & Buka, 1995).

According to Table 6.1 Nr 5, it appears that 64% of the subjects were identified with their main risk condition, such as cleft lip and palate and Down syndrome, at an early stage, at birth or during the first four weeks of life, i.e. the perinatal period. The reasons for the successful early identification of these conditions can relate to the visual nature of cleft lip and palate and the relative familiarity of health care professionals with Down syndrome (Gerber, 1990; Lubker, 1991). Down syndrome is also the most frequently occurring chromosomal disorder involving the number of chromosomes and one of the major presenting diagnoses in genetics (Gerber, 1990; Van Dyke, 1995) while cleft lip and palate is considered as one of the most common congenital anomalies (Kernahan & Rosenstein, 1990). The early identification of subjects indicates that the majority of them could benefit from ECI at a very early age if referrals to ECI were successful. The remainder 47 (31%) of the subjects were identified after the perinatal period and is displayed in Table 6.5.

Table 6.5. provides an analysis of the different risk conditions which were identified later in the subjects and the different persons responsible for first noticing the risk conditions in the subjects. The table was compiled using the CHRIB Database Table "Client", converting the table to a *Microsoft® Excel* worksheet and copy and transfer the edited version to *Microsoft® Word*.

Table 6.5 Subjects identified with a risk condition or communication delay after the perinatal period (N=47)

Client ID	Risk condition	Age: CHRIB assessment	Age of identification by a professional or when problems were first noticed by parents
14	Communication delay	24.8m	At 18m by child psychiatrist
25	Communication delay associated with low birth weight	16.5m	At 14m by paediatrician
29	Cleft palate	5.1m	At 4m by Oral-Facial-Maxillo surgeon
30	Communication delay	36m	Grandparents noticed delay after 12m
35	Cleft palate	15.2m	At 6 weeks by Oral-Facial-Maxillo surgeon
36	Communication delay	26.9m	At 18m by parents
46	Down syndrome	9.3m	At 6 weeks by paediatrician
50	Down syndrome	17.6m	At 2m by paediatrician
52	Communication delay associated with low birth weight	18.6m	At 12m mother was concerned
57	Autism	47.1m	Mother was concerned “at a very early age”, started ECI at 3 years
59	Cleft palate	9m	At 6 weeks by Oral-Facial-Maxillo surgeon
62	Sensorineural hearing loss	38.1m	Parents noticed problem before 12m
63	Communication delay associated with multiple birth	22.7m	Parents were concerned at 18m
64	Communication delay associated with multiple birth	22.7m	Parents were concerned at 18m
77	Communication delay associated with fetal alcohol syndrome	23m	At 20m mother noticed delayed communication development
78	Pervasive developmental disorder	41.1m	At 8m parents noticed problems
81	Communication delay associated with low birth weight	28.1m	Parents were concerned at 18m
82	Communication delay	23.1m	Mother was concerned at 18m
84	Communication delay associated with multiple birth	32.1m	At 17m parents were concerned
85	Communication delay associated with multiple birth	32.1m	At 17m parents were concerned
86	Communication delay associated with low birth weight	30.4m	Parents were concerned after 9m
89	Communication disorder associated with subarachnoid haemorrhage	29.4m	Diagnosed after surgery to remove cyst at 28m (Acquired condition)
94	Communication delay associated with low birth weight	3m	At 2m parents were concerned
99	Communication delay associated with hyperactivity	32m	Diagnosed by child psychiatrist at 30m
110	Communication delay associated with low birth weight	4.1m	Mother concerned after 3m
111	Communication delay	25.9m	At 18m parents were concerned
115	Autism	35.3m	At 18m parents were concerned
117	Communication delay	24.2m	At 18m mother was concerned
119	Communication delay	39.5m	At 31m parents were concerned
122	Communication delay associated with unknown syndrome	26.9m	At 18m parents were concerned
127	Communication delay	25.1m	Playgroup teacher was concerned at 19m
138	Communication delay associated with low birth weight	19m	Mother concerned after 4m

Table 6.5 continued

Client ID	Risk condition	Age: CHRIB Assessment	Age of identification by a professional or when problems were first noticed by parents
131	Cleft palate	6.9m	At 2m by Oral-Facial-Maxillo surgeon
145	Agenesis of the corpus callosum	21.4m	At 12m diagnosed by paediatrician
146	Communication delay	31.4m	Since 24m parents were concerned
148	Communication delay associated with multiple birth	34m	At 24m by paediatrician
149	Communication delay associated with multiple birth	34m	At 24m by paediatrician
150	Communication delay	22.9m	At 16-18m parents was concerned
151	Sensorineural hearing loss	16.9m	Diagnosed by audiologist at age 12m after subject contracted meningitis at the age of 4m (Acquired condition)
154	Hyperactivity	20m	Diagnosed at 18m by child psychiatrist
157	Autism	45.1m	At 30m parents were concerned
163	Communication delay	30.1m	Mother was concerned at 24m
166	Communication delay associated with multiple birth	31.6m	Mother was concerned at 24m
167	Communication delay associated with multiple birth	31.6m	Mother was concerned at 24m
168	Communication delay associated with low birth weight	5.8m	Mother concerned after 4m
171	Microcephaly	73.6m	Parent noticed problem at 3 years
172	Cleft palate	13.1m	At 3m by Oral-Facial-Maxillo surgeon

According to Table 6.5 the identification of risk conditions in 47 (31%) subjects after the perinatal period includes a surprisingly wide spectrum of conditions, from established risk conditions such as cleft palate and Down syndrome, which are relatively easily diagnosable at birth, to conditions which only become apparent when the child fails to start talking, to acquired conditions which can only be identified after the causative incident. Apart from the *variety of conditions* identified after the perinatal period in the subjects, these subjects were identified at *different times* in their lives by *different people*. Each of these variables will be analyzed in the following discussion.

Table 6.6 provides a summary of the different risk conditions identified in the subjects after the perinatal period and the number of subjects involved.

Table 6.6 Number of subjects per risk condition identified after the perinatal period (N=47)

Risk condition	# Subjects	%
1. Established risk conditions	16	34%
2. Acquired risk conditions for communication delay	2	4%
3. Communication delay associated with low birth weight	8	17%
4. Communication delay associated with multiple birth	8	17%
5. Communication delay associated with hyperactivity	1	2%
6. Hyperactivity only	1	2%
7. Communication delay only	11	24%
Total	**47**	**100%**

According to Table 6.6, and upon closer inspection of Table 6.5, the 16 subjects with *established risk* conditions diagnosed after the perinatal period include five subjects with cleft palate in the absence of a cleft lip, which results in a less visible disorder and possibly easier to overlook at birth, the four subjects with autism/PDD who were already discussed as a subgroup of children most likely to be identified late, two subjects with Down syndrome and one subject with each of the following disorders: fetal alcohol syndrome, sensorineural hearing loss, microcephaly, a syndrome which could not be diagnosed at the time of data collection and agenesis of the corpus callosum.

The two subjects with *acquired conditions* associated with communication disorders, were subject Nr 89 with a sensorineural hearing loss due to meningitis and subject Nr 151 with a subarachnoid haemorrhage after surgery to remove a cyst (See Table 6.5).

The other subjects in Table 6.6 with conditions identified after the perinatal period, involved the 16 subjects with *biological risk conditions* present at birth, i.e. low birth weight, prematurity and multiple births. Although presenting with risk conditions early in life, these subjects were only identified when their communication delay became a concern. The two subjects with hyperactivity were both identified by a child psychiatrist, also when their communication development became a concern. The one subject with hyperactivity was found to present with a communication delay but the other subject was found to present with normal communication development, but at risk for communication delay when assessed at CHRIB.

The last group of subjects identified after the perinatal period, concerns the 11 subjects in Table 6.6 who presented with a communication delay in the absence of either established or biological risk factors (See also Table 6.1 Nr 4 and Table 6.5, subjects with Client ID 14, 30, 36, 82, 111, 117, 119, 127, 146, 150 and 163). Two of the 11 subjects were subsequently found to present with a general developmental delay as well, but could not be classified as such in the results, as the *ICD-10* (CSS, 1996) used in the CHRIB database, does not provide such a diagnostic classification.

Nine of the 11 subjects with speech and language delay were therefore distinguishable from the other two subjects on the basis of their poor expressive language skills relative to other areas of development and appears to be toddlers with expressive specific language impairment or late talkers (Rescorla & Goossens, 1992; Whitehurst, Fischel, Lonigan, Valdez-Menchaca, Arnold & Smith, 1991).

The wide variety of conditions in the subjects identified after the perinatal period provides possible explanations to the concern raised by Kochanek and Buka (1995) that epidemiological data revealed low identification rates of children with disabilities between the ages of birth and three years. Since the problem of late identification in the subjects was not restricted to one the type of risk condition only, it could relate to a failure of parents and professionals to respond to the first identifiable signs of any of the risk conditions in the subjects. This failure to detect the earliest signs of a disorder could relate to a lack of knowledge about the condition as well as the subtlety of its initial stages.

In order to illustrate this point, further analysis of the subjects with expressive specific language impairment is required. Using data from Table 6.5 and Appendix E, selected characteristics of these subjects are displayed in Table 6.7.

Table 6.7 Characteristics of subjects identified with expressive specific language impairment (N=9)

Category	Value
Age of identification	Range:16 – 31 months Average age: 20 months
Age of assessment at CHRIB	Range: 22,9 – 31,4months Average age: 27months
History of recurrent otitis media	Yes: 8 subjects No: 1 subject
Person who identified delayed speech development	Parents: 7subjects Child psychiatrist: 1 subject Playgroup teacher: 1 subject

According to Weismer, Murray-Branch and Miller (1994) late talkers evidence slow expressive language development in the absence of any other developmental delay or risk condition and are only identified by the time they fail to develop speech, displaying a restricted vocabulary. As new evidence indicates that these late talkers continue to display subtle communication delays relative to their peers, even after their expressive language abilities have improved (Plante & Beeson, 1999), it appears that the subjects represent a group of young children who may also be underserved in ECI, as in the case of young children with autism/PDD. Only nine out of the 153 subjects presented with expressive specific language impairment. As very little is known about the prelinguistic development of toddlers with expressive specific language impairment (Rescorla & Goossens, 1992) they are difficult to identify early, as indicated in the subjects displayed Table 6.7. The subjects' communication delay was only identified at an average age of 20 months and came into contact with ECI services for the first time at the average age of 27 months.

The significance of recurrent otitis media found in eight of the subjects with expressive specific language impairment cannot be determined in the small sample, but can also not be ignored as recurrent otitis media is found to negatively impact on a child's language development (Hugo, *et al*., 2000). Rescorla and Goossens (1992), however, found that the toddlers with expressive specific language impairment did not differ from a control group concerning the presence or absence of recurrent otitis media. Using the

CHRIB database for continued data collection of toddlers with expressive specific language impairment, will provide a larger sample upon which more valid inferences can be drawn (Leedy, 1997).

Although the sample size is small, it is significant to note that parents, and not professionals, played an important role in identifying the subjects with expressive specific language impairment. According to Table 6.7 seven of the nine parents involved, first identified the delay in communication development in their children. The finding that parents only brought their children for an assessment at CHRIB on average seven months later, indicate that they possibly lacked information about the disorder, its effect on the child's future academic progress and the importance of commencing with ECI as early as possible. According to Whitehurst, *et al*. (1991) the beginning stages of expressive specific language disorder are subtle and can occur in young children who are developing age appropriate in all other areas.

The results relating to the subjects with acquired communication disorders, expressive specific language impairment, autism/PDD and hyperactivity indicate that not all subjects requiring ECI services could be identified before or at birth, as there were no established or biological markers to indicate a risk status in the subjects. It appears that a conceptual framework for effective ECI services at CHRIB should make provision for earlier identification subgroups of children who can only be identified later in life when their communication development becomes a concern.

As the effectiveness of ECI depends on the earliest possible identification of those children requiring the services (Rossetti, 1996), the identification of clients should be viewed on a continuum. Depending on the particular subgroup of children requiring ECI and the nature of the child's communication disorder, early identification is an ongoing process over time and an ECI service provider must be knowledgeable *when* certain subgroups of children can be identified and *who* the likely people are to identify them first. It appears that an early identification model relying on risk factors only will overlook some important subgroups of children requiring ECI. A relevant model has to afford a key position to parents as it appears that they are uniquely positioned to identify communication delays in their children provided they have the necessary knowledge about ECI. The importance of parents at each stage on the continuum of early identification of risk conditions in their children echoes the centrality already afforded to parents in the entire service delivery process of ECI (Guralnick, 1997; Rossetti, 1996).

The identification of communication delay in some of the subjects after the perinatal period therefore corresponds with observations made by Kochanek and Buka (1995) about the low identification rates in children with disabilities in the infant/toddler period. Further analysis of the data on the identification of the subjects after the perinatal period revealed the following about the different times of identification. Despite being overlooked at birth, it appears that the subjects with established risk conditions were still identified earlier than those subjects with other risk conditions or displaying communication delay only*. As can be expected, it appears that the presence of an established risk condition assisted the earlier identification of communication delay in the subjects***.**

Table 6.8 indicates the range and average ages of the subjects who were identified after the perinatal period, either by their parents or by professionals.

Table 6.8 Ages of subjects identified with communication delay after the perinatal period (N=45)*

Subjects identified after the perinatal period	Age of identification of risk condition	Age of CHRIB assessment
Subjects with established risk conditions, N=16	Range: 6 weeks – 36m Average age: 10m	Range: 5.1m – 73.6m Average age: 27m
Subjects with communication delay without established risk conditions, N=29	Range: 2m – 36m Average age: 19m	Range: 3m – 39.5m Average age: 25m

Key

- The two subjects, CHRIB ID 89 and 151, with acquired conditions were omitted

According to Table 6.8 the subjects with communication delay *in the absence of established risk factors* were identified at the average age of 19 months while the subjects *with established risk conditions*, even though they were identified after the perinatal period, were identified much earlier, at an average age of 10 months. This finding confirms Rossetti’s view (1996) that special attention should be afforded to the identification of infants at-risk, as the identification rate of infants with established risks is much higher.

Upon further analysis of the subjects in Table 6.8 it is clear that the age of identification of the risk conditions in the subjects did not result in an earlier age of assessment at CHRIB. Similar findings were also revealed in the subjects with specific expressive language impairment in Table 6.7.

Numerous factors, some of which were already discussed earlier (See 6.2.2, Subjects older than three years), can be presented as possible explanations for the time lapse between the age of identification of risk conditions in a subject and the CHRIB assessment. Some of the factors already discussed in 6.2.2 which could have influenced the age of the CHRIB assessment in certain of the subjects relate to late identifications, late referrals, consultations requested by speech-language therapists and audiologists, late response of parents to referrals and the unavailability of ECI services. Additional reasons for the time lapse between the age at which a risk condition was noticed by parents or identified by professionals and the CHRIB assessment in some of the subjects, could be that the parents and/or professionals were not aware of ECI and the benefits for very young children and that a waiting list at CHRIB could have delayed some assessments.

Despite the different contributing factors to the late identification of risk conditions in the subjects in Table 6.5, it is clear that the subjects’ parents once more played an important role in the identification of risk conditions in their young children. Table 6.9 summarizes the data and demonstrates the roles which parents and professionals played in identifying risk conditions or communication delay in the 47 subjects who were identified after the perinatal period.

Table 6.9 The roles of parents and professionals in identifying risk conditions in subjects after the perinatal period (N=47)

Person who identified risk condition	# Subjects	%
Parents	30	64%
Paediatrician	6	13%
Oral-Facial-Maxillo surgeon	5	11%
Child psychiatrist	3	6%
Play group teacher	1	2%
Neurosurgeon	1	2%
Audiologist	1	2%
Total	**47**	**100%**

Most of these subjects, i.e. 64% (30) in Table 6.9, were first identified by their parents when they noticed a communication delay in their children. The remainder of the subjects, 36% (17) were identified by professionals as presenting with a condition associated with communication delay or a communication disorder, but it can be reasoned that the parents of these subjects had to be concerned about their children in the first instance in order to consult a professional. This confirms the major role that parents play in identifying risk conditions in their children and reiterates recent findings that parents are correct 79% of the time when they suspect a problem with their child's development (Rossetti, 1998).

As indicated earlier the parents of the subjects had information needs regarding risk factors for communication delay in very young children and regarding ECI services. Although they identified communication delays in their children, there was an average time lapse of six to 18 months between the age of identification of the risk condition in the subjects and the age of their assessment at CHRIB (See Table 6.8). Since the role of parents are found to be central in the ECI process at CHRIB, their specific needs must be investigated further, so that more effective services can be rendered to them.

In contrast with the high identification rate of communication delay by parents, professionals identified only 32% of the subjects after the perinatal period. In a study on the knowledge of paediatricians in the Gauteng Province of South Africa regarding ECI, Mulder (1998) found that they had adequate knowledge of risk factors which can contribute to communication disorders or delay. The study (Mulder, 1998) found, however, that the paediatricians lacked knowledge on normal communication development in children, the availability of ECI services and the referral of children to these services. Since 82% of the subjects utilized in the current empirical study are from the Gauteng Province (See Table 5.1, Chapter 5), it can be concluded that some of the paediatricians who may have seen the subjects for medical reasons did not identify and refer these subjects for ECI services due to their lack of knowledge about ECI services and communication development in children.

Not only paediatricians, however, identified communication delay in the subjects in a limited way after the perinatal period. In comparison with the subjects' parents, it appears that professionals in general (See Table 6. 9) played a limited role in the identification of communication delay in the subjects after the perinatal period. One of the possible reasons could be that parents have uninterrupted access to their children and can follow their children's communication development on a continuous basis, an opportunity not afforded to professionals (Squires, *et al.,* 1996).

The results demonstrated in Table 6.8 therefore emphasize the major potential of parents in identifying risk conditions for communication development in their children provided that they have knowledge about the value of ECI, the benefits of early commencement with intervention and how to access the services. Increased public awareness of ECI can lead to more effective partnerships between parents and professionals, resulting in improved services provided by CHRIB to younger clients. According to Louw (1997) the education of parents, professionals and the public is one of the roles which speech-language therapists and audiologists must assume in order to address the needs of infants and families requiring ECI.

In summary, the results of the different stages of identification of risk conditions in the subjects as depicted in Table 6.1 indicate that technology is beginning to contribute to the earlier diagnoses of risk conditions in unborn children, some of whom became subjects in the empirical study. The prenatal counseling of parents concerning the risk factors for communication development and ECI services identified a new client basis for CHRIB.

The results of the low identification rate during the infant period in the subjects with communication disorders, such as autism/PDD and subjects with communication delays associated with low birth weight and prematurity, multiple births and expressive specific language delay, emphasize the presence of different subgroups in the subjects and the importance of targeting them in an effective early identification programme. The results indicate that increased knowledge of ECI among professionals and the public can increase the effectiveness of CHRIB and develop the field of ECI.

As the results indicated that those subjects with communication delay *in the absence of* established risk conditions were generally identified later than subjects *with* established risk conditions, the subjects' families required specific knowledge about the early signs of communication disorders and appropriate action upon identification of these signs. The results indicate the need for CHRIB to play a greater role in the earlier identification of communication delay in children in order to provide more effective ECI services and expand the field of ECI among professionals and potential clients.

The discussion of the main characteristics of the 153 subjects utilized in the empirical study revealed the large volumes of data stored in the CHRIB database and the wide variety of data manipulation and presentation possibilities using the different functions of the software programmes. The results revealed that during 1996 to 1999 CHRIB served a diverse population of young children requiring ECI whose characteristics indicated the following:

- CHRIB, as an ECI service provider, succeeds in providing services to infants from the neonatal stage, but the average age of 18 months in the subjects at the time of the CHRIB assessment suggests that earlier recruitment of clients must take place.

- As national epidemiological data indicates that the majority of infants requiring ECI will be from communities who are disadvantaged and those not aware of ECI (See Tables 3.2 and 3.3), late identification and referrals of clients can be expected. The results of the study demonstrated that CHRIB accommodated a few subjects with late identification of their risk conditions, therefore indicating the expansion of the target age range of birth to three to birth to five years in order to provide ECI services which will meet the needs of clients.
- CHRIB's consultation services rendered at the Facial Deformities Clinic succeeded in providing ECI services to a special population of infants, i.e. those with cleft lip and palate, from birth onwards. The success of these services are particularly relevant as Savage (1997) reported on a lack of programmes focusing on the developmental needs of infants with cleft lip and palate. This same model of consultation services provided by the CHRIB staff at the Facial Deformities Clinic should be adapted to enable CHRIB to extend services to community-based clinics in order to serve a wider population of infants and their families requiring ECI services (Fair & Louw, 1999).
- The consultation services rendered to other speech-language therapists emphasized the need for CHRIB to share expertise and should be extended to provide specialist consultations to clinicians new in the field of ECI.
- The results indicated the major potential of parents in identifying communication delay in their children. As some of the subjects' parents were aware of their children's problems long before they were assessed at CHRIB, it could indicate that they had specific information needs which should be addressed in public awareness programmes.

The characteristics of the subjects thus far suggested a diversity of mainly biological risk conditions, i.e. conditions relating to risk factors within the subjects, which include established and other biological conditions. As biological risk conditions relate to the majority of the subjects, these conditions require further analysis (See Figure VI.II).

6.3 ANALYSIS OF THE DIAGNOSTIC CLASSIFICATIONS FOUND IN THE SUBJECTS

The CHRIB database allows entry of multiple diagnostic classifications per subject, resulting in a comprehensive description of all the different biological risk conditions identified in a subject. Although this approach only considers the biological factors, it permits a more descriptive view on the causality of communication disorders in a particular subject and possible interaction between the risk condition can become apparent. This approach is a departure from the single-factor predictive models of the past which were found to be defective (Billeaud, 1998; Kochanek and Buka, 1995; Rossetti, 1996). The consideration of multiple biological risk factors impacting on a child's communication development results in a dynamic risk profile for each subject which continuously stimulates adaptations in an individualized ECI programme of a particular family.

6.3.1 Number of diagnostic classifications per subject

All the different diagnostic classifications displayed by the subjects were coded according to the *ICD-10* (CSS, 1996) classification system and subcategories were created to differentiate between the numerous types of clefts found in the subjects. Table 6.10 displays the statistical analysis of the diagnostic classifications allocated to the subjects in the CHRIB database and also explains how the *ICD-10* (CSS, 1996) was used in the empirical study.

Table 6.10 Analysis of diagnostic classifications per subject

Measures of Variability	Value
Number of subjects	153
Mean diagnostic classification entries per subject	3.54
Standard deviation (Position of data values away from the mean, Maxwell and Satake, 1997)	1.28
Minimum diagnostic classification entries per subject	1.00
Maximum diagnostic classification entries per subject	7.00
Total sum of diagnostic classification entries in CHRIB database	543

Table 6.11 Diagnostic Classifications of the Subjects (N=153)

Description of diagnosis according to the *ICD-10 Manual* (CSS, 1996)	***ICD-10* Classification**	*** Frequency**	*** %**
1. Specific developmental disorders of speech and language	F 80	143	94%
2. Specific speech articulation disorders	F 80.0	5	3%
3. Expressive language disorder	F 80.1	1	<1%
4. Childhood autism	F 84.0	3	2%
5. Pervasive developmental disorder	F 84.01	1	<1%
6. Hyperactivity	F 90.8	2	1%
7. Petit mal without grand mal seizures	G 40.7	2	1%
8. Muscular dystrophy	G 71.0	2	1%
9. Spastic quadriplegia with left-sided paresis	G 80.01	1	<1%
10. Chronic otitis media	H 65	84	55%
11. Sensorineural hearing loss	H 91.2	3	2%
12. Triplet pregnancy	O 30.1	5	3%
13. Twin pregnancy	O 30.0	18	12%
14. Small for gestational age	P 05	33	22%
15. Low birth weight (< 2 500g)	P 07	39	26%
16. Minor prematurity (37 weeks gestation)	P 07.1	16	11%
17. Extreme prematurity (< 30 weeks gestation)	P 07.2	2	1%
18. Moderate prematurity (31-36 weeks gestation)	P 07.3	39	26%
19. High birth weight	P 08	9	6%
20. Microcephaly	Q 02	1	<1%
21. Agenesis of the corpus callosum	Q 04.0	1	<1%
22. Congenital cerebral cysts	Q 04.6	1	<1%
23. Iris coloboma	Q 13.0	1	<1%
24. Ventricular septal defect of the heart	Q 21.0	8	5%
25. Atrium septal defect of the heart	Q 21.1	3	2%
26. Tetralogy of Fallot	Q 21.3	1	<1%
27. Congenital heart defect (unspecified)	Q 21.9	6	4%
28. Patent ductus arteriosis	Q 25.0	1	<1%
29. Choanal atresia	Q 30.0	1	<1%
30. Nose deformity (Tessier cleft 2/3 & 4)	Q 30.9	1	<1%
31. Cleft of the soft palate only	Q 35.3	11	7%
32. 40% cleft of the soft palate	Q 35.3.1	1	<1%
33. Cleft of the hard and soft palate	Q 35.5	4	3%
34. Cleft of the hard and soft palate (Pierre Robin Sequence)	Q 35.5.1	12	8%
35. Submucous cleft of the hard and soft palate	Q 35.5.2	1	<1%
36. 5% cleft of the hard palate and cleft of the soft palate (Goldenhar syndrome)	Q 35.5.4	3	2%
37. 80% cleft of the hard palate and cleft of the soft palate (van der Woude syndrome)	Q 35.5.8	1	<1%
38. Sub-mucous cleft, bifid uvula	Q 35.7	1	<1%
39. Bilateral cleft lip	Q 36.0	1	<1%
40. Left-sided cleft of the lip and maxilla	Q 37. 1.1	2	1%
41. Left-sided cleft of the lip and maxilla, 🗎 partial palate and complete cleft of the soft palate	Q 37.2	1	<1%

Table 6. 11 continued

Description of diagnosis according to the *ICD-10 Manual* (CSS, 1996)	***ICD-10* Classification**	*** Fre-quency**	*** %**
42. Left-sided cleft lip, intact hard palate and cleft of the soft Palate	Q 37.3	3	2%
43. Complete bilateral cleft lip, hard and soft palate	Q 37.4	10	7%
44. Complete bilateral cleft lip, hard and soft palate (van der Woude syndrome)	Q 37.4.1	1	<1%
45. Left-sided cleft lip, hard and soft palate	Q 37.5	9	6%
46. Left-sided cleft lip, hard and soft palate (part of an unknown syndrome)	Q 37.5.1	1	<1%
47. Left-sided cleft of the lip, bilateral cleft of the hard and soft palate	Q 37.5.2	1	<1%
48. Left-sided incomplete cleft of the lip, 20% cleft of the hard palate, complete cleft of the soft palate	Q 37.5.3	1	<1%
49. Left-sided complete cleft of the lip and maxilla, 50% cleft of the hard palate, complete cleft of the soft palate	Q 37.5.5	1	<1%
50. Right-sided cleft of the lip, hard and soft palate	Q 37.7	11	7%
51. Right-sided cleft lip and palate, partial left-sided cleft palate	Q 37.7.1	1	<1%
52. Right-sided incomplete cleft lip, 👌 cleft of the hard palate, complete cleft of the soft palate	Q 37.7.2	2	1%
53. Tongue tie	Q 38.3	1	<1%
54. Duodenal stenosis	Q 41.0	1	<1%
55. Craniostenosis	Q 75.0	1	<1%
56. Fetal alcohol syndrome	Q 86.0	1	<1%
57. Fetal *Roaccutane*® syndrome	Q 86.8.1	1	<1%
58. Unknown congenital condition / syndrome	Q 89	2	1%
59. Down syndrome, Trisomy 21	Q 90.0	22	14%
60. Down syndrome, Mosaic type	Q 90.1	1	<1%
61. Traumatic subarachnoid haemorrhage	S 06.6	1	<1%
Total	-	**543**	**N/A.**

Key to table headings

- Frequency: These numbers refer to the number of times each diagnostic classification was used
- %: The percentages do not add to 100% as more than one diagnostic classification entry was used to describe each subject's risk profile

As presented in Table 6.10 the mean number of diagnostic classification entries were approximately four per subject, with a minimum of one entry and a maximum of seven entries per subject. The method of multiple diagnostic classification entries per subject resulted in a total of 543 diagnostic classification entries in the CHRIB database (See also Table 6.11). The diagnostic classifications of the subjects were alphabetically organized according to the ICD-10 (CSS, 1996) coding system and presented in Table 6.11 as a complete list of all the different established and biological risk conditions occurring in the subjects. When a subject presented with different risk factors, the established risk condition (if any) was considered as the main diagnostic classification. In the case of biological risk factors only, the main condition present at birth, such as low birth weight, was entered as the main diagnostic classification of the subject.

According to Table 6.11 a total number of 61 diagnostic classifications were used to code the different conditions occurring in the 153 subjects. This way all the different established and biological risk factors known to be present in a subject could be listed, so that a clear communication risk profile of each subject emerged. For example, a subject presented with muscular dystrophy (G71.0), a submucous cleft of the hard and soft palate (Q35.5.2), had low birth weight (P07), was moderately premature (P07.3) and had a speech and language delay (F80). Appendix E provides a complete list of all 153 subjects' *ICD-10* (CSS, 1996) classifications.

The large number of different diagnostic classifications found in the subjects demonstrates the variety of clients requiring ECI in CHRIB.

6.3.2 Biological risk profile for communication disorders in the subjects

The risk profile of biological and established risk conditions relating to the subjects as a group and emerging from Table 6.11, is one of diversity. Under the nine main classifications (originally presented in Table 6.1 Nr 5) of cleft lip and palate, Down syndrome, eight other established risk conditions, autism/PDD, multiple pregnancies, low birth weight and premature birth, speech and language delay, tongue tie and hyperactivity, most subjects presented with more than one risk condition (See Table 6.10). Upon close inspection of Table 6.11 many risk conditions occurred only once in the sample, but added to the diversity of the risk profile of the total group of subjects.

The following discussion of Table 6.11 involves an explanation of the most prevalent characteristics of the 153 subjects and an analysis of the largest subgroups of subjects which can be derived from the results.

.1 *Communication disorders*

The *ICD-10* (CSS, 1996) diagnostic classifications which occurred in all but four (2%) of the subjects, were the three codes associated with communication disorders, i.e., specific developmental disorders of speech and language, specific speech articulation disorders and expressive language disorder (See Table 6.11 Nr 1, 2, & 3).

An additional table, Table 6.12, is a printout of a query created to display the four subjects found without any speech and language delay. The column headed "Explanation" in Table 6.12 was added to the printout for reasons of clarification and displays the flexibility of the CHRIB database to manipulate data to suit the researcher's needs.

Table 6.12 Print out of CHRIB Database query of subjects without speech and language delay (N=4)

File No. – LINK	Diagnosis	Explanation
94	**P07**	**Low birth weight**
94	P07.3	Moderate prematurity
154	**F90.8**	**Hyperactivity**
154	H65	Chronic otitis media
154	PO8	High birth weight
168	**P07**	**Low birth weight**
168	P07.3	Moderate prematurity
173	**Q37.1.1**	**Left-sided cleft of the lip and maxilla**
173	H65	Chronic otitis media

Key

- File No. - LINK refers to the client's ID number in the CHRIB database
- Main diagnostic classification printed in bold

According to Table 6.12 all four subjects presented with some biological risk conditions associated with communication disorders which warranted an assessment. The subjects were found to present with normal communication development and recommended for a follow-up assessment if the parents were concerned about their subsequent development.

The fact that almost all of the subjects displayed some form of language delay in Table 6.11 validates CHRIB's communication based EI service delivery approach and Rossetti's viewpoint that communication based intervention should start as early as possible since it can determine a young child's future success at school (Rossetti, 1996). As delays in other developmental areas, such as motor development were not included in the subjects' diagnostic classifications due to the limitations of the *ICD-10* (CSS, 1996), the occurrence of language delay in relation to other developmental delays in the subjects cannot be determined from these results. It therefore appears that language delay is the most common developmental delay occurring in the subjects, but further analysis of the data relating to the subjects' communication functioning is necessary to confirm this supposition.

The prevalence of language delays in the subjects should be viewed against the background of the strong correlation which exists between cognition, comprehension and production of language (Rossetti, 1996). This implies that language delays found in the subjects will predict developmental delays in other areas and should be accommodated in the basic approach to ECI in CHRIB.

.2 Chronic otitis media

According to Table 6.11 the second most prevalent diagnostic classification found in the subjects is chronic otitis media. Chronic otitis media, interpreted for the purposes of the study as a history of one or more incidences of the infection, occurred in 55% of the subjects. As developmental delays and disorders, craniofacial anomalies, stigmata and other anomalies associated with syndromes known to affect the outer and middle ear, are high risk factors for middle ear disease (Plante & Beeson, 1999), a high rate of chronic otitis media is to be expected among the subjects as they represent a high risk population for this disease.

As expected, the incidence of otitis media did in actual fact occur in more than 55% of the subjects (See communication functioning of the subjects). Since the parents did not report a history of recurrent middle ear disease in many instances and no medical confirmation of the condition suspected in the subjects was carried out by the time of data collection, these subjects were not classified as having chronic otitis media. Since the incidence of otitis media peaks in the seven to twelve month old population (Plante & Beeson, 1999), it confirms the subjects' high risk for the disease and the importance of an appropriate audiological management plan integrated into the overall ECI programme (Hugo, *et al*., 2000).

Since the management of chronic otitis media requires regular assessments, the results emphasize the importance of the role of the pediatric audiologist on the ECI team, not only for assessment purposes, but also for parent guidance and collaboration with speech language therapists and medical professionals (Hugo & Pottas, 1997; Kile, Schaffmeyer & Kuba, 1994). The results also confirm the importance of recognizing the link between chronic middle ear disease of the subjects and their risk for later auditory processing disorders, which indicates another contributing factor to their language disorders and subsequent risk for school failure (Hugo, *et al.,* 2000).

.3 Multiple births

The next diagnostic classification to be discussed concerns the occurrence of twins and triplets in the subjects. According to Table 6.11 (Nr 12 and 13) 23 (15%) of the subjects were associated with multiple births, a condition which accounts for approximately 1% of all births in the general population and posing a major risk for developmental delay (Batshaw, 1997; Sadler, 1995). The increased prevalence of subjects associated with multiple births in the sample also indicates their risk for communication delay.

As indicated earlier in Table 6.1 Nr 5, however, only 15 subjects from multiple births were listed, but those subjects did not include the eight children with additional established risk factors. As the eight subjects relating to multiple births and with additional established risk conditions were included in the established risk category in Table 6.1, it appeared as if only 15 subjects were twins or triplets.

Table 6.13 was compiled by filtering the data of Appendix E to reveal all 23 subjects relating to multiple births. The subjects' ages at the time of data collection and prior ECI involvement were added to the table.

According to Table 6.13 (See following pages) all the subjects associated with multiple births displayed delayed communication development as well as various risk conditions which can be related to their communication development. All the subjects, except those where one of the twins died prenatally (CHRIB ID Nr 24, 125, and 128), displayed additional biological risk factors associated with premature birth and ten of those subjects displayed established risk conditions as well. The occurrence of perinatal deaths of the one of the pairs in three of the subjects can be related to the higher incidence of perinatal and prenatal mortality and morbidity associated with twin pregnancies (Sadler, 1995).

The occurrence of monozygotic twins could pose an additional indicator for risk factors in the subjects. According to Table 6.13, ten of the 23 subjects associated with multiple births were monozygotic twins and a higher concordance of diagnostic classifications than in the dizygotic twins occurred in them. This finding corresponds with evidence in the literature that a higher rate of concordance of disorders, also communication disorders, are found in monozygotic twins due to their identical genotypes, than in dizygotic twins (Lewis & Thompson, 1992; Shprintzen, 1997). The second child of all the dizygotic twins in the subjects had normal communication development, while both subjects of a monozygotic pair displayed delayed communication development. It therefore appears that the monozygotic twins were particularly at risk for a communication delay. This finding provides insight into

Table 6.13 Subjects relating to multiple births and age at CHRIB assessment (N=23)

CHRIB ID	Age at CHRIB assessment	Risk conditions present in subject	Prior ECI
16	12.1 months	-One of dizygotic twins, 2nd child normal development* **-Cleft lip and palate*** -Low birth weight -Moderate premature birth -Delayed communication development -Chronic otitis media	Yes
19	6 months	-One of triplets, other children CHRIB ID 20 and 21 -Low birth weight -Moderate premature birth -Delayed communication development -Chronic otitis media	No
20	6 months	-One of triplets, other children CHRIB ID 19 and 21 -Low birth weight -Moderate premature birth -Delayed communication development	No
21	6 months	-One of triplets, other children CHRIB ID 19 and 20 -Low birth weight -Moderate premature birth -Small for gestational age -Delayed communication development	No
24	21.9 months	-One of a twin, 2nd child died after birth -**Cleft palate, possible syndrome** -Delayed communication development,	Yes
28	12.1 month	-One of dizygotic twins, 2nd child normal development -**Cleft lip and palate** -Petit mal -Moderate premature birth -Delayed communication development	Yes
54	12.6 months	-One of dizygotic twins, 2nd child normal development -**Cleft palate** -Low birth weight -Moderate premature birth -Small for gestational age -Delayed communication development -Chronic otitis media	Yes
63	22.7 months	-One of triplets, 2nd child CHRIB ID 64, 3rd child died -Low birth weight -Moderate premature birth -Delayed communication development	No
64	22.7 months	-One of triplets, 2nd child CHRIB ID 63, 3rd child died -Low birth weight -Moderate premature birth -Delayed communication development	No
70	12.7 months	-One of monozygotic twins, 2nd child CHRIB ID 72 -**Cleft lip and palate** -Moderate premature birth -Delayed communication development -Chronic otitis media	Yes
72	12.7 months	-One of monozygotic twins, 2nd child CHRIB ID 70 -Moderate premature birth -Delayed communication development -Chronic otitis media	Yes
84	32.1 months	-One of monozygotic twins, 2nd child CHRIB ID 85 -Small for gestational age -Delayed communication development	No

Table 6.13 continued

CHRIB ID	Age at CHRIB assessment	Risk conditions present in subject	Prior ECI
85	32.1.months	-One of monozygotic twins, 2nd child CHRIB ID 84 -Low birth weight -Delayed communication development	No
100	21.4 months	-One of monozygotic twins, 2nd child CHRIB ID 101 -**Spastic quadriplegia** -Low birth weight -Moderate premature birth -Delayed communication development -Chronic otitis media	Yes
101	21.4 months	-One of monozygotic twins, 2nd child CHRIB ID 100 -Low birth weight -Moderate premature birth -Delayed communication development -Chronic otitis media	Yes
125	10.6 months	-One of a twin, 2nd child died prenatally -**Cleft lip and palate** -Delayed communication development -Chronic otitis media	Yes
128	11.3 months	-One of a twin, 2nd child died prenatally -**Cleft palate** -Delayed communication development -Chronic otitis media	Yes
139	12.4 months	-One of dizygotic twins, 2nd child normal development -**Down syndrome** -Low birth weight -Moderate premature birth -Small for gestational age -Delayed communication development -Chronic otitis media	Yes
148	33.7 months	-One of monozygotic twins, 2nd child CHRIB ID 149 -Moderate premature birth -Delayed communication development	No
149	33.7 months	-One of monozygotic twins, 2nd child CHRIB ID 148 -Moderate premature birth -Delayed communication development	No
151	16.9 months	-One of dizygotic twins, 2nd child normal development -**Acquired sensorineural hearing loss** -Moderate premature birth -Delayed communication development	Yes
166	31.6 months	-One of monozygotic twins, 2nd child CHRIB ID 167 -Low birth weight -Moderate premature birth -Delayed communication development	No
167	31.6 months	-One of monozygotic twins, 2nd child CHRIB ID 166 -Moderate premature birth -Delayed communication development	No

Key

- In case of twins, both children were assessed, but if one child was found with normal development, the data of that child was not entered into the CHRIB database
- All established risk conditions are indicated in bold

the nature of communication disorders to be expected in children from multiple pregnancies which can lead to earlier identification of their risks for communication delay and earlier commencement of ECI.

As indicated in Table 6.13 the 23 (15%) subjects associated with multiple births presented with a unique combination of risk factors in complex interaction with one another which were in constant change after birth. The negative impact of the risk factors on the subjects' communication development relates to:

- *Risks relating to identical genetic phenotypes*. This implies a higher risk in monozygotic twins for both children to have a developmental disorder or communication delay than in the case of dizygotic twins (Lewis & Thompson, 1992).
- *Environmental risks*, i.e. the unique language learning environment of close dependence which twins experience, is considered to be a risk factor as it often leads to delayed communication development in twins (Crystal, 1997). Due to less frequent mother-child-interactions, a shared language model and the presence of a second child of the same age while acquiring language, a private form of communication and delayed language development can result (Crystal, 1997; Lewis & Thompson, 1992).
- *Biological risks* due to low birth weight and premature birth as a result of intra uterine crowding (Batshaw, 1997) and associated perinatal conditions (Lewis and Thompson, 1992) are generally accepted to be risk factors for communication delay in multiple pregnancies (Rossetti, 1996).
- *Established risks.* Upon calculation of the data in Table 6.13 it appears that 10 (43%) of the subjects presented with the established risk conditions. These ten subjects associated with established risk conditions and multiple pregnancies included seven subjects with cleft lip and palate and one subject with each of the following conditions: Down syndrome, spastic quadriplegia and acquired sensorineural hearing loss (Subjects with CHRIB ID Nr 16, 24, 28, 54, 70, 100, 125, 128, 139 and 151, See Table 6. 13).

The occurrence of established risk conditions, which includes congenital anomalies such as cleft lip and palate and Down syndrome (Rossetti, 1996) found in the subjects and associated with multiple births, can be related to the causes of congenital anomalies as explained by Sadler (1995). While the causes of 40-60% of congenital anomalies are unknown, chromosome and genetic syndromes account for approximately 15%, environmental factors cause about 10%, a combination of genetic and environmental influences produces 20-25% and twinning causes 0.5-1% of all congenital anomalies (Sadler, 1995). Furthermore, the findings of Largo, Pfister, Molinari, Kundu, Lipp and Duc (1989) in a large longitudinal cohort study on the development of premature infants indicate that the twins among the subjects displayed significantly more minor congenital anomalies than the control group of full-term subjects. It is therefore to be expected that infants associated with multiple pregnancies will display more congenital anomalies.

Knowledge of the unique combination of risk factors found in the subjects associated with multiple births can alert the CHRIB clinicians to public information needs and to employ specific strategies to identify these children as young as possible. Further analysis of the data revealed that the subjects could have been identified earlier. As previously indicated in Table 6.8 and now again occurring in the subjects associated with multiple births, the presence of an established risk condition appears to assist the earlier identification of communication delay in the subjects. According to Table 6.13 the subjects with additional established risk conditions to multiple pregnancy were assessed at CHRIB at an earlier age and were already receiving some form of ECI services prior to the time of data collection. When calculating the average ages of the ten subjects with established risk conditions, the results indicate that they were assessed at an average age of *14 months*. In contrast, the average age of the subjects with biological risk conditions and multiple pregnancy only (Subjects with CHRIB ID Nr 16, 19, 20, 21, 63, 64, 84, 85, 148, 149, 166, and 167) was *25 months* and they did not receive any ECI prior to the CHRIB assessment. Some of these subjects only started with ECI at the age of 33.7 months.

It appears that the parents of the subjects associated with multiple births without established risk conditions, were not aware of the risk for communication delay in their children and sought help only when the subjects' communication delay became evident. The only exceptions were the triplets (CHRIB ID Nr 19, 20 and 21), the children of a speech-language therapist, who were assessed at the relatively early age of six months.

As multiple births were associated with numerous risk conditions for communication delay in the subjects, it appears that those parents could have benefited from information about the relationship between biological risk factors, established risk factors and the risks involved associated with the unique language learning environment of their children in order to have started earlier with ECI. The late identification of communication delay in some of the subjects associated with multiple pregnancies could be related to parental lack of knowledge about the specific set of risk factors for communication development occurring in their children. As multiple births are now usually identified very soon prenatally, parents need information in the prenatal period about the risks for communication delay associated with their children. In order to provide improved ECI services to this subgroup of clients, it is necessary to identify children from multiple pregnancies much earlier than the subjects of the empirical study were.

.4 *Birth weight and gestation*

As demonstrated in Table 6.1 Nr 4, low birth weight and premature birth, as a single diagnostic classification, occurred in only 7% of the subjects. However, according to Table 6.11 low birth weight occurred in 26% of the subjects and premature birth (moderate and extreme) occurred in 27% of the subjects *as part of* their multiple diagnostic classifications. Since these two conditions are not mutually exclusive, i.e. low birth weight can occur with or without premature birth, further clarification of the results is necessary.

By process of elimination the data in the table displaying all the *ICD-10* (CSS, 1996) diagnostic classifications per subject (See Appendix E) were sorted to

Table 6.14 Subjects with low birth weight and/or premature birth (N=52)

#	**Client ID**	***ICD-10***	***ICD-10***	***ICD-10***	***ICD-10***	***ICD-10***	***ICD-10***	***ICD-10***	**Main Diagnostic Classification**
1	10	Q35.5.1	F80	P05					Cleft lip and palate
2	15	Q86.8.1	P07	P05	F80				Fetal *Roaccutane®* syndrome
3	16	Q37.7	O30.0	P07	P07.3	F80	H65		Cleft lip and palate
4	19	O 30.1	P07	P07.3	F80	H65			Multiple pregnancy
5	20	O 30.1	P07	P07.3	F80				Multiple pregnancy
6	21	O 30.1	P07	P07.3	P05	F80			Multiple pregnancy
7	25	P07.2	P07	P05	F80	H65			High risk infant
8	26	Q35.5	P07.3	F80					Cleft lip and palate
9	28	Q37.7	O30.0	G40.7	P07.3	F80	H65		Cleft lip and palate
10	29	Q35.5.2	G71.0	P07	P07.3	F80			Cleft lip and palate
11	35	Q35.3	P07	P05	F80	H65			Cleft lip and palate
12	42	Q90.0	P07	P07.1	P05	F80			Down syndrome
13	49	Q90.0	P07	P07.1	F80	H65	Q21.0		Down syndrome
14	54	Q35.3	O30.0	P07	P07.1	P05	F80	H65	Cleft lip and palate
15	56	Q37.4.1	P07	P05	F80				Cleft lip and palate
16	58	Q37.5.1	P07	P07.3	P05	F80	H65		Cleft lip and palate
17	59	Q35.7	P07	P07.3	F80	H65			Cleft lip and palate
18	63	O 30.1	P07	P07.3	F80				Multiple pregnancy
19	64	O 30.1	P07	P07.3	F80				Multiple pregnancy
20	66	Q90.0	P07.3	F80					Down syndrome
21	67	Q90.0	P07.3	F80					Down syndrome
22	68	P07	P07.1	P05	F80				High risk infant
23	69	Q90.0	P07	P07.1	P07.3	P05	F80		Down syndrome
24	70	Q37.7	O30.0	P07.3	F80	H65			Cleft lip and palate
25	72	O30.0	P07.3	F80	H65				Multiple pregnancy
26	81	P07	P07.3	F80					High risk infant
27	85	O30.0	P07	F80					Multiple pregnancy
28	86	P07	P07.3	F80	H65				High risk infant
29	93	P07.2	P07	F80					High risk infant
30	94	P07.3	P07						High risk infant
31	99	F90.8	P07.3	F80	H65	PO8			Hyperactivity
32	100	O30.0	P07.3	P07	G80.01	F80	H65		Multiple pregnancy
33	101	O30.0	P07.3	P07	F80	H65			Multiple pregnancy
34	112	Q37.4	P07	P05	F80	H65			Cleft lip and palate
35	116	Q90.0	P07.3	F80	Q21.9				Down syndrome
36	121	Q90.0	P07	P05	F80	H65			Down syndrome
37	122	P07.3	P07	F80	H65	Q21.9	Q89		High risk infant
38	123	Q37.5	P07	P07.3	F80	H65	Q21.9	Q04.6	Cleft lip and palate
39	129	Q37.5	P07	P07.3	P05	F80			Cleft lip and palate
40	138	P07.3	P07	F80					High risk infant
41	139	Q90.0	O30.0	P07.3	P07	P05	F80	H65	Down syndrome
42	143	Q37.7	P07	P05	F80.0	H65			Cleft lip and palate
43	147	Q37.5.5	Q75.0	P07.3	P07	F80			Cleft lip and palate
44	148	O30.0	P07.3	F80					Multiple pregnancy
45	149	O30.0	P07.3	F80					Multiple pregnancy
46	151	O30.0	H91.2	P07.3	F80				Multiple pregnancy
47	152	Q37.5.3	P07.3	F80					Cleft lip and palate
48	158	Q37.4	PO3.7	P07	P05	F80	H65		Cleft lip and palate

Table 6.14 continued

#	Client ID	*ICD-10*	*ICD-10*	*ICD-10*	*ICD-10*	*ICD-10*	*ICD-10*	*ICD-10*	Main Diagnostic Classification
49	166	O30.0	P07	P07.3	F80				Multiple pregnancy
50	167	O30.0	P07.3	F80					Multiple pregnancy
51	168	P07.3	P07						High risk infant
52	172	Q35.3	P07	P05	F80	H65			Cleft lip and palate

reveal only the subjects with at least one of the following four diagnostic classifications, namely P05 (small for gestational age), P07 (low birth weight), P07.3 (moderate prematurity) and P07.2 (extreme prematurity) and displayed in Table 6.14. The classification of minor prematurity (infants born at 37 weeks gestation), which occurred in 16 (11%) of the subjects (See Table 6.11), was omitted since it is not regarded by all authors as prematurity (CSS, 1996; Rossetti, 1996).

For the sake of clarity the subjects demonstrating low birth weight and premature birth in the absence of any other condition, are referred to as high risk infants.

According to Table 6.14 a total number of 52 (34%) subjects were found to suit the description of low birth weight and or prematurity. Since the prevalence of low birth weight is approximately 7% of all births and that of prematurity approximately 10% of all births in the USA (Blair & Ramey, 1997) it is clear that an increased rate of low birth weight and premature birth occurred in the sample employed in the current empirical study.

Apart from the high risk infants in Table 6.14, subjects classified with cleft lip and palate, multiple pregnancies, Down syndrome, hyperactivity and fetal *Roaccutane®* syndrome were also found to present with low birth weight and prematurity. A further table, Table 6.15 depicts the number of subjects represented in each of these diagnostic classifications who also presented with low birth weight and prematurity.

Table 6.15 Number of subjects in each diagnostic classification with low birth weight and prematurity (N=52)

Diagnostic Classification *ICD-10* (CSS, 1996)	**# Subjects**	**% of particular classification**
Cleft lip and palate	18 of 79	23%
Multiple pregnancies	14 of 23	61%
High risk infants	10 of 10	100%
Down syndrome	8 of 23	35%
Fetal *Roaccutane*® syndrome	1	-
Hyperactivity	1	-
Total	**52**	**N/A**

The finding that subjects with Down syndrome and those with multiple pregnancies were associated with low birth weight is well known and reported by various authors (Lubchenco, 1987; Sadler, 1995; Batshaw, 1997). The increased rate of low birth weight and premature birth found in the subjects with cleft lip and palate is, however, not generally reported. The only literature support for this result found to date is in a large Swedish study derived from database records of that country's infants born with clefts since 1965. Becker, *et al.* (1998) found that infants with cleft lip and palate were significantly lighter and shorter at birth than the control group of infants without cleft lip and palate. Becker, *et al.* (1998) also determined a positive correlation to exist between intra uterine growth retardation and clefting in the subjects, i.e. the more severe the intra uterine growth retardation, the more severe the clefting was found. The authors found that subjects with isolated cleft lip did not differ from the control group, but subjects with isolated cleft palate and those with cleft lip and palate differed significantly from the control group regarding birth weight and body length (Becker, *et al.,* 1998).

Except for the study of Becker, *et al*. (1998) it appears that low birth weight in infants with cleft lip and palate was not investigated since the various problems associated with the established risk were serious enough for clinicians to handle. Following the increased awareness in recent years about EI in all disciplines who have traditionally been treating infants and young children, infants with cleft lip and palate are now viewed from an EI perspective (Savage, 1997). As the importance of other risks is now being recognized in these infants, ECI programmes can be developed to effectively meet the unique needs of infants with cleft lip and palate and their families.

The occurrence of low birth weight, but full term in the subject with fetal *Roaccutane*® syndrome pregnancy (See Appendix E, Client ID 15) is not a feature described in the information released by the manufacturers of the drug (Roche Products (Pty) Ltd., 1996). *Roaccutane*® or isotretinoin is a vitamin A isomer used for the treatment of severe recalcitrant cystic acne and is a potent human teratogen. Use of this drug during pregnancy is associated with a high risk for fetotoxicity resulting in a high proportion of spontaneous abortions and a high risk for anomalies involving the central nervous system, craniofacial features, the cardiovascular system, branchial arch mesenchymal tissue, thymic defects and miscellaneous anomalies (Briggs, Freeman & Yaffe, 1994). Since the limited documentation available on fetal *Roaccutane*® syndrome only describes the congenital anomalies of the syndrome and not the perinatal conditions and developmental expectations of these children, no direct support for the low birth weight occurring in the specific subject could be found.

The occurrence of low birth weight and normal gestation, however, indicating intra uterine growth retardation in infants with other congenital anomalies, is described in the literature. According to Allen (1995) maternal ingestions which have a teratogenic effect, are associated with intra uterine growth retardation which co-occur with the congenital anomalies. Infants with fetal *Roaccutane*® syndrome are therefore at risk for intra uterine growth retardation and low birth weight as found in the particular subject discussed.

The subject with hyperactivity and low birth weight is also in agreement with literature findings as attention deficit disorder (ADD) with or without hyperactivity is considered as one of the so called minor disorders associated with low birth weight (Bennett, 1995). Since these infants can be associated with biological risk factors such as low birth weight as in the case of the subjects, it is possible to identify them early. It appears, however, that these children are often referred for services only when their difficulties cause them problems at school (Plante & Beeson, 1999).

It appears that the occurrence of low birth weight and prematurity of minor to moderate degree found in the subjects identifies some subgroups of young children at risk for communication delays not widely reported in the literature. Extensive literature reporting, however, on the prevalence of major developmental disabilities, i.e. permanent conditions with a neuro-developmental basis which negatively impacts on a child’s functioning, such as cerebral palsy, cognitive impairment, visual and hearing impairments in infants with very low birth weight, are found (Bennett, 1995; Blair & Ramey, 1997; Rossetti, 1996; Rubin, 1995). In addition, infants with very low birth weight are now increasingly associated with the so called new morbidities of prematurity which include language, fine motor, perceptual, socio-emotional learning and attention dysfunctions (Bennett, 1995). While these dysfunctions are consistently associated with infants with very low birth weight, it is not clear to what extent these conditions can be associated with infants with moderate to minor low birth weight and premature birth.

Since the classification of extremely premature birth occurred in only two subjects of the empirical study (See Table 6.11 Nr 17 and Table 6.14, subjects with CHRIB ID Nr 25 and 93) it is important to analyze the results regarding the other categories of low birth weight and prematurity occurring in the subjects. An approach, using the concept of small for gestational age and distinguishing between preterm small for gestational age and full-term, but small for gestational age, to analyze the occurrence of low birth weight and premature birth in the subjects, was followed (Allen, 1995).

The classification of small for gestational age (See Table 6.14, *ICD-10* Code P05), measured according to standardized norms (Lubchenco, 1987), and referring to infants weighing significantly less than expected for their degree of maturity at birth (Allen, 1995), is usually regarded as a product of low birth weight and premature birth. Small for gestational age, which reflects poor fetal growth in utero, resulting in some degree of intra-uterine growth retardation, occurred in 33 (22%) of the subjects with low birth weight and premature birth.

Although there are many causes of intrauterine growth retardation such as genetic, congenital infections, maternal ingestions (alcohol, medical drugs and illicit drugs), maternal conditions, uteroplacental abnormalities and unknown causes, 11% of the population of preterm small-for-gestational age infants are reported to present with a recognizable chromosomal or dysmorphic syndrome (Allen, 1995). The increased rate of subjects who were small-for-gestational age in the present study may therefore be related to the large number of subjects with congenital anomalies, such as cleft lip and palate, Down syndrome and other anomalies found in the sample (See Table 6.11).

Using the concept of small for gestational age results in a better understanding of the study reported by Becker, *et al.* (1998) and already discussed, which determined a correlation between intrauterine growth retardation and infants with cleft lip and palate. The subjects reported in the study (Becker, *et al*., 1998) were not necessarily premature, but displayed lower birth weight than the control group of infants without cleft lip and palate.

Small for gestational age, however, occurred in 15 subjects in the absence of low birth weight and premature birth in the subjects (See Appendix E and Table 6.14, *ICD-10* diagnostic classification P05) and depicted in Table 6.16. This appears to be an interesting observation and according to Allen (1995) full-term, but small for gestational age infants, are reported not to have an increased incidence of major developmental disabilities. Evidence, however, clearly suggest that full-term, but small for gestational age children, demonstrate a high rate of subtle signs of central nervous system dysfunction which includes speech and language problems, minor neuromotor dysfunction, learning disability, attention deficits, hyperactivity and behaviour problems (Allen, 1995; Kurtz, *et al*., 1996).

Table 6.16 Occurrence of small for gestational age but full-term in the Subjects (N=15)

Developmental disorder	# Subjects
Cleft lip and palate	7
Down syndrome	4
Sensorineural hearing loss	1
Multiple pregnancy	1
Agenesis of the corpus callosum	1
Microcephaly	1
Total	**15**

The increased rate of low birth weight and prematurity of a less severe degree found in the subjects should therefore be related to the more subtle manifestations of developmental disabilities found in children with intra-uterine growth retardation as described by Allen (1995) and to the increased rate of congenital anomalies found in the subjects. The high prevalence of low birth weight and prematurity found in the subjects who are all at risk for communication disorders, points to the diversity of associated conditions contributing to the risk profile of the subjects and the complexity of communication disorders exhibited by the subjects.

According to Table 6.11 Nr 19 the occurrence of high birth weight was classified as a diagnostic category in nine of the subjects. This classification is included in the *ICD-10* (CSS, 1996) since it can be an underlying cause of infant mortality. The condition is therefore not considered as a direct cause for communication disorders, but can lead to fetal distress, delivery problems and birth trauma which are risk factors for developmental disorders (Roberton, 1986). The presence of high birth weight alone does not indicate excessive risk (Rossetti, 1986) and was therefore not regarded as an important risk factor in the subjects.

The increased prevalence of low birth weight, prematurity and small for gestational age and found in subgroups of the subjects at risk for communication delays, but not usually associated with these conditions provides a better understanding of the nature of subsequent developmental problems these subjects are at-risk for. The finding reiterates Rossetti's view (1990a) that low birth weight is a multifactorial neonatal medical complication which is a major determinant of infant mortality and of developmental delay in surviving infants.

.5 Congenital heart defects

In Table 6.11 rows number 24-28 refer to conditions associated with various forms of heart anomalies which occurred 19 times in the subjects. Since three subjects displayed more than one heart defect, a total of only 16 subjects presented with heart defects. The number of subjects presenting with heart defects is arranged according to each diagnostic classification in Table 6.17.

Table 6.17 Number of subjects in each diagnostic classification with congenital heart defects (N=16)

Diagnostic Classification *ICD-10* (CSS, 1996)	**# Subjects**	**% of particular classification**
Cleft lip and palate	5 of 79	6%
Down syndrome	9 of 23 (3 subjects had multiple defects)	39%
Unknown congenital syndrome	2 of 2	100%
Total	**16**	**n. a.**

The results in Table 6.17 correspond with those of Sadler (1995) who reports that heart defects are associated with a number of genetic and chromosomal syndromes. According to Wolf and Glass (1992) the incidence of congenital heart defects, characterized by an anatomic defect in the cardiovascular system resulting in abnormal blood flow, is 8% per 1 000 live births. In slightly more than 50% of these cases, congenital heart disease occurs as an isolated defect, and in the remaining cases it occurs in conjunction with a malformation, chromosomal defect, syndrome or a syndromic association (Wolf & Glass, 1992: 347).

According to Shprintzen (1997) it has been well established that 10% of all infants with some form of clefting have congenital heart disease as a result of a syndromic association. Cardiac abnormalities are often associated with craniofacial defects as the neural crest cells contribute to both the development of the heart, the head and the neck during embryogenesis (Sadler, 1995). The results of the current empirical study found that heart defects occurred in the subjects with cleft lip and palate, but at a rate of 6%, thus with a lower prevalence than quoted by Shprintzen (1997). The lower prevalence of heart defects found in the subjects could possibly due to the small sample of subjects in the empirical study.

According to Van Dyke (1995) 35-40% of children with Down syndrome present with congenital heart disease which can present as single defects as well as multiple defects. Some authors, however, report the prevalence of heart defects in these children as high as 40-50% (Spiker & Hopmann, 1997) and according to Batshaw (1997) two thirds (66%) of infants with Down syndrome have heart defects. The rate of heart defects occurring in the subjects with Down syndrome confirm the results of Van Dyke (1995) as 39% of subjects were found to present with some form of congenital cardiac abnormality. The subjects with Down syndrome therefore appears to be a representative sample of individuals with the disorder.

The presence of heart defects adds to the risk profile of the subjects and emphasizes some of the health concerns and feeding difficulties which must be considered in assessment and intervention. In order to reveal their multiple anomalies, the diagnostic profiles of the 16 subjects with congenital heart defects are presented in Table 6.18.

As indicated in Table 6.18, *all* 16 subjects with congenital heart defects presented with another congenital condition as well. Furthermore, 13 of the 16 subjects with congenital heart defects presented with a known syndrome, a sequence or with congenital anomalies indicative of a syndrome, but not yet diagnosed at the time of the CHRIB assessment. This finding reiterates the statement by Wolf and Glass (1992) that congenital heart defects are frequently associated with congenital anomalies.

Table 6.18 Diagnostic profiles of subjects with congenital heart defects (N=16)

Client ID	Diagnostic Profile of the Subjects
37	1. Goldenhar syndrome with 5% cleft of hard palate and cleft of soft palate **2. Ventricular septal defect of the heart*** 3. Delayed speech and language development- 4. Recurrent otitis media
41	1. Down syndrome **2. Ventricular septal defect of the heart** 3. Minor prematurity 4. Delayed speech and language development
49	1. Down syndrome **2. Ventricular septal defect of the heart** 3. Low birth weight 4. Minor prematurity 5. Delayed speech and language development 6. Recurrent otitis media
50	1. Down syndrome **2. Ventricular septal defect of the heart** 3. Delayed speech and language development 4. Recurrent otitis media
53	1. Down syndrome **2. Ventricular septal defect of the heart** 3. Duodenal stenosis 4. Low birth weight 5. Delayed speech and language development
97	1. Down syndrome **2. Ventricular septal defect of the heart** **3. Atrium septal defect of the heart** 4. Delayed speech and language development
109	1. Unknown congenital condition or syndrome 2. Sensorineural hearing loss **3. Tetralogy of Fallot** 4. Choanal atresia 5. Iris coloboma 6. Delayed speech and language development
116	1. Down syndrome **2. Unspecified congenital heart defect** 3. Moderate prematurity 4. Delayed speech and language development
118	1. Down syndrome **2. Unspecified congenital heart defect** 3. Delayed speech and language development
120	1. Pierre Robin Sequence **2. Unspecified congenital heart defect** 3. Delayed speech and language development 4. Recurrent otitis media
122	1. Unknown congenital condition / syndrome **2. Unspecified congenital heart defect** 3. Low birth weight 4. Moderate prematurity 5. Delayed speech and language development 6. Recurrent otitis media
123	1. Left-sided cleft lip and palate **2. Unspecified congenital heart defect** 3. Congenital cerebral cysts 3. Low birth weight 4. Moderate prematurity 5. Delayed speech and language development 6. Recurrent otitis media

Table 6.18 continued

Client ID	Diagnostic Profile of the Subjects
126	1. Down syndrome **2. Ventricular septal defect of the heart** **3. Patent ductus arteriosis** 4. Petit mal without grand mal seizures 5. Delayed speech and language development 6. Recurrent otitis media
135	1. Down syndrome **2. Ventricular septal defect of the heart** **3. Atrium septal defect of the heart** 4. Minor prematurity 5. Delayed speech and language development 6. Recurrent otitis media
155	1. Cleft of the heart and soft palate **2. Atrium septal defect** 3. Delayed speech and language development
159	1. Right-sided cleft of the lip, hard and soft palate **2. Unspecified congenital heart defect** 3. Small for gestational age 4. Delayed speech and language development

***Key:** All congenital heart defects are indicated in bold

When calculating the mean number of diagnostic classifications in each subject with a congenital heart defect, the results confirm the statement by Wolf and Glass (1992) from another perspective. The mean number of diagnostic classifications found in the subjects with congenital heart defects is *four to five classifications*, with a minimum of three and maximum of six classifications according to the *ICD-10*. As indicated previously in Table 6.10, the mean number of diagnostic classifications found in all the subjects of the empirical study was *three to four classifications*, with a minimum of one classification and a maximum of seven classifications.

It appears that the presence of a congenital heart defect may assist the clinician in investigating the possibility of a syndrome or sequence in an infant or toddler. Congenital heart defects, although not of a serious degree found in most of the subjects with the defect, are therefore very important indicators of syndromes in the subjects. The occurrence of a heart defect was found to be in conjunction with a syndrome in most of the subjects.

Although congenital heart defects occurred in a small percentage of the subjects, the results revealed one of the hidden characteristics of the subjects which occurred in conjunction with different other congenital anomalies as depicted in Table 6.18. The importance of paying attention to so called minor symptoms is reinforced by Shprintzen (1997) when stating that, in order to avoid poor and ineffective care for a client, it is essential to make a diagnosis when multiple anomalies occur in a child.

Since children with congenital heart defects present with various degrees of congenital heart disease, resulting in a failure to thrive and feeding difficulties which can cause them to tire before taking in sufficient volumes of food (Wolf & Glass, 1992), it is important for the clinician in ECI to be aware of the possible effects of congenital heart defects on the development of clients.

In contrast with small number of congenital heart defects found in the subjects, the next diagnostic classification to be discussed represents the major group of congenital anomalies found in the subjects.

.6 *Subjects with cleft lip and palate*

The next *ICD-10* (CSS, 1996) diagnostic classification recorded in Table 6.11 involves the 79 subjects presenting with various forms of cleft lip and palate, which also varies greatly in severity. The numerical classification Q35 indicates all the subjects with various forms of cleft palate (34 or 43% subjects), Q36 refers to cleft lip only (1 or <1% subject) and Q37 marks the subjects with various degrees of unilateral or bilateral cleft lip and palate (44 or 56% subjects). Approximately half of the subjects presented with cleft lip and palate which indicates the same distribution of this cleft type reported in the literature (Plante & Beeson, 1999). It therefore appears that the sample utilized in the empirical study is representative.

As the presence of a cleft lip only is usually not associated with a communication disorder or delay (Brenner & Levin, 1998), these infants are normally not referred to CHRIB. Eiserman, Shisler and Ferguson (1996), however, describe the risk for co-occurring developmental delays in children with cleft lip only and should therefore at least be assessed for communication delay. The one subject with a bilateral cleft lip presented with an additional risk factor for communication delay, i.e. recurrent otitis media and was followed up with an assessment and parent guidance.

Upon further analysis of Table 6.11 the most salient feature of the subjects with cleft lip and palate is the large variety of cleft types, indicating the broad spectrum of severity of clefting conditions occurring in the subjects. Twenty two different diagnostic classifications (See Table 6.11, rows number 31 to 52) were used to describe the different degrees of clefting in the subjects, from a facial cleft, a sub-mucous cleft of the palate to various degrees of clefts of the lip, the soft and hard palate and indicated by percentages as diagnosed by the oral, facial and maxillo surgeon or plastic surgeon. The large variety of clefts described in the subjects can be attributed to the excellence of the surgeon to pay attention to detail when making a diagnosis.

The large variety in cleft types in the subjects is also central to the complexity of cranio-facial disorders and is extensively described in the literature (Bütow, 1995; Shprintzen, 1997; Robinson & Sadler, 1992). The great variation in cleft types can, however, be sidelined in a clinical context such as CHRIB where the emphasis is on the assessment of communication skills of the clients. It is therefore important that the ECI clinician views the young child with cleft lip and palate in totality, yet consider all the detail about the child’s specific disorder when assessing and compiling an intervention plan

Apart from the diversity in cleft types and associated conditions such as low birth weight, premature birth, multiple pregnancy, heart defects, delayed communication development and recurrent otitis media occurring in the subjects with cleft lip and palate and discussed previously, a variety of additional conditions were identified in the subjects. In 24 (30%) instances the presence of some form of cleft lip and/or palate in a subject co-occurred with the following conditions: Muscular dystrophy, petit mal without grand mal seizures, congenital cerebral cysts, a Tessier type cleft, Pierre Robin sequence, Goldenhar syndrome, van der Woude syndrome, an unknown syndrome, and craniostenosis (See Table 6.11, Nr 7, 8, 22, 30, 34, 36, 37, 44, 46 and 55).

The results confirm research findings that coexisting anomalies frequently occur in children with cleft lip and palate (McWilliams, 1992). According to Robinson and Sadler (1992) more than 250 recognized disorders, in which facial clefts may be an associated feature, have been described. Similarly, 40% of children with clefts are reported to present with associated anomalies (Wolf & Glass, 1992). The results indicate that the subjects with cleft lip and palate present with a multiple risk profile which adds to the complexity of the problems associated with cranio-facial disorders and their developmental speech and language problems, which poses a challenge to early assessment and intervention.

According to Savage (1997) infants with cleft lip and/or palate are biologically at risk for developmental delay. The results of the empirical study indicated that the *risk profile* of the subjects comprises of events which originated at different periods in life and from different but interacting sources, namely:

- Events transpiring in the periconceptual phase which cause various genetic syndromes, muscular dystrophy and multiple pregnancy.
- Abnormal embryogenesis associated with Pierre Robin Sequence, Tessier Type cleft, congenital heart defects, cleft lip and palate and intrauterine growth retardation. Although these conditions found in the subjects originated during embryogenesis, they can be precipitated by genetic disorders (Shprintzen, 1997).
- Central nervous system involvement responsible for petit mal seizures and congenital cerebral cysts.
- Risks during the perinatal period associated with low birth weight and premature birth.
- Risks during the postnatal period and later in life and associated with recurrent otitis media.

The biological risks identified in the subjects with cleft lip and palate therefore involve multiple systems and indicate vulnerable periods when potential damaging events can occur in a so called cascading manner (Shprintzen,

1997) in the subjects. These vulnerable periods for biological risks in children with cleft palate span from conception, through the prenatal period of embryogenesis, the perinatal period, the postnatal period and the later stages of early childhood. Biological risk conditions are, however, not the only risk conditions contributing to the communication disorders of the subjects with cleft lip and palate. The subjects with cleft lip ad palate comprised that largest subgroup of subjects in the empirical study and additional data analysis revealed more of their characteristics and risk conditions (See 6.4.1 and 6.4.2).

The results regarding the subjects with cleft lip and palate indicated that professionals involved in ECI must look beyond the obvious visible established risk of these young children, as they present with a multifaceted disorder which should be described in detail in order to fully understand the nature of their communication disorder.

.7 Subjects with Down syndrome

The last diagnostic classification to be discussed according to Table 6.11, codes Q90.0 and Q90.1 (*ICD-10*, CSS, 1996), concerns the 23 subjects with Down syndrome. This subgroup of consist of 22 subjects with Trisomy 21 and one subject with Down syndrome mosaicism, implying that both the normal number of chromosomes and an extra number 21 chromosome are present in this subject (Thomson, 1995).

Based on Appendix E and by filtering the data, Table 6.19 displays the characteristics of the subjects with Down syndrome.

Table 6.19 Characteristics of subjects with Down syndrome (N=23)

Characteristic	Value / Description	
Age at CHRIB assessment	Average: 9.83 months Range: 0.8 – 26.8 months	
Number of diagnostic classifications entries per subject	Average: 4 entries Range: 2 – 7 entries	
Different diagnostic classification entries apart from Down syndrome found in the subjects	**Description**	**Value**
	1. Speech and language delay	23 / 100%
	2. Congenital heart defects	9 / 39%
	3. Small for gestational age	6 /26%
	4. Recurrent otitis media	6 / 26%
	5. Low birth weight	5 / 22%
	6. Minor prematurity	4 / 17%
	7. Moderate prematurity	4 / 17%
	8. Petit mal seizures	1 / 4%
	9. Duodenal stenosis	1 / 4%
	10. Twin pregnancy	1 / 4%

According to Table 6.19 most of the subjects with Down syndrome were assessed at CHRIB at a young age, some as young as about three weeks of age (0.8 months). Although diagnosed earlier, some of the subjects were assessed for the first time after two years of age and commencing with ECI at that time.

The characteristics displayed by the subjects in Table 6.19 and coded according to the *ICD-10* (CSS, 1996) are all consistent with the multiple symptoms occurring with an increased prevalence in children with Down syndrome and described in the literature (Van Dyke, 1995). The only exception appears to be seizures which are documented in the Down syndrome population, but do not occur at a higher rate than in the general population (Van Dyke, 1995).

The mean number of diagnostic classification entries per subject is four and similar to those found in the total number of subjects of the empirical study (153) and is displayed in Table 6.10. Since Down syndrome represents a disorder involving almost all organ systems, resulting in a wide spectrum of health and developmental consequences, some of which are life threatening (Spiker & Hopmann, 1997), the use of the *IDC-10* (CSS, 1996) is inadequate to describe the subjects' characteristics. The number of diagnostic classifications in the present study do not distinguish between the subjects with Down syndrome and those with other conditions, as the mere listing of biological risk conditions does not indicate the severity of risk for communication delay. Since the *ICD-10* (CSS, 1996) does not provide a separate entry for developmental delay, the distinguishing factor for the subjects with Down syndrome is to be found in describing the far reaching implications of the chromosomal disorder itself.

Similar to the syndromes associated with cleft lip and palate found in the subjects, Down syndrome is also a multiple anomaly syndrome, but extends much further than those syndromes. Down syndrome is the most commonly known cause of cognitive impairment and congenital anomalies with a vast complexity of health impairments, developmental delays across all domains and distinctive patterns of communication impairment (Kumin, Councill & Goodman, 1999; Msall, DiGaudio & Malone, 1995; Van Dyke, 1995). Yet, these typical characteristics of the subjects with Down syndrome do not emerge when utilizing the *ICD-10* (CSS, 1996) which only lists the different biological risk conditions in the subjects and does not indicate the severity of the disorder. Another tool is therefore required to adequately describe the characteristics of the subjects with Down syndrome.

In summary, the analysis of the results of the biological risk profiles of the subjects displayed in Table 6.11 revealed a large amount of detailed information. Based on a biological approach to the classification of risk conditions for communication delay in the subjects the following can be concluded:

- The multiple diagnostic entries listed for each subject provided a rich description of the different biological factors impacting on a subject's communication development.
- The different diagnostic classification entries had to be prioritized in terms of the severity of impact of the condition on a subject's communication development. In each subject the established risk factor, if present, was listed first. Using this approach, the subjects with cleft lip and palate and

those with Down syndrome emerged as the two largest distinctive subgroups.

- Although occasional cleft lip and palate has been described in persons with Down syndrome (Shprintzen, 1997) these two conditions were found to be mutually exclusive in the subjects. However, biological risk conditions such as multiple pregnancy, low birth weight, premature birth, small for gestational age, congenital heart defects and otitis media were found to occur in both subgroups of subjects.
- All but four of the 153 subjects displayed delayed communication development, which is the only developmental domain of the subjects which could be coded according to the *ICD-10* (CSS, 1996). Since CHRIB is an ECI facility with a communication-based focus, the results emphasize the importance of such an early intervention approach.
- The approach of multiple listing of biological risk conditions in the subjects, resulted in emphasizing the cascading effect of sequenced biological events from conception till later in postnatal life, which shaped the specific risk profile of the subjects with cleft lip and palate.

In conclusion, the use of the *ICD-10* (CSS, 1996) to categorize the different diagnostic classifications found in the subjects, *proved to be sufficient to comprehensively describe the different established and biological risks* relating to the subjects' communication development. The *ICD-10* (CSS, 1996), however, adheres to a medical approach to the classification of developmental disabilities and communication disorders and only uses the terms *specific developmental disorders of speech and language*, *specific speech articulation disorders* and *expressive language disorder* to describe communication disorders. These three terms are classified under the main category of *Mental and Behavioural Disorders* and the subcategory of *Disorders of Psychological Development*. Although the user is able to add subcategories to accommodate specific needs, the conceptual framework of the *ICD-10* (CSS, 1996) *largely omits communication disorders and other developmental disabilities.* The new classification system released by the

WHO, the *ICIDH2* (WHO, 1999), appears to classify developmental disabilities in a more comprehensive manner and will be used in future.

Notwithstanding the benefits of multiple listing and prioritizing risk factors, as well as indicating cascading effects of biological events to create a risk profile of the subjects, the *ICD-10* (CSS, 1996) therefore proved to be limiting in describing delays in developmental domains other than communication development in the subjects. Moreover, the environment as a powerful force to interact on the subjects' biological risk profiles and to shape their developmental outcomes (Kochanek & Buka, 1995), has been omitted. For this reason the following results will focus on some perinatal and postnatal biological and environmental events which influenced the subjects' communication development.

6.4 CHARACTERISTICS OF THE SUBJECTS IN THE PERINATAL AND POSTNATAL PERIODS

In order to provide a description of the early events and their effects on the subjects' communication development, selected data from the CHRIB database relating to the perinatal and postnatal periods of the subjects' development will be described (See Figure VI.II).

6.4.1 Characteristics of the subjects in the perinatal period

The data relating to the characteristics of the subjects in the perinatal period was obtained from the CHRIB Case History Form (Louw & Kritzinger, 1995a) as completed by the parents and then entered into the CHRIB database. By means of a process of data manipulation the results are now presented in Table 6.20.

Table 6.20 Characteristics of perinatal risk factors experienced by the subjects (N=153)

Characteristic	Category	# Subjects	%
1. Gestation age	-Range	25-44 weeks	-
	-Extreme prematurity	2	2%
	-Moderate prematurity	39	25%
	-Minor prematurity	16	10%
	-Full term	94	61%
	-Post mature	2	2%
2. Birth weight	-Range	760-4200 grams	-
	-Extremely low birth weight	4	3%
	-Low birth weight	35	23%
	-Normal birth weight	105	66%
	-High birth weight	9	8%
3. Subjects in incubator	-Never in incubator	71	46%
	-1-5 days in incubator	48	32%
	-6-84 days in incubator	34	22%
4. Subjects in special care nursery (SCN) or NICU	-Never in SCN or NICU	90	59%
	-1-7 days in SCN or NICU	26	17%
	-8-90 days in SCN or NICU	37	24%
5. Breast feeding, N=34	-Never breast fed	119	78%
	-Breast fed after birth	22	14%
	-Breast fed after 2-7 days	9	6%
	-Breast fed after 8-84 days	3	2%
6. Bottle feeding, N=119	-Bottle fed after birth	19	16%
	-Successful after 2-7 days	49	41%
	-Successful after 8-150 days	51	43%

As indicated in Table 6.20 six perinatal risk factors were selected to provide a perinatal risk profile of the subjects as a group. Although numerous perinatal complications such as those described by Als (1997) and Rossetti (1996) and which occurred in the subjects can be listed, only six perinatal risk factors were selected. The six risk factors listed in Table 6.20 are characteristics of the subjects which parents are likely to remember as they represent markers of progress or transitions in the infant’s early life. Knowledge of risk conditions such as respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosis, retinopathy of prematurity, apnea and bradycardia, intercranial haemorrhage and necrotizing enterocolitis (Als, 1997; Rossetti, 1996) occurring in a subject provides valuable knowledge to CHRIB as a service provider, but are often not accurately reported by parents.

The six risk factors are listed in the order of prevalence of occurrence in the subjects. This implies that the least occurring risk factors were low birth weight and prematurity and the most prevalent risk factor experienced by the subjects during the perinatal period and listed in Table 6.20 was feeding difficulties.

As previously indicated in Table 6.11, and according to Table 6.20, extreme and moderate premature birth occurred in 27% of the subjects and extreme and moderate low birth weight occurred in 26% of the subjects. It was also highlighted earlier (Table 6.15) that these perinatal risk conditions co-occurred in subjects with a variety of conditions, namely in subjects with cleft lip and palate, Down syndrome, multiple births, hyperactivity and fetal *Roaccutane*® syndrome or presented on its own. Since low birth weight and prematurity is considered the most frequently occurring neonatal medical risk complications (Rossetti, 1990b) these conditions represent the basis of the subjects' perinatal risks.

Table 6.20 indicates some further perinatal risk factors found in the subjects. Since only 26-27% of subjects presented with low birth weight and prematurity, which in itself destines a subject for incubator and/or special care/NICU care after birth (Rossetti, 1996), it is surprising that many more subjects, namely 54% and 42% respectively, required incubator care and care in a high care nursery or the NICU. This finding indicates that a substantial number of infants were not ready to cope with the demands of the extra-uterine environment for reasons other than prematurity and low birth weight. These reasons may be attributed to the increased number of congenital anomalies found in the subjects (See Table 6.11).

The results of the last perinatal risk factor listed in Table 6.20 pertains to the feeding difficulties which the subjects experienced after birth. A total of 112 (73%) subjects experienced some degree of feeding difficulties (See Table 6.20, Nr 5 & 6), either with breast feeding or with bottle feeding. Only 14% of the subjects were successfully breast fed since birth while 16% were successfully bottle fed since birth, which implies that the subjects could suck and swallow adequately for sufficient food intake per feed.

Although bottle feeding could have been the mother’s choice and may not indicate feeding difficulties in the subject, a large percentage of subjects, 78%, did not breast feed at all, but received bottle feeding only. However, as there is currently a general public awareness of the numerous advantages of breast feeding (Bergh & Bosman, 1995), it could rather have been that the subjects experienced difficulties with breast feeding than that their mothers chose to bottle feed them. Bottle feeding is considered an easier way of feeding in comparison with breast feeding (Wolf & Glass, 1992) and it appears that the subjects’ mothers could have resorted to bottle feeding as a result of feeding difficulties in the subjects. Underlying feeding difficulties could therefore have contributed to the high prevalence of bottle feeding found in the subjects.

Since the sample represented infants with numerous risk conditions the results regarding a prevalence of feeding difficulties among the subjects correspond with findings in the literature that almost all types of disabilities are associated with nutrition or feeding problems in infancy (Litchfield, Brotherson, Oakland & McClintic, 1995). The identification of early feeding difficulties in the subjects points to a specific ECI need required by the subjects before they were assessed at CHRIB.

In contrast with the feeding problems experienced by the subjects, an analysis of the subjects who succeeded with breast feeding can provide more insight into the nature of the early feeding experiences of the subjects. Table 6.21 provides the results of the subjects who succeeded with breast feeding.

According to Table 6.21 subjects with a variety of risk conditions succeeded with breast feeding, either from birth onwards, or after two to seven days. The three subjects who succeeded in breast feeding only after an extended period of time, were infants with extremely low birth weight and prematurity. It is remarkable that these subjects could eventually breast feed successfully, as their respiratory insufficiency and subsequent intubation, together with other neonatal medical complications allow them to feed orally only after sufficient growth, maturation and experience have taken place. The subjects’ mothers need to be commended since the successful transition from non-oral feeding methods to oral feeding and breast feeding can only be achieved with support, feeding therapy and much persistence (Wolf & Glass, 1992).

Table 6.21 Subjects who succeeded with breast feeding (N=34)

Subject's condition	# Subjects	% of condition
1. Down syndrome	13 of 23	57%
2. Expressive specific language impairment	6 of 9	67%
3. Autism/PDD	3 of 4	75%
4. Low birth weight and prematurity (after 8-84 days only)	3 of 52	6%
4. Subjects with acquired conditions	2 of 2	100%
5. Multiple pregnancy and communication delay	2 of 23	9%
6. 40% cleft of the soft palate	1 of 79	1%
7. Hyperactivity	1 of 2	50%
8. Fetal alcohol syndrome	1 of 1	100%
9. Microcephaly	1 of 1	100%
10. Tongue tie	1 of 1	100%
Total	**34**	N/A

As further indicated in Table 6.21, the groups of subjects who were the least successful with breast feeding were the subjects with cleft lip and palate, low birth weight and prematurity and multiple pregnancy. The difficulties with breast feeding found in the different subgroups of subjects can be related to the following:

- Only one of the 79 subjects with cleft lip and palate could succeed with breast feeding. As very few instances of successful breast feeding in infants with cleft palate have been reported in the literature, Wolf and Glass (1992) explain that an infant may develop adequate compression and suction to form and position the nipple if the cleft is minor. Since the subject with cleft palate had a 40% cleft of the soft palate only, it appears that he was the only subject with cleft palate who could compensate sufficiently to breast feed successfully.
- As a result of the interrupted caretaking by the mother when the infant is in the NICU and medical complications in the infant, breast feeding is often not successful in infants with low birth weight and prematurity (Morris & Klein, 1987; Wolf & Glass, 1992). It appears that these factors could have

contributed to difficulties with breast feeding found in the group of subjects with low birth weight and prematurity.

- As a result of the extra care involved in infants from multiple pregnancies and differences in timing of feeds and feeding needs of the infants, it appears that sustained breast feeding is often not successful (Bergh & Bosman, 1995). The reports from literature concerning breast feeding in twins validates the finding that only two subjects from a group of 23 could breast feed successfully.

As further indicated in Table 6.21 the subgroups of subjects who were more successful in breast feeding were the subjects with Down syndrome, expressive specific language impairment, autism/PDD and those with acquired disorders. The following explanations are offered to interpret the results:

- Although feeding difficulties as a result of low muscle tone and heart defects in infants with Down syndrome have been reported extensively (Baird, Ingram & Peterson, 1998; Wolf & Glass, 1992), breast feeding is strongly advocated in this group of infants (Van Dyke, 1995). It could be that the subjects with Down syndrome experienced less adverse conditions which could prevent breast feeding or that the parents of these subjects received feeding therapy and support and persisted with breast feeding in spite of feeding difficulties as they were aware of the health benefits of breast milk and the opportunity for early parent-infant attachment associated with breast feeding.
- No specific feeding difficulties during the perinatal period are reported in the infants with expressive specific language impairment in the literature (Rescorla & Goosens, 1992), but the sample size of nine subjects is too small to draw further inferences.
- In the case of the subjects with autism/PDD the sample size also does not allow further interpretation of the results. Amato and Slavin (1998), however, found oro-motor deficits which included chewing difficulties and abnormal oral sensitivity to food texture in young children with autism.

These findings could relate to the early feeding difficulties found in one of the subjects with autism/PDD in the present study.

- The subjects with acquired disorders did not display any risk conditions prior to the event causing their disorder and could therefore breast feed successfully.
- Successful breast feeding in the other groups of subjects indicated in Table 6.21 can also not be explained further as the sample sizes are limited.

In contrast with the groups of subjects who displayed successful breast feeding, Table 6.22 provides an analysis of the 51 subjects who experienced the most feeding difficulties as indicated by the time period before they could feed successfully by means of a bottle (See Table 6.20 Nr 6).

Table 6.22 Subjects with successful bottle feeding only after 8–150 Days (N=51)

Subjects' condition	# Subjects	% of Condition
Cleft lip and palate	35 of 79	44%
Down syndrome	5 of 23	22%
Low birth weight and prematurity	5 of 52	10%
Multiple pregnancy	3 of 23	22%
Subjects with an unknown condition	2 of 2	100%
Delayed language development and developmental delay	1 of 1	100%
Total	**51**	**N/A**

According to Table 6.22 a substantial number of subjects with cleft lip and palate experienced feeding difficulties of a serious nature as they only succeeded to feed successfully by means of a bottle after a period of time. The fact that only one subject with cleft palate could breast feed successfully (See Table 6.21), further emphasizes the finding that most of the feeding difficulties found in the subjects occurred in those with cleft lip and palate, as could be expected (Savage, 1997).

The following results in Table 6.22 serve to indicate the broad spectrum of feeding skills which were found in the subjects. While Table 6.21

demonstrated that some subjects with Down syndrome, low birth weight and prematurity and those from multiple pregnancies could display adequate feeding skills to breast feed successfully, Table 6.22 disclosed that the same groups of subjects could also display serious feeding difficulties. The analysis of feeding skills found in the subjects indicated both *a high prevalence* of feeding difficulties and *a large variation* in feeding skills, which ranged from successful breast feeding to serious feeding difficulties within some of the subgroups of subjects. The results also reiterate the statement by Bu'Lock, Woolridge and Baum (1990) that feeding difficulties make up a major proportion of problems which are found in fullterm as well as preterm infants. Since effective feeding is a prerequisite for the survival of newborn infants (Bu'Lock, *et al.,* 1990) it was an important risk factor to identify in the subjects, not only for their wellbeing and growth, but also for their development.

The importance of feeding difficulties in the perinatal period as a predictor of communication delay in infants with low birth weight and prematurity has been indicated in a previous study (Kritzinger, 1994). This study found that, in comparison with other perinatal risk factors such as low birth weight, prematurity, perinatal infections, gender, low Apgar scores and the length of time spent in the incubator, the subjects' feeding difficulties best predicted their communication development at 12 months. The longer the time lapse before the infants could feed successfully, the more delayed their communication development was at 12 months. Since the results of the present study already indicated a communication delay in 98% of the subjects (See Table 6.11) it is clear that the feeding difficulties experienced by most of the subjects in the perinatal period must relate to their communication delay. The feeding difficulties experienced by clients and subsequent appropriate intervention and support to parents are therefore important facets of ECI.

Feeding difficulties during the perinatal period can be viewed as a product of an infant's functioning during that time and provides a more descriptive manner of defining the infant's condition than just a statement such as low birth weight or prematurity. Moreover, it is postulated that feeding difficulties could be a more sensitive indicator of future communication development in low birth weight and premature infants than the number of days an infant spent in the incubator or in a special care nursery or the NICU. The period of time the infant spends in the incubator or in the special care nursery/NICU may not only depend on the infant's response to the extra uterine life, but could also depend on exogenous factors such as a decision made by the medical team involved. As the study cited (Kritzinger, 1994) only relates to low birth weight and premature infants and the present study also included other groups of infants at risk for communication delay, ongoing research is necessary to determine the factors predicting their communication development. However, it appears that a description of the feeding difficulties in the subjects succeeded in emphasizing a prevalent risk factor in the perinatal period.

The perinatal risk profile of the subjects, of whom approximately 80% display established risk conditions (See Table 6.1), is that a significant number of the subjects spent some time in an incubator, an additional number spent time in a special care nursery/NICU while still an additional number experienced feeding difficulties. The results serve to illustrate the concept of continuum of risk as proposed by Rossetti (1996). The beginning point of communication delay in the subjects is not the time they fail to utter their first words at an age appropriate phase of development. The origins of the communication delay in the subjects may be traced back to biological or environmental influences relating to events earlier in life. (Rossetti, 1996). The concept of continuum of risk does not only elucidate the subjects' past, but also points to their continued risk in the postnatal period and the future.

In order to illustrate this concept further, selected characteristics of continued risk factors in the subjects' postnatal period will be presented.

6.4.2 Characteristics of the subjects in the postnatal period

A key feature of the subjects during the postnatal period was selected to provide a description of some of the environmental risks experienced by the subjects during this developmental phase. The number of surgical procedures performed on the subjects during the postnatal and later stages, instead of illnesses, were selected to illustrate the continuum of risk factors for developmental delay which the subjects experienced.

In order to assure reliable results, it was postulated that the subjects' parents were more likely to accurately remember details about surgical procedures than details about all illnesses in their young children. An analysis of the surgical procedures experienced by the subjects was therefore carried out and presented in Table 6.23. The data was originally obtained from the CHRIB Case History Form (Louw & Kritzinger, 1995a) completed by the parents and entered into the CHRIB database.

According to Table 3.23 a total number of 93 (61%) of the subjects underwent a total of 187 surgical procedures at the time of the CHRIB assessment and data collection. This implies that each of the 93 subjects had an average of two surgical procedures, with a minimum of one and a maximum of seven surgical procedures per subject. The results also indicate that the majority of surgical procedures were performed on the subjects during their first year of life, with the peak period for surgeries between the ages of five to eight months in the subjects.

As depicted in Table 6.23 a total number of 22 different surgical procedures were performed on the subjects, of which ten different procedures directly relate to the 79 subjects with cleft lip and palate. The surgical procedure most prevalent in the subjects was, however, the insertion of ventilation tubes for the treatment of otitis media with effusion and relates to the prevalence of otitis media in 55% in all the subjects (See Table 6.11). The peak period of five to eight months for surgeries performed on the subjects could relate to the surgical protocol of the Facial Deformities Clinic where the majority of the subjects with cleft lip and palate were treated (Bütow, 1995) and the peak period of seven to twelve months for acute otitis media in children (Plante & Beeson, 1999). The other surgical procedures listed in Table 6.23 serve to illustrate some of the health concerns of the subjects which warranted surgical intervention and could pose a subsequent risk for delayed language development.

Table 6. 23 Type and number of surgical procedures performed on the subjects (N=93)

Category	Value
- Number of subjects who underwent surgery - Number of subjects without surgery	93 (61%) 60 (39%)
- Total number of surgical procedures performed - Number of surgical procedures on each client	187 Range: 1-7 Average: 2
- Number of surgical procedures per age group	0-4 months: 33 5-8 months: 96 9-12 months: 24 13-18 months: 18 19-37 months: 16 **Total: 187**
Type of surgical procedure	**# Surgical procedures**
1.Ventilation tubes inserted	46
2. Soft palate repair*	43
3. Lip and hard palate repair	22
4. Hard and soft palate repair	21
5. Lip repair	8
6. Columella lengthening	7
7. Hard palate repair	5
8. Hernia repair	5
9. Circumcision	4
10. Lip and soft palate repair	3
11. Strabismus repair and other eye surgery	3
12. Heart surgery	3
13. Neurosurgery	3
14. Foot operation	3
15. Tonsillectomy	3
16. Oro-facial surgery	2
17. Lip, hard and soft palate repair	1
18. Submucous cleft repair	1
19. Frenulum cut	1
20. Adenoidectomy	1
21. Mastoidectomy	1
22. Pilorotomy (stomach surgery)	1
Total	**187**

Key*
- Surgical procedures typed in bold indicate procedures related to cleft lip and palate

The multiple surgical procedures experienced by a subject could impact both on the subject's emotional and communication development as well as on the family. Eiserman, *et al.* (1996) state that hospitalization for surgery, separation from the family and restrictions of physical activity following the surgery were some of the most salient stressors not only for the family with a child with cleft lip and palate, but also for the child's own development. Surgical procedures, characterized by increased family concern about the infant and accompanied by periods of hospitalizations, can be interpreted as added stressors for families with infants at risk for disabilities. According to Guralnick (1997) the stressors for families created by the child's disability add to the factors influencing the developmental outcomes for young children.

Rossetti (1996) adds an emotional dimension to the different stressors impacting families which can be applied to families of infants with cleft lip and palate. The lack of opportunity afforded to parents to provide care while their child is hospitalized, reduces attachment and interaction and could affect caregiver involvement in later intervention (Rossetti, 1996). Wolf and Glass (1992) emphasize the emotional effect of hospitalizations on infants and describe the difficulties in maintaining trustful relationships the child may experience when needs for comfort and food are not met.

The emphasis on surgical procedures as a postnatal risk factor for communication delay added to the continuum of risk evidenced in the subjects which can be traced from the prenatal period, through the perinatal, postnatal and later periods of life. The demonstration of risk conditions experienced by the subjects throughout their short lives points to the responsibility of CHRIB to meet the needs of families by providing a responsive presence during the periods when events can occur which can contribute to communication delays later in life.

The needs of families, however, can only be adequately met if an analysis of their characteristics are carried out.

6.5 CHARACTERISTICS OF THE SUBJECTS' FAMILIES

According to Guralnick (1997) individualized ECI programmes for young children and their families have been a centrepiece of EI services from the start, but limited empirical information is available to clinicians to adapt programme features to fit the unique profiles of children and families. The analysis of family circumstances is therefore an important component of the current empirical study.

Since the groundbreaking longitudinal studies of Escalona (1982; 1987) of young children with low birth weight and living in poverty, the influence of adverse family circumstances on the development of children at risk for developmental delays has been widely accepted. Escalona (1982; 1987) found a dramatic downward trend in the cognitive development of infants with low birth weight in the second year of life. Moreover, infants found to be at the greatest risk for early death and compromised developmental outcomes in the USA, are those raised by mothers who are black, single, adolescent, abusing drugs, uneducated and with a low income (Rossetti, 1998).

Figure VI.IV was compiled to provide an outline of the chronological order in which the results regarding the main characteristics of the subjects' families will be presented.

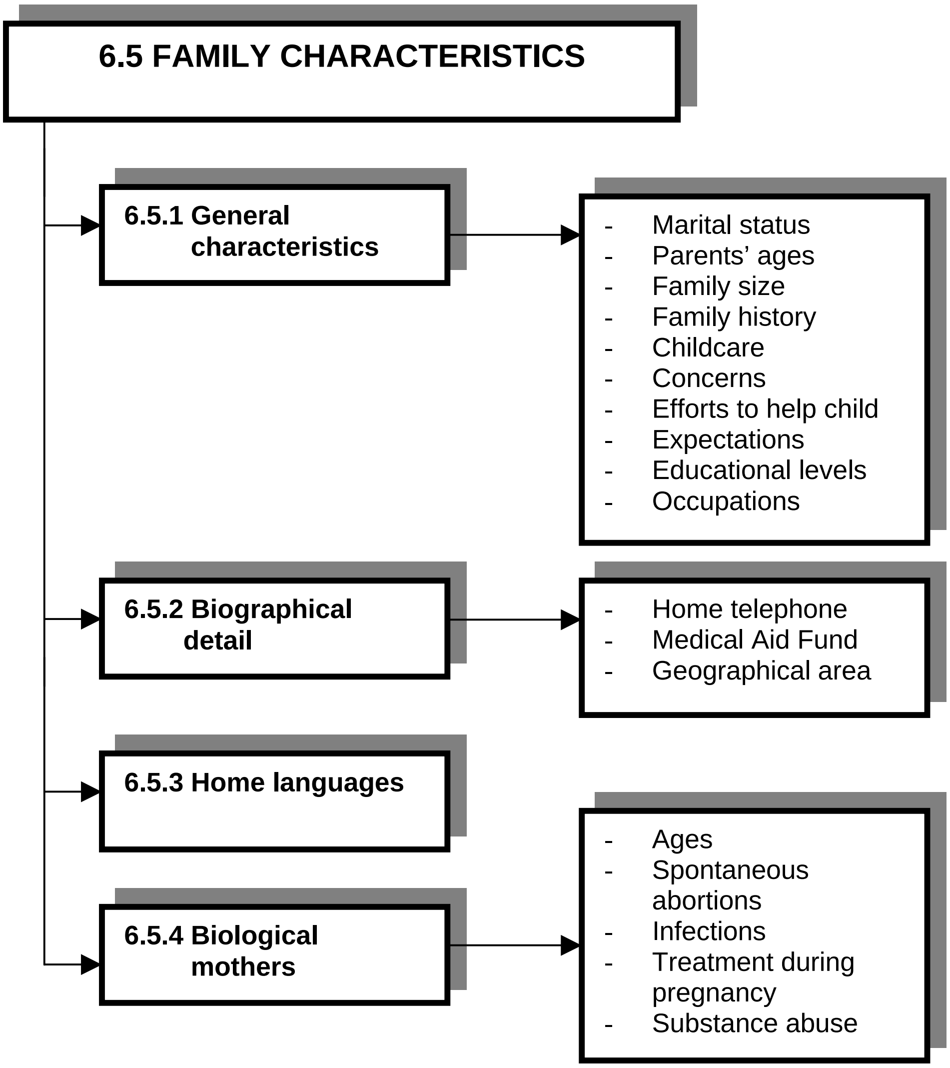


Figure VI.IV Outline of results regarding the characteristics of the subjects' families

In order to identify possible risks in the subjects' families a description of the main characteristics of the 145 families, retrieved from the CHRIB database, is presented in Table 6.24. A total of only 145 families as opposed to 153 children were involved in the empirical study as the families of twins and triplets were only counted once.

Table 6.24 General characteristics of the subjects' families (N=145)

Characteristic	Category		# Subjects		%
1. Marital status of parents	Married		134		92%
	Divorced		5		4%
	Separated		4		3%
	Never married		2		1%
2. Caregiver's relationship to subjects	Biological parents		143		98%
	Adoptive parents		1		1%
	Grandparents		1		1%
3. Mother's age at assessment of child	Range		20-52 years		-
	Average age		30 years		-
4. Father's age at assessment of child	Range		22-62 years		-
	Average age		33 years		-
5. Family size	I Child		50		34%
	2 Children		62		43%
	3 Children		19		13%
	4 Children		9		6%
	5 Children		4		3%
	6 Children		1		1%
6. Persons with speech, language or hearing problems in family	Yes		36		25%
	No		109		75%
7. Other children with developmental disorders	Yes		6 siblings		4%
	No		139 siblings		96%
8. # subjects in daily child care facilities and nursery schools, N=153	Yes		89		58%
	No		64		42%
9. Mentioned concern about subject's general development, N=153	No concern		97		63%
	Unsure		20		13%
	Concerned		36		24%
10. Mentioned concern about child's communication development, N=153	No concern		7		5%
	Did not mention		8		5%
	Concerned		138		90%
11. Reported efforts to help child, N=153	Reported		134		88%
	No efforts mentioned		19		12%
12. Listed family expectations of assessment, N=153	Listed		140		92%
	Did not state		13		8%
13. Parents' educational level	**Category**	**# M**	**# F**	**%M**	**%F**
	No Schooling	3	0	2%	-
(M= Mother; F= Father)	Primary school	1	1	1%	1%
	High school	16	18	11%	13%
*Fathers' educational levels: 5 missing values of one-parent families	Matric	65	51	45%	36%
	Certificate	1	0	1%	-
	Diploma	18	25	12%	18%
	Graduate	30	32	20%	23%
	Postgraduate	11	13	8%	9%
	Total	**N=145**	**N=140***	**100%**	**100%**

14. Parents' occupations (M= Mother; F= Father) *Fathers' occupations: 5 missing values of one-parent families	**Category**	**# M**	**# F**	**% M**	**% F**
	-Full time mother	58	-	40%	-
	-Professional & technical	36	75	24%	54%
	-Managerial	18	34	12%	23%
	-Secretarial	11	-	8%	-
	-Clerical & sales	20	7	14%	5%
	-Artisan	-	12	-	8%
	-Self employed	1	7	1%	5%
	-Domestic worker	1	1	1%	1%
	-Not employed	-	6	-	4%
	Total	**N=145**	**N=140***	**100%**	**100%**

6.5.1 General characteristics of the subjects' families

According to Table 6.24 the majority of subjects were from intact families and living with their biological parents. Only 11 (8%) subjects were raised by single mothers, one subject was adopted and one subject was living with her grandparents. Since 88% of the subjects are from white families (See Table 5.1), the results can be compared to divorce rates among this population group in South Africa. The divorce rate among whites is high and approximately 65% of minor children affected are white, 27% are coloured and 7% are Indians (Patel, 1994). In a survey conducted in 1993 (Barberton & Woolard, 1998) it was estimated that only one third of African children were growing up with both parents present in the household. The results 92% of intact families found in the subjects are therefore not representative of the South African situation, especially in the light of the AIDS crisis, estimated to orphan 250 000 children during 2000 (Bridgraj, 1999). It appears that CHRIB, a tertiary based ECI provider, attracts clients who are mostly white, but not representative of the white community concerning family intactness.

The average ages of the parents at the time of data collection were 30 years for the mothers and 33 years for the fathers. The upper margins of the parents' ages are high, 52 and 62 respectively, but refer to the two grandparents raising their grandchild, the one pair of adoptive parents and a few parents over 36 years.

Upon further analysis of Table 6.24 (See Nr 5) most of the subjects (90%) are from small families of three and less siblings. Only 10% of the subjects are from families of four to six siblings, indicating possible risks for family stress as parenting and financial resources have to be shared among a larger number of siblings, one of whom making more demands on these resources as a result of a disability (Ostfeld & Gibbs, 1990). The findings that 90% of the subjects are from relatively small families and that 92% of the subjects are from two parent families indicate that these subjects did not experience the stressors related to large families and disrupted family life as a result of divorce.

The following family characteristic concerns the presence of communication disorders in the nuclear family and/or extended family. In Table 6.24, Nr 6, 25% of families have a history of communication disorders of which 4% occur within the nuclear family (See Table 6.24, Nr 7). These results could relate to the possible genetically inherited basis of some of the disorders occurring in the subjects, such as cleft lip and palate and sensorineural hearing loss (Shprintzen, 1997). The results of a familial concentration of communication disorders in the subjects can also be compared with the results of Tomblin (1989) who found a strong familial association for developmental language disorder and that the likely mode of transmission appears to be genetic. The results indicate that a positive family history of communication disorders can be regarded as a risk factor for communication disorders and may be used to identify communication disorders in children. If parents among the general public are aware that communication disorders in their family pose a risk for communication disorders in their children, there is a possibility that these children can be identified and treated earlier.

Table 6.24 Nr 8 indicates that 58% of the subjects attended some form of daily child care facility, such as a day mother or a crèche, or an early educational facility such as a playgroup or a nursery school. A substantial number of subjects (42%) were at home with their mothers. The finding that so many subjects are full time in the care of their mothers, indicates positive outcomes for the subjects' communication development (Oren & Ruhl, 1997). Since all the subjects presented with risks factors which can negatively impact on their communication development, there is so much more opportunity for their mothers to provide “contingent, encouraging, affectively warm, non-intrusive, appropriately structured, discourse-based and developmentally sensitive patterns of caregiver-child interactions” to optimize their children’s development (Guralnick, 1997: 6). The finding emphasizes an ideal situation for effective ECI in CHRIB provided that the mothers of the subjects are trained and supported to establish routine patterns of optimal parent-child communication interaction which will facilitate their children’s development.

The results also indicate the possibility of decreasing the incidence of otitis media in some of the subjects as research has shown that children in group day care settings and crowded living conditions are at an increased risk for middle ear disease (Plante & Beeson, 1999). The use of daily childcare facilities in 58% of the subjects can therefore contribute to the chronic middle ear disease already found in 55% of the subjects. The number of subjects in childcare facilities also relates to the mothers’ occupational status to be discussed later under Nr 14 (Table 6.24).

Table 6.24 Nr 9 to 12 relate to the parents’ concerns about their child’s development and their involvement in the child’s communication problem at the time of the CHRIB assessment. The results indicate that in only 24% of instances, parents were concerned about the subjects’ general development, but that in 90% of instances the parents were concerned about the subjects’ communication development. This indicates that parental focus was on the child’s main problem area which is also confirmed by the next result. An equally high percentage of subjects’ parents (88%) reported on their efforts to assist their child in acquiring communication skills. These efforts ranged from applying the home programmes received at the Facial Deformities Clinic to reporting on talking, reading and pronouncing words clearly to the subjects. It is clear that a high percentage of parents displayed a high degree of awareness of, and involvement in, their child’s communication problems, as their focus is directed specifically at the area of communication development. Since all but 4 of the 153 subjects displayed some form of communication delay or disorder (See Table 6.11), the results of high parental involvement in their child's communication problems therefore indicate that the subjects' parents were in touch with their child's most prevalent needs. The results indicate a positive attitude toward ECI in the subjects' parents, which increases the possibility of effective services since a high degree of parental involvement is one of the main factors determining the effectiveness of ECI (Rossetti, 1996).

The family's expectations of the CHRIB assessment also confirm the high degree of involvement of the parents in their child (See Table 6.24, Nr 12). A total of 92% of parents listed their expectations of the assessment. An analysis of the parental responses to the question about expectations of the assessment (See Appendix B), which was entered into the CHRIB database as text data, revealed that they had specific information needs. Although most parents only listed one need they wanted to be addressed during the CHRIB assessment, collectively their needs centered around the following four themes:

- The cause(s) of their child's communication problems.
- The current level of their child's functioning.
- What to expect of their child and his/her communication problems in future.
- What they, as parents, can do to improve their child's communication problems.

Although the parents demonstrated a high degree of awareness and involvement in their child's communication problems, it should not be assumed that they have sufficient information about their child's communication disorder. The parents clearly stated their needs in a logical set of responses, stating that they wanted to know about the past, present and future of the subjects' communication problems and what their role as parents should be in the intervention process.

The collective pattern of information requirements of 92% of the subjects' parents emerging from the results can be related to what Guralnick (1997, p 8) refers to as the "crisis of information about the child's health and development families often experience". Guralnick (1997) identified almost the same type of questions which families ask about their child's health and development. These questions relate to parental needs on how to interpret their child's behaviour, which implies that they wanted to know whether their child's functioning is age appropriate. According to Guralnick (1997) parents also want to know what can be changed in order to help their child and what the future developmental expectations of the child is. Lastly, parents ask questions regarding the nature and effectiveness of therapeutic services. It is interesting to note that the last question posed by Guralnick (1997) was not raised by the parents in the current study. This finding correlates with previous results which indicated that the parents lacked knowledge about ECI services and when to commence with the services (See Tables 6.7, 6.8 and 6.9).

The need to know about the cause of the communication problem was clearly stated by the subjects' parents in the current study, but not mentioned by Guralnick (1997) as a source of information need. The finding that the subjects' parents required knowledge about the causes of communication disorders in their children must be addressed in CHRIB as it could indicate limited public awareness about communication disorders. According to Rossetti (1998) parents frequently ask questions about the cause of their child's problem and the inquiry can reveal some degree of guilt which the parents may experience. It may be that a request by parents for clarification of the cause of the problem could specifically relate to communication disorders as children with specific expressive language disorders or autism/PDD for example display no physical anomaly to which the problem could be attributed to.

Whatever the questions parents ask, Guralnick (1997) states clearly that information needs created by the child's disability are very important and he regards it as one of the potential stressors for families which can negatively affect child developmental outcomes.

As the results of the empirical study have already identified other information needs of the subjects' parents, the present results only underscores the importance of meeting parents' information needs in CHRIB since it is one of the environmental risks which can negatively affect the programmes' outcomes. The need to act on parents' concerns about their child's development has already been identified as one of the elements on the continuum of parameters for effective service delivery in ECI (See Figure II.IV).

The last set of family characteristics depicted in Table 6.24 (See Nr 13 and 14) refer to the parents' educational level and their occupations. The results indicate that the majority of parents had a high level of education with only a small percentage of parents not completing their high school education. The results indicate an exceptionally high percentage of parents with tertiary levels of education, with 50% of the subjects' mothers and 40% of the subjects' fathers with diploma, graduate and postgraduate qualifications. According to Patel (1994) only 16% of the white population in South Africa has some form of tertiary education. In a study on education and poverty, Woolard and Barberton (1998) found a strong correlation between education attainment and standard of living in South Africa. The high educational levels of the subjects' mothers in the current study should also be emphasized, since it is widely accepted that a child's health is directly related to the mother's level of education (Sanders, 1999). In the light of these findings, it is clear that most of the subjects could be raised in homes with an adequate to a high standard of living as only 14% of mothers and 14% of fathers did not finish high school education or grade 12.

The analysis of the parents' occupations revealed that only 4% of fathers were unemployed. Approximately half of the fathers have a professional or technical training and are employed as such. A total of 40% of the mothers are full time at home and the results relate to Nr 8 (Table 6.24) which revealed that 42% of mothers did not make use of daily care facilities for the subjects. The difference of 2% in the results could relate to mothers making use of domestic workers or extended family members to look after their children while they are at work. Similar to the fathers, it appears that the largest group of mothers who are employed, hold professional or technical positions in their occupations. Since the majority of the subjects' parents is employed and does not experience financial stressors associated with unemployment, the subjects' home environments appears optimal for their development which can contribute to positive ECI outcomes (Guralnick, 1997).

In summary, the results of selected characteristics of the subjects' families demonstrated that stressors, such as divorce, single parents, very young mothers, large families, families with more than one child with a disability, low educational levels and unemployment occurred in less than 10% of the families. It should be noted that the characteristics of most of the families discussed thus far indicate that the subjects' families represent an advantaged group which is not even typical of the white population in South Africa. It is also important to note that only 8-12% of the families did not state any concern about the subjects' communication development, did not mention any efforts to help the subject thus far and listed no expectations regarding the CHRIB assessment. As no statistical analysis was carried out to determine a possible relationship between the degree of family involvement in the subject and levels of stress the families experienced, no reasons for the presumed low family involvement in this minority group of subjects can be provided. By far the majority of subjects did not experience adverse environmental risks in their homes, which can positively impact on the subjects' development and effectiveness of ECI services provided to them. The finding of the limited family stressors identified in the subjects could imply greater family involvement in the intervention process, a critical component for effective ECI.

It is, however, important to note that adverse familial circumstances did occur to a certain extent in the population of infants with communication disorders served by CHRIB and that there were families who could not articulate their involvement in the subjects. The implication is that the CHRIB programme must provide in the special needs of families with very diverse characteristics, ranging from unemployed parents with low levels of education to highly educated professional parents.

Furthermore, it should be borne in mind that the characteristics used to describe the subjects' families in Table 6.24 are only crude indicators and do not measure family functioning, stress and adjustment. Each of the subjects' families has a child with a certain degree of communication disorder and almost all families expressed their concerns about the child (See Table 6.24, Nr 10). According to Ostfeld and Gibbs (1990) the birth of an infant with a disability exerts unexpected stresses and demands upon the family system and places the family as a whole as well as individual members at increased risk for ineffective coping. The results therefore only provide a superficial analysis of the different stressors relating to the subjects' families. It is therefore important to investigate the specific risks of each family during an assessment if individualized family-centered intervention wants to be carried out.

6.5.2 Biographical detail of the subjects' families

The following data, extracted from the CHRIB database and presented in Table 6.21, serves to provide some biographical and personal detail in order to give additional data on the living standard of the subjects' families.

Table 6.25 Biographical detail of the subjects' families (N=145)

Feature	Category	# Subjects	%
Home telephone	Yes	138	95%
	No	7	5%
Belong to a medical aid fund	Yes	109	75%
	No	36	25%
Geographical area of residence	-Pretoria Region	84	58%
	-Gauteng excluding Pretoria	41	28%
	-Northern Province & Mpumalanga	5	3%
	-North West Province	5	3%
	-KwaZulu Natal	4	3%
	-Free State	4	3%
	-Turkey	1	1%
	-Zimbabwe	1	1%
	Total	**145**	**100%**

According to Table 6.25, only 5% of the subjects' families do not have a home telephone, which can relate to a low-income status of the family. The use of telecommunication indicates a family has access to sources of information, support and facilities and can be contacted. This implies that the subjects' families can establish communication networks and can be contacted for ECI arrangements. The finding correlates with earlier results that the majority of subjects' parents are employed.

The results in Table 6.25 indicate that 75% of the subjects' families belong to a medical aid fund. The results compare well with health care statistics in South Africa which indicate that 76% of white families belong to medical aid funds (Soal, 1999). Since the majority of the subjects are from white families it appears that the subjects are representative of white South Africans regarding membership of a medical aid fund.

A total of 25% (36) of the subjects' parents do not belong to a medical aid fund, which does not assist them in the payment of the families' medical expenses. Since membership of a medical aid fund is dependent upon monthly contributions deducted from a member's salary, unemployed people are usually not able to sustain their contributions and medical aid fund membership is terminated. As indicated in Table 6.24, only 4% of fathers of the subjects were unemployed, but 25% (36) of families do not belong to a medical aid fund. Upon further analysis of the data in the CHRIB database it appears that a number of parents chose not to belong to a medical aid fund and make use of their own income to pay for medical expenses or make use of the state aided health services. The possible reasons for parents not belonging to a medical aid fund are outlined in Table 6.26.

Table 6.26 Characteristics of subjects' parents not belonging to medical aid funds (N=36)

Employment status of main breadwinner in family	Marital status	# Families	Remarks
1. Self employed: Owns own business, farms or works as professional person	Married	17 / 47%	Parents are economically independent and choose not to belong to a medical aid fund
2. Employed as voluntary worker in church	Married	3 / 8%	Income is too low to belong to a medical aid fund

3. Unemployed	Married	3 / 8%	No medical aid fund
4. Unemployed	Single mother	5 / 14%	No medical aid fund
5. Self employed	Single mother	2 / 6%	Income is too low to belong to a medical aid fund
6. Employed: Clerical worker, mine worker, domestic worker	Married	4 / 11%	Income is too low to belong to a medical aid fund
7. Employed: Artisan	Married	2 / 6%	Income is too low to belong to a medical aid fund
Total	**-**	**36 / 100%**	**-**

According to Table 6.26, a total number of 17 families do not belong to a medical aid fund as a result of their own choice, while the remainder 19 families or 13% of the 145 families, have no access to a medical aid fund as a result of unemployment or low income. It is also significant to note that seven of the 12 single mothers in the study (See Table 6.26 Nr 4 and 5) do not have the benefits of a medical aid fund and reiterates the finding in the USA that the variables of single mothers, unemployment and low income often co-occur and poses a risk for optimal child development (Escalona, 1987; Rossetti, 1998).

The last variable in Table 6.21 pertains to the geographical area in which the subjects reside. The results indicate that CHRIB mostly serves a population of infants and toddlers whose families are able to travel if they are not living in Pretoria. The fact that 42% of the subjects' families traveled from outside the Pretoria region, some as far as other provinces and countries, implies that CHRIB is providing a necessary service in ECI to families living in areas where such services are not yet established. Although factors such as the parental preferences can also determine their utilization of a particular ECI facility, the results provide some evidence of the unavailability of ECI services in South Africa. According to Haasbroek (1999) ECI is an emerging service among private practitioners and in the public sector in South Africa, but by far not available in all contexts and towns. The results of the biographical profile of the subjects' families strongly indicate that CHRIB is an important ECI service provider as subjects were drawn from six of the nine different provinces in South Africa, as well as from other countries.

The last characteristic of the subjects' families to be discussed pertains to their home languages.

6.5.3 Subjects' home languages

Table 6.27 provides an analysis of the different languages the subjects are exposed to in their homes based on the parents' responses in the CHRIB Case History Form (Louw & Kritzinger, 1995a).

The results in Table 6.27 indicate that although most of the subjects have Afrikaans or English as a single home language, 18% of the subjects are exposed to two or more home languages. The rich diversity of home languages also reflects the multilingual and therefore multicultural nature of the South African context in some of the subjects.

Table 6.27 Languages spoken in the subject's homes (N=153)

Language	# Subjects	%
Single home language		
Afrikaans	95	62%
English	28	17%
Northern Sotho	3	2%
Portuguese	1	1%
Subtotal	**127**	**82%**
More than one home language		
English* & Afrikaans	11	6%
English & Urdu	1	1%
Afrikaans & English	2	1%
Afrikaans & German	2	1%
Afrikaans & Sotho	1	1%
Portuguese & English	2	1%
Turkish & English	1	1%
Zulu & English	1	1%
Urdu & English	1	1%
Swazi & Zulu	1	1%
Subtotal	**23**	**15%**
More than 2 home languages		
Afrikaans, English & German	1	1%
Portuguese, English & Afrikaans	1	1%
English, Portuguese & Italian	1	1%
Subtotal	**3**	**3%**
Total	**153**	**100%**

***Key:** The first language reported indicates the dominant language of the family

When comparing the results of the subjects' home languages with recent statistics of the distribution of first language in greater Pretoria, it appears that Afrikaans is the most prevalent first language among the residents, with Sepedi and English as the second and third most prevalent first languages, which may partly explain why Afrikaans was found to be the dominant language in the majority of the subjects (Ngwesi, 1999). As indicated in Table 6.25, 58% of the subjects live in the Pretoria region.

The linguistic and cultural diversity in some of the subjects points to the special information needs of their families as all the subjects are already at risk for, or display an array of communication disorders with a subsequent risk for school failure in the future. According to Baker (2000) when one language is better developed it is advantageous to concentrate on developing the stronger language first when delayed or disordered communication development is evident in a child. As 58% of the subjects are already attending a daily childcare facility or a nursery school (See Table 6.24 Nr 8) where the subject's dominant language may not be spoken, the parents of the multilingual subjects must be provided with information regarding their children's present and future educational needs.

The discussion of the results regarding the characteristics of the subjects' families revealed that while most of the families had an adequate standard of living and experienced no serious risks which could interact negatively on the subjects' development, environmental risk conditions were found amongst some of the families. The environmental risks emerging from the results and the corresponding percentages occurring in the subjects' families are summarized in Table 6.28.

Table 6.28 Environmental risks found in the subjects' families

Risk Condition	%
1. Single mothers	8%
2. Large families	10%
3. No concern, efforts to help or expectations listed about subject	10%
4. Low educational levels of parents	14%
5. Low income families	Less than 10%
6. Income too low to belong to a medical aid fund	13%

These environmental risk conditions occurred to a limited extent in the subjects' families and cannot be interpreted as a profile of a certain subgroup of the subjects since correlations between the variables were not determined. It is, however, of importance that these environmental risk conditions occurred in the vulnerable families served by CHRIB. Efforts must be directed to meet the needs of these families in ECI as strong associations are found among stressful family characteristics, family interaction patterns and non-optimal child development outcomes (Guralnick, 1997).

Apart from the environmental risks identified in a minority of the subjects, stressors and informational needs regarding the subjects' communication problems were already identified in more than 90% of the subjects' families (See Table 6.20, Nr 10). The results therefore provide some important guidelines for appropriate ECI service delivery to meet the unique set of needs of each family.

In order to provide a comprehensive analysis of the different risk conditions found in the subjects, specific maternal risks were identified.

6.5.4 Characteristics of the subjects' biological mothers

Selected characteristics of the 145 biological mothers of the subjects are presented in Table 6.29 in order to indicate possible biological risks which could have affected the subjects since the earliest stages of their development. Since the data of the subjects' parents and their biological mothers differ, a description of the subjects' biological mothers is necessary (See 6.5.1). There were 145 biological mothers since the mothers of twins and triplets were counted only once.

Table 6.29 Characteristics of biological mothers of subjects during pregnancy (N=145)

Characteristic	Category	# Subjects	%
1. Mother's age at time of pregnancy	Average Range Mothers 18-19 years old Mothers older than 36 years	27.95 years 18-42 years 5 mothers 5 mothers	- - 4% 4%
2. Spontaneous abortions or stillborn infants	Yes No	24 121	17% 83%
3. Viral infections and other	Yes	16	11%

infections	No	129	89%
4. Health problems	Yes No	72 73	50% 50%
5. Medical treatment	Yes No	67 78	46% 54%
6. Smoking, alcohol or drugs	Smoking Alcohol -*Prozac®* under subscription -*Roaccutane®* to abort fetus -Anticonvulsants for epilepsy	9 1 1 1 1	6% 1% 1% 1% 1%

According to Table 6.29 there were only 4% of mothers between 18 and 19 years old and 4% of mothers older than 36 years at the time of the subjects' birth. Since maternal age is regarded as a critical factor to increase the risk potential of her child (Rossetti, 1986), additional data was retrieved from the CHRIB database and manipulated to be presented as a scatter graph in Figure VI.V.

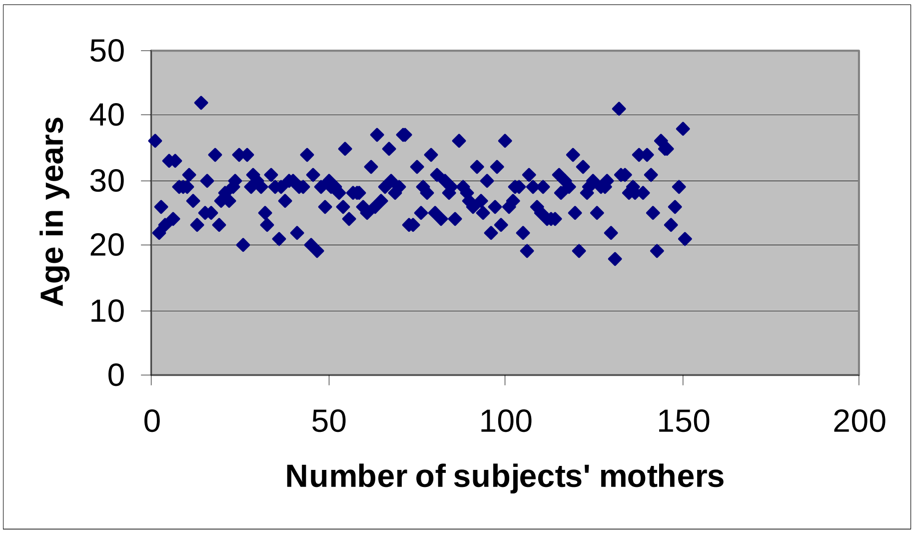


Figure VI.V Scatter graph of ages of subjects' biological mothers at the time of the subjects' birth (N=145)

Figure VI.V displays the ages of the subjects' *biological mothers* at the time of the subjects' birth. According to Rossetti (1986; 1996) mothers younger than 16 years and older than 36 years display a higher risk for a number of conditions such as premature births, repeated miscarriage, cervical incompetence, stillbirth, placental abnormalities, intrauterine growth

retardation, blood group problems, unexplained fetal or neonatal deaths, genetic disease and chromosomal disorders. As depicted in Figure VI.V the average age of the mothers was approximately 28 years and does not indicate a risk factor, but the lower margin of 18 years can pose the particular risks usually associated with adolescent pregnancies. According to Rossetti (1996) pregnant women between 15 and 19 years are likely to be unmarried and not receiving prenatal care before their third trimester of pregnancy.
Upon further analysis of the results in the CHRIB database it appears that all five mothers between the ages of 18 and 19 years gave birth to subjects with various forms of cleft lip and palate (See Appendix E, Subjects with CHRIB ID Nr 58, 124, 140, 152 and 165). Apart from the fact that adolescent mothers as a group give birth to four times as many infants with disabilities as the general population (Gerber, 1990), these interesting results of the current study regarding the young mothers and their cleft lip and palate children cannot be interpreted further. The sample size is too small and no literature support could be found relating maternal age directly to the prevalence of cleft lip and palate (Becker, *et al*., 1998; Gerber, 1990; Sadler, 1995).

Further analysis of the results in the CHRIB database revealed that the five biological mothers who were older than 36 years, gave birth to subjects displaying the following risk conditions: Extremely low birth weight and prematurity, fetal alcohol syndrome, twins with low birth weight and delayed communication development, Down syndrome and cleft palate. Except for the cleft palate and fetal alcohol syndrome, the high ages of the subjects' biological mothers and the corresponding conditions in their children can be associated with the maternal risks described by Rossetti (1986; 1996).

Further results depicted in Table 6.29 (Nr 2) indicate that a total of 24 mothers (17%) experienced spontaneous abortions or gave birth to stillborn infants. Since these conditions are prevalent in 50-60% of all conceptions (Sadler, 1995), it can be expected to occur to some extent in the sample of the current study. Further analysis of the results is presented in Table 6.30.

Table 6.30 Risk conditions of subjects whose mothers had spontaneous abortions and stillborn infants (N=24)

Subjects' Condition	# and % of Subjects
Cleft lip and palate (various types)	15 / 63%
Prematurity	3 / 13%
Down syndrome	2 / 8%
Microcephaly	1 / 4%
Unknown syndrome	1 / 4%
Hyperactivity and language delay	1 / 4%
Specific expressive language impairment	1 / 4%
Total	**24 / 100%**

The most salient feature depicted in Table 6.30 is the 15 (63%) subjects with various types of cleft lip and palate whose mothers had spontaneous abortions, some of whom had multiple abortions, and stillborn infants. Again no literature support was found for the results relating to cleft lip and palate. According to Sadler (1995) chromosomal anomalies are responsible for 50% of spontaneous abortions and stillbirths while maternal disease and teratogens can also be contributing factors to these early losses.

The following results in Table 6.29 (Nr 3, 4 & 5) relate to infections, health problems and medical treatment the mothers had during the pregnancy with the subject. A total of 16 (11%) mothers reported infective conditions such as colds, influenza, bronchitis, bladder, kidney, urinary tract, vaginitis and a tooth abscess occurring during their pregnancies. Health problems experienced by 50% of the biological mothers during pregnancy included hypertension, pre-eclampsia, threatened abortions, hyper- and hypothyroidism, kidney stones, low blood pressure, stress, premature rupture of membranes, haemorrhage and epilepsy. A total of 46% of mothers received medical treatment for these conditions just mentioned, which implies that some of those experiencing health problems did not receive treatment for the conditions.

Furthermore, Table 6.29 Nr 6, indicates smoking, use of medication and habits of substance abuse in the subjects' mothers. Nine mothers smoked actively during the pregnancy and five of them had infants with various types of cleft lip and palate. The other conditions occurring in the mothers who smoked during pregnancy included sensorineural hearing loss, fetal alcohol syndrome and two subjects with specific language impairment. Apart from the drugs used under doctors' supervision for infections during pregnancy and included in Nr 5, other instances of drug usage in the mothers involved the following:

- A mother using alcohol and the subject displayed fetal alcohol syndrome.
- One mother used *Prozac*® during pregnancy and the subject had a general developmental delay.
- Another mother used *Roaccutane*® and the subject presented with fetal *Roaccutane*® syndrome.
- A mother used anticonvulsants to control her epilepsy and the subject displayed a bilateral cleft lip and palate.

Although smoking and use of drugs occurred in only 9% of instances, the results indicate that most of these subjects displayed congenital anomalies. Maternal smoking is known to be associated with cleft lip and palate (Becker, *et al*., 1998; Sadler, 1995) and the use of various anticonvulsants during pregnancy is associated with different congenital anomalies, of which craniofacial anomalies are also described (Sadler, 1995). Although the sample is too small to warrant further statistical analyses, some of the results in Table 6.29 such as maternal infections, health problems and use of substances during pregnancy are in agreement with research results reported in the literature. According to Sadler (1995) poor maternal health (specifically hypertension and renal and cardiac disease), the use of cigarettes, alcohol and other drugs, such as Vitamin A, minor and major tranquilizers, antihypertensive agents, anticonvulsants, aspirin and amphetamines are potentially harmful to the developing embryo and fetus. These conditions and the effects of teratogens, as also indicated in the subjects of the current study, can have various effects, from early death to intra-uterine growth retardation, premature birth and congenital anomalies (Sadler, 1995).

The results concerning the occurrence of cleft lip and palate in the subjects with young mothers, the spontaneous abortions and stillbirths in the mothers of subjects with cleft lip and palate need to be investigated further to determine their significance when more data has been accumulated in the CHRIB database.

The results of biological risks present in the subjects from early in life emphasize the notion to move away from earlier conceptual models which presumed that an increased risk for disability in infants *originate* from adverse circumstances surrounding the birth process (Kochanek & Buka, 1995). The current notion implies that greater significance is now awarded to the cascading effects of gene actions and exogenous factors, interacting with one another during different periods as described by Rubin (1995). These periods in a child's life represent a continuum of vulnerability or risk and include the prenatal period, which is subdivided into the preconceptual, periconceptual, embryogenesis, fetal growth and maturation periods, the perinatal period and postnatal periods (Rubin, 1995). Since the periods when biological events posing risks for communication disorders are likely to occur are known, the possibility of identifying risk factors earlier in life can lead to more effective ECI.

6.6 CONCLUSION

The current study proved that a database as an ECI research tool can be used effectively to provide a rich and detailed description of a sample of the population served by CHRIB, a tertiary based ECI provider. The use of descriptive methodology revealed remarkable detail and unique characteristics of the 153 subjects and their families employed in the empirical study which would not have been possible without a relational database system.

The critical importance of time of identification of risk conditions and commencement with ECI services were illustrated by the results. While very few subjects were late referrals for ECI, *certain subgroups* of subjects could have been identified earlier as the parents of these subjects were concerned about their children's communication development from an early stage or knew about the risk condition from an early age. It appears that the parents of the subjects with autism/PDD, multiple pregnancies, low birth weight and prematurity, expressive specific language impairment lacked information on risk conditions for delayed communication development, the benefits of ECI and local ECI facilities. The results indicated further limitations in the early identification of the subjects since a number of *subjects with established risk* conditions, who could have been identified at birth, were only identified after the perinatal period. It appears that lack of knowledge about ECI was *not only limited to the subjects' parents*, but that *health care professionals* who came in contact with the subjects at first, also required guidelines for the early identification of risk conditions for communication disorders in the subjects and referral for ECI.

The primary role of parents in the early identification of risk conditions in the subjects was indicated. The results revealed that *parents identified the subjects' risk conditions earlier than the professionals*, thereby confirming results of previous research indicating that parents' concerns about their children's development are mostly accurate and a sensitive indicator of the presence of disability (Rossetti, 1998). The results indicate that parental involvement in ECI should not only be seen as benefiting the effectiveness of the intervention component of the ECI process only, but that their potential in improving on the identification age of risk conditions in their children should be recognized and utilized.

The results also revealed the *different roles of CHRIB* as an ECI service provider in South Africa. A new role for CHRIB is to provide supportive counseling and information to parents whose unborn children have been diagnosed with risk conditions for communication disorders. While technological advances now allow the prenatal diagnosis of certain risk conditions in children, the increased risk for communication disorders in these children, such as those from multiple pregnancies may not be recognized at that time. The role of CHRIB in providing consultative services to clinicians in the field of EI was clearly demonstrated in the results. The findings of referrals to CHRIB illustrate the recognition of CHRIB as a specialist ECI service provider and indicate that *CHRIB clients* do not only include families with young children at risk for communication disorders, but include professionals in the field of EI as well.

A biological risk profile was presented by using the *ICD-10* (CCS, 1996) diagnostic classification system which indicated that each subject displayed between two and seven different diagnostic classification entries. *The multiple risk profile* was an authentic strategy to describe the different characteristics of the subjects although the *ICD-10* (CCS, 1996) proved to be limiting in describing the different developmental disabilities and communication disorders and to reflect the degree of disability found in the subjects. The diagnostic entries occurring most in the subjects were communication disorders, recurrent otitis media, multiple births, low birth weight and prematurity, heart defects, cleft lip and palate and Down syndrome. The results emphasized the importance of a thorough knowledge about the multiple risk profile of each subject as it contributes to an individualized approach to ECI. The results revealed *interesting findings not extensively described in the literature,* such as the complex nature of the risks contributing to communication disorders found in the subjects associated with multiple births. Additional findings indicated that low birth weight and prematurity were associated with subjects with cleft lip and palate and that low birth weight, prematurity and intrauterine growth retardation of a less severe degree occurred in different subgroups of subjects with congenital anomalies. Furthermore, all subjects with heart defects also exhibited additional congenital anomalies which emphasize a genetic basis for a cascade of early biological events causing congenital anomalies. Results also revealed risk factors for communication disorders in the perinatal period, with feeding difficulties as the most prevalent risk condition in the subjects. The subjects also exhibited a large number of surgical procedures interpreted as environmental risk factors and stressors to the family which can negatively impact on the subjects communication development in the postnatal and later stages in life. A continuum of risk events were identified in the subjects, indicating critical points for the origins of these events in the subjects.

A recurring theme in the findings of the empirical study was the late identification of risk conditions for communication disorders. The results indicated that the subjects' parents had specific information needs which related to the recognition of the early signs of risk conditions in their children which can results in communication disorders. The parents of the subjects were identified as the key members of the ECI team involved in their young children as they were mostly the first to know about the risk condition, but neither knew how to interpret their knowledge about the child nor how to act upon their concerns about the delayed communication development in their children so that ECI could be initiated as early as possible.

The sample of the empirical study were mostly boys of 18 months with cleft lip and palate, living in the Pretoria region and from white Afrikaner families. Additional analysis of their families revealed that most were intact families with two or three children and that the parents were employed, belonged to medical aid funds and were highly educated. In contrast with the group of families who experienced few life stressors which can negatively impact on the subjects' communication development and the ECI process, approximately 10% of the families had adverse circumstances ranging from single parents, unemployed or low income, low education levels and large families. The characteristics of the subjects' families reveal the diversity of clients requiring ECI services at CHRIB, which also reflects some of the characteristics and diversities of young children and their families requiring ECI services in South Africa.

The results and discussion indicated a continuum of risk events in the subjects which leads to the conclusion that a conceptual framework for the early identification of risk conditions in children must be presented.

The descriptive results of the empirical study were derived from data stored in the CHRIB database and indicated that the CHRIB database is a rich source of data which can be used in future research. As all the data is available in the CHRIB database further research can now be conducted by using inferential statistics to determine correlations between the different variables. Additional data can be obtained by entering new data into the database, therefore increasing the number of subjects in order to increase the reliability of the results. The CHRIB database has now been established as a viable ECI research tool, using new technology to define ECI in a new century.

6.7 SUMMARY

In order to demonstrate the capabilities of the CHRIB database and the functions of the different software programs linked to one another when used for data manipulation and data analysis, a rich description of selected characteristics of the 153 subjects and their families was provided. The detailed description of the subjects involved the interpretation of results regarding their gender, ages, prior ECI experiences, diagnostic categories, time of identification of their risk conditions, perinatal and postnatal characteristics. The different diagnostic classifications used to describe the risk conditions in the sample revealed a multiple risk profile of the subjects.

A description of the subjects parents followed by interpreting the results regarding their marital status, ages, the family size, family history of disabilities, use of child care facilities, their concerns, efforts to help their children and their expectations of ECI. Further results involved the description of the parents' educational levels, occupations, biographical detail and home languages. Furthermore, the results relating to the subjects' biological mothers were presented and their ages and history of the pregnancies were discussed.

Lastly, the results obtained from the CHRIB database demonstrated the use of computer technology in ECI research in South Africa. The study indicated that the CHRIB database is a viable tool for ECI research in the 21st century which will be driven by technology.

CHAPTER 7

CONCLUSIONS AND IMPLICATIONS

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Aim: The aim of the chapter is to provide the conclusions regarding the research findings against the background of the original research problem, discuss the implications of the entire research project, critically review the methodology and results, indicate the clinical and theoretical implications of the study and make recommendations toward further research in early communication intervention.

7.1 INTRODUCTION

The vision at the start of the century and the new millenium is a world abundant with information and with tools to use it wisely (Cerf, 2000). The amount of information currently available is literally exploding and the value of data as an organizational asset is widely recognized. Without the ability to manage this large store of data and to quickly find the information as the amount of information increases, the data can become a liability instead of an asset (Ramakrishnan, 1998). As a result of continuous growth over the past years, in terms of technology, applications and their enormous capacity to store and organize large amounts of data (Ramakrishnan, 1998), database systems are part of the new technologies defining the new century.

While database systems have many different uses, it is the application of relational database technology in research which offers vast possibilities to the scientific community of the 21st century. Extensive databases, such as the database used in *Human Genome Project* (Ramakrishnan, 1998) which has just completed sequencing 97% of the human genome, are already offering valuable information to scientists all over the world (Lemonick, 2000). By tapping into this public database scientists can extract information about genes and isolate DNA which has already been coded, a process which would have amounted years of work if data could not be shared between different databases. It is predicted that the rate at which discoveries are made will increase substantially with the increase of information becoming available from the *Human Genome Project* database (Lemonick, 2000).

Databases are therefore recognized and managed as valuable research tools, providing the end user with extensive possibilities of applications in different disciplines. The application of a research database system in an early communication intervention (ECI) programme in the current empirical study proved to be a viable research tool, making large volumes of data available to the researcher in a timely fashion. The abundance of data in the CHRIB database provided the source for a rich description of a sample of the population of young children at risk for communication delays and their families served by a tertiary based ECI facility. Since a descriptive study is often the first step in an epidemiological investigation (Beaglehole, Bonita & Kjellström, 1993), the question arises how to apply the results of the empirical study to better understand the needs of the population requiring ECI services at CHRIB and to expand the use of the CHRIB database. This step is necessary to meet the research needs of the particular ECI service provider and contribute to the field of ECI.

In order to answer this question, the conclusions regarding the establishment of the CHRIB database as an organizational asset, and conclusions and implications of the results of the empirical study, will be discussed in order to make recommendations which will contribute to the use of database technology in the discipline of ECI in South Africa. Figure VII.I was created to guide the discussion of the main themes of the chapter, i.e. the conclusions, implications, critical review and recommendations of the study.

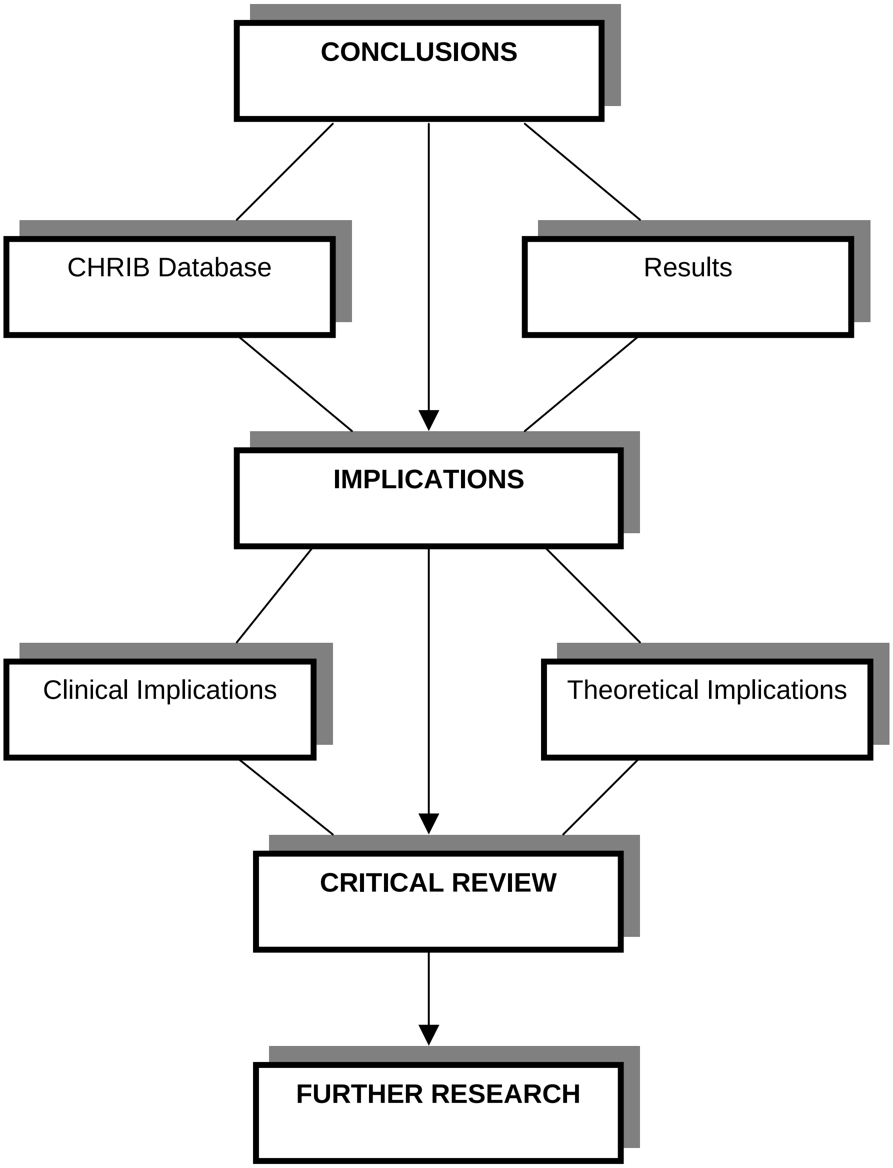

Figure VII.I Outline of chapter contents

7.2 CONCLUSIONS

The scientific method of solving the initial research question of how to establish and utilize a computer database system in a tertiary based ECI facility, has become the initiary process to identify further problems (Leedy, 1997). This implies that the process of drawing conclusions from the results of the empirical study will lead to further questions, thereby ensuring the continuation of the research endeavor to find solutions to new problems in the field of ECI.

The CHRIB database is a sophisticated research tool proven to be viable to continue the research process initiated by the current study and to maintain research output in order to contribute to second generation research in early intervention (EI). In order to draw conclusions from the results of the empirical study it is necessary to discuss the findings against the framework of the entire CHRIB database system, a large collection of data which was utilized to describe the infants and toddlers at risk for communication disorders and their families.

7.2.1 Conclusions regarding the establishment of the CHRIB database system

In an effort to develop discipline specific research methods and tools for ECI in South Africa and to contribute to the development of field of ECI, the CHRIB database system was designed and successfully applied in the empirical study.

The CHRIB database system was modeled on the CHRIB Case History Form (Louw & Kritzinger, 1995a) (See Appendix B) and the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) (See Appendix C) and consists of 16 different tables (See Table 5.3), containing a complete set of data of each of the 153 subjects employed in the empirical study. The eleven tables labelled on the Main Form as Client, Parentship, Persons involved, Referring persons, Persons, Diagnosis, Language, General illnesses, Surgery, Viral infections and Perinatal were utilized in the empirical study and yielded large volumes of data which was analyzed and presented as results.

The data of the subjects in the remaining four tables labelled as Assessments, Assessment on the Main Form 2, Parent-child-interaction and Memos, originally based on the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b), was not utilized in the current study. The CHRIB database generated large quantities of data which required that the research problem had to be delimited. The empirical study was delimited in order to comply with the aims of the research project and to keep the focus so that an in depth analysis of data could be accomplished. The fact that delimitation of the research problem was necessary (Leedy, 1997), already indicates the research output capabilities of the CHRIB database. The data in the database tables not utilized in the empirical study contain the subjects' communication functioning which warrants a series of separate, but related empirical studies.

The current empirical study provided valuable insights for the continued management of the CHRIB database as a research tool and asset to a tertiary based ECI service provider. The CHRIB database has multiple functions and can be utilized both as a management and a research tool. The current study utilized only part of the research capabilities of the CHRIB database. Since the three different components of the model for second generation research in EI as proposed by Guralnick (1997) (See Figure V.I) include the investigation of the EI programme, the characteristics of the clients and the nature of the programme outcomes, it appears that the CHRIB database can contribute comprehensively to second generation research in EI. Since the aim of the empirical study was to describe the characteristics of the subjects, the full research capacity and functions of the CHRIB database could not be demonstrated in the empirical study. Figure VII.II was compiled in order to illustrate the flexibility of design and application capabilities of the CHRIB database for continued ECI research.

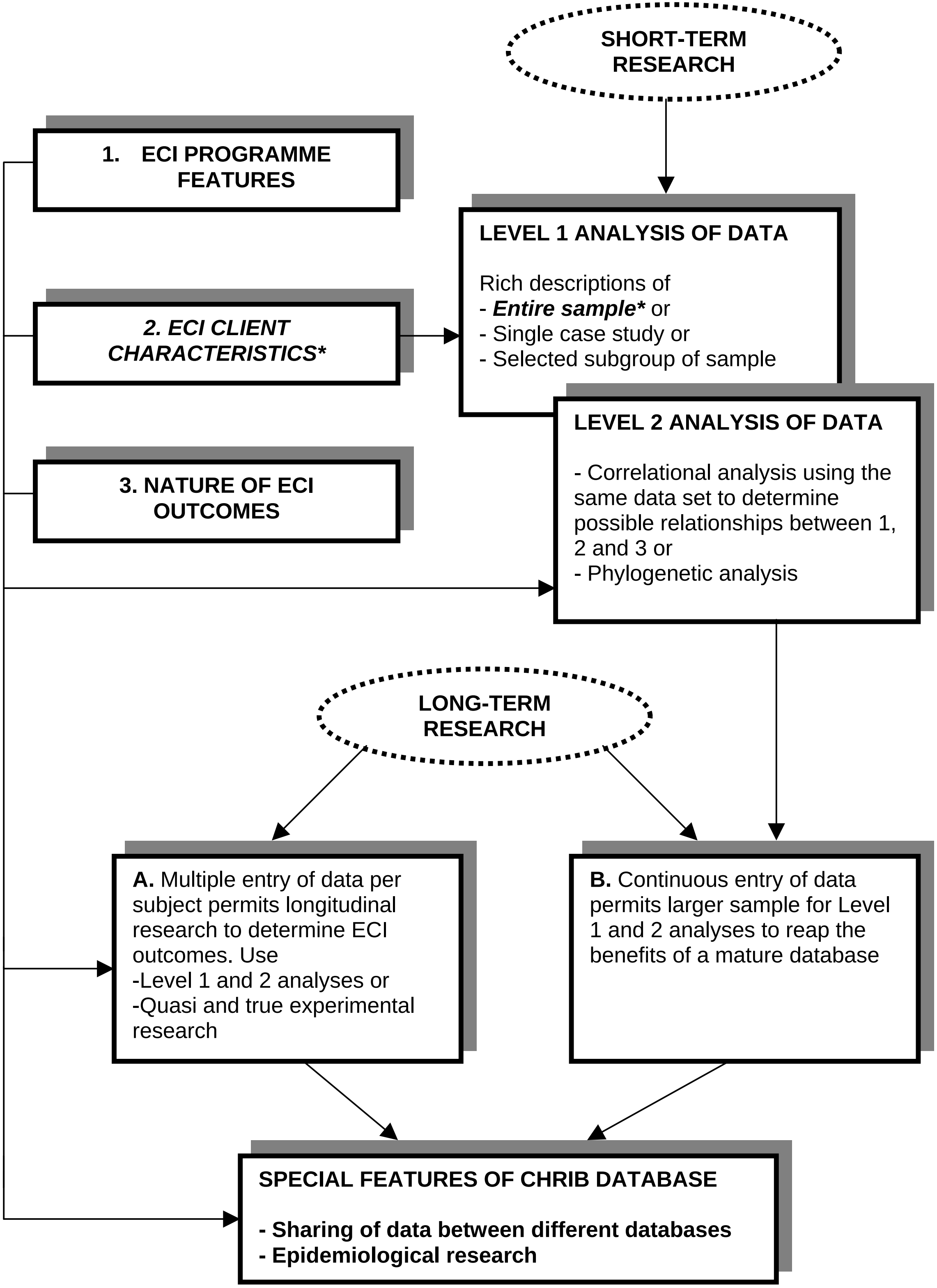

Figure VII.II Research capabilities of the CHRIB database
Conceptualized from: Guralnick, 1997; Kruger, 2000a; Leedy, 1997; Beaglehole, *et al.,* 1993. **Key*** Italics indicate the extent of the current empirical study

As illustrated in Figure VII.II the extent of the current empirical study, printed in italics, can be viewed against the background of the three components or research questions of the second generation EI research model (Guralnick, 1997) and the short-term and long-term research capabilities of the CHRIB database. The CHRIB database design permits the storage of data in a structured manner, data retrieval by means of creating queries and various ways of data analysis, all within the researcher's immediate control. Depending on the types of data in the database structure, such as data on different populations of young children at risk for communication disorders in different contexts, various research projects can be undertaken. Based on Figure VII. II the CHRIB database can therefore be utilized for future second generation research in EI by means of the following different research applications:

- Since the CHRIB database can create baselines of young children's communication functioning, time slices of development and chronologies of development (Nieuwoudt, 2000), different applications involving groups studies as well as single case studies are possible. The CHRIB database can also provide data for different research designs so that the investigation is not only limited to descriptive research, but may also include correlational research, e*x post facto* research, longitudinal research, quasi-experimental and true experimental research (Leedy, 1997).
- The rich descriptions of subjects, permitted by the data management process of the CHRIB database system, can be extended and varied to include case studies or smaller subgroups of special interest to the researcher. As the end user of the database is in close contact with the data, the possibilities of data management depend on the user's experience and creativity, which can result in an original approach to data analysis and presentation. Independent data management by the user can also be a cost-effective approach to research, since fewer consultations with statisticians are necessary. Consultations with statisticians can also be on a more sophisticated level, since the researcher is forced to be in control of data management and gains

more insight into the process. This approach can facilitate the use of database technology in ECI, since developments make technology more accessible to the user and the user become more accessible to technology (Nieuwoudt, 2000).

- Using the same data set as utilized for descriptive studies, the CHRIB database can also be applied in correlational research as indicated in Figure VII.II as so-called Level 2 analyses. Statistical investigations of the relationship between one factor and one or more other factors can be conducted which allow the prediction of certain conditions in subjects. Predicting subject outcomes is of great value in ECI since preventative measures can be taken in advance, thereby improving the effectiveness of the intervention (Leedy, 1997; Rossetti, 1996).
- The same data set in the CHRIB database can also be used for a different approach to data analysis than the statistical techniques typically used for correlational and experimental research. Phylogenetic analysis, using the PHYLIP or PAUP computer software packages, is currently proposed when subcategories of subject characteristics are suspected. A phylogenetic analysis aims to reveal patterns of correlation in data, using the metaphor of single or multiple inheritance patterns of certain characteristics or variables occurring in the subjects. By generating sets of possible patterns of groups, visually presented as phylogenetic inheritance trees, subcategories can be identified, which typically would have been masked by conventional statistical techniques (Kruger, 2000a; Kruger, 2000b). The data in the CHRIB database can therefore be used as a platform to explore the new research methodologies of the 21st century and apply them to ECI.
- As the CHRIB database design also permits multiple entry of data per subject across time, serial assessments, a special feature of ECI (Rossetti, 1990b), can be accommodated in the research. This function of the database will allow the execution of *ex post facto*, longitudinal, quasi-experimental and true experimental research. These research designs allow the investigation of change in young children’s behaviour or development over a period of time in

order to determine patterns of development, such as normal-abnormal development, abnormal-abnormal development and catch-up growth (Rossetti,1996).

- The possibility of sharing data between different databases exists, provided that the data sets are compatible. Data sharing provides one way of increasing the sample and optimizing the storage capacity of the CHRIB database. Although further developments in database technology are required to ensure the semantic compatibility of data sets, data sharing offers new possibilities in collaborative research efforts in ECI (Nieuwoudt, 1999).
- A mature CHRIB database with large samples of the population under investigation, accumulated over years, can provide data for epidemiological research in order to study the distributions and determinants of communication disorders found in the subjects. Since epidemiological data provides distributions and determinants of health related states and events in populations, its application in ECI is to investigate the causes of, or related factors, surrounding communication disorders in young children. Knowledge of the distribution of communication disorders and its causes in different populations of young children is particularly useful to both clinicians and researchers to guide ECI programme planning and policy (Beaglehole, *et al.,* 1993; Lubker, 1991).
- In comparison with intervention efforts later in a child's life, ECI is in the unique position to conduct prospective, in stead of retrospective research, on subjects. Since the timing of data collection can take place early in a child's life and subsequent data entry of events can occur as they happen, a complete chronology of a child's development is possible and more accurate data for follow-up studies can be ensured (Beaglehole, *et al.*, 1993).

The CHRIB database can therefore ensure a continuous output of data to be used for various research projects and different research designs, which cannot be accomplished without a computer-based data approach. By utilizing a research tool unique to the field of ECI, the methods employed can be refined to fulfill the research needs of CHRIB as a tertiary based ECI facility and to develop discipline specific research methodologies.

As indicated earlier, the CHRIB database has multiple functions and can also be used as a management tool in CHRIB to oversee the ECI programme (Hebbeler, 1993). Administrative functions, such as generating statistical annual reports of clinical activities, providing quick access to subjects' records and providing address lists of clients and professionals involved in the clients, are possible (Aitken, *et al.,* 1997). The immediate availability of the data and the convenience of continuous renewing the data set, provides a reliable source for client follow-up, communication with other professionals and ECI programme planning.

The CHRIB database, both as a research and ECI programme management tool, has the features and capacity to significantly contribute to the development of clinical practice and theory of ECI in South Africa. In order to demonstrate the successful application of the CHRIB database in the empirical study, the conclusions regarding the results will now be discussed.

7.2.2 Conclusions regarding the results of the empirical study

The results of the empirical study provided a detailed account of the subject characteristics and their families, but in a broad overview of all the results three main findings can be identified. These three findings are as follows:

- *The majority of the subjects, 74%, presented with various different established risk conditions for communication disorders of which the largest subgroup comprised of infants and toddlers with cleft lip and palate.*
- *The late identification of risks for communication disorders in certain subgroups of the sample is of great concern to the ECI service provider.*

- *The lack of parental knowledge to identify early signs of communication delay as risks for communication disorders, which they have noticed in their young children.*

In order to elaborate on the three outstanding results of the empirical study each finding will be discussed separately.

Firstly, of the 74% of subjects with established risks for communication disorders, 52% of the total number of subjects presented with cleft lip and palate and demonstrated an array of risk conditions, some known to be associated with this congenital disorder and some with risk conditions not extensively described in the literature. Since the results clearly indicate further investigation it appears that a phylogenetic analysis could reveal patterns in the characteristics which are not yet evident. The results demonstrated a multiple risk profile of the subjects with cleft lip and palate which extends far beyond the obvious visible established risk for communication disorders. Figure VII.III (on the following page) provides a synopsis of the interesting risk profile found in the subgroup of subjects with cleft lip and palate.

As illustrated in Figure VII.III the interesting findings regarding the subjects with cleft lip and palate not widely reported in the literature pertains to an increased prevalence of low birth weight and prematurity and subsequent perinatal risks, increased prevalence of multiple births and young mothers. No literature support could be found to establish whether the 6% of young mothers indicate an increased prevalence. Apart from the findings not found in the literature, it also appears that the comprehensive risk profile of the subjects with cleft lip and palate emerging from the results, is also not emphasized in the literature. This confirms the view that infants with cleft lip and palate are generally underserved in ECI service delivery (Savage, 1997). It also appears that the rich description of the subjects only became possible with the use of a database uniquely designed to suit the researcher’s requirements.

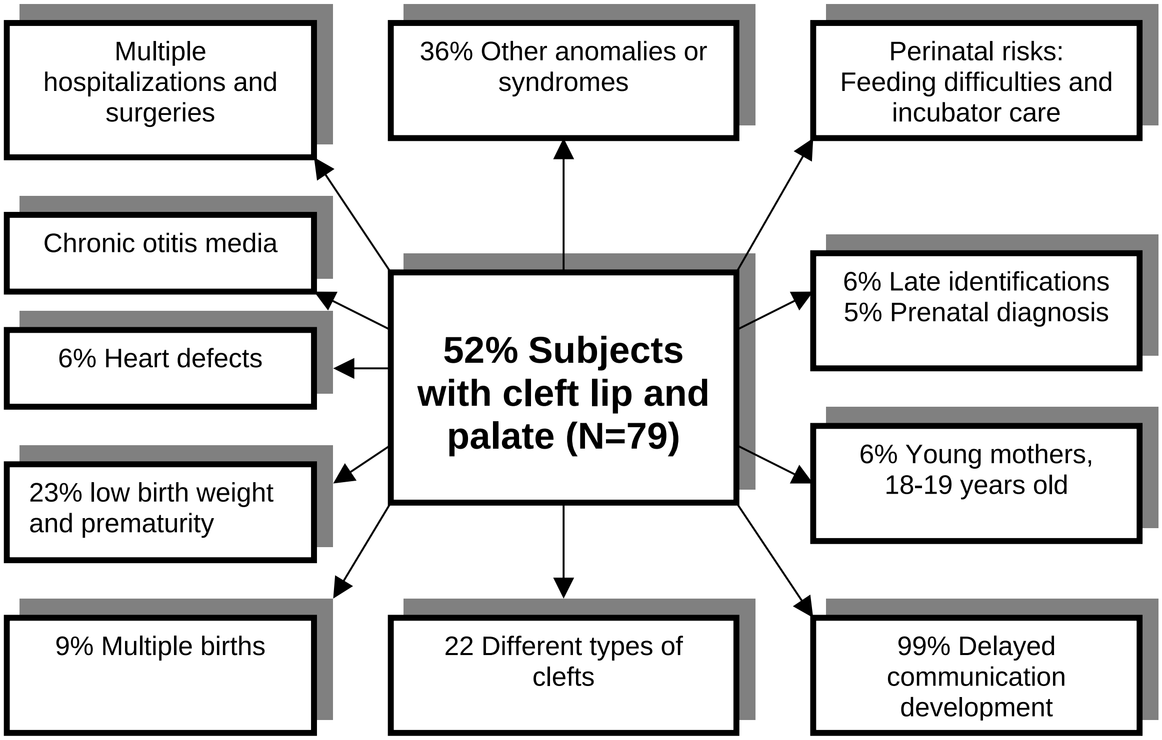

Figure VII.III Risk profile of subjects with cleft lip and palate

The risk profile of the subjects with cleft lip and palate illustrated in Figure VII.III indicates the diverse needs of the largest group of subjects requiring services at CHRIB. This subgroup of infants and toddlers with a unique set of established, biological and environmental risk events for communication disorders, occurring at different times in their lives, serves as an example of many other groups requiring ECI services. Best practice in ECI determines that the unique risk profile of the group, together with the particular risk profile of the young child within a particular family system of interdependent members (Hammer, 1998) will be considered when an individualized ECI programme is compiled.

Secondly, the next outstanding finding relates to the identification of risk conditions in the subjects. Upon considering the risk profiles of the different subgroups emerging from the results, it became clear that there were limitations in the early identification of young children at risk for communication disorders. Although most of the established risk conditions for communication disorders in the subjects were well known and commonly occurring congenital disorders, such as cleft lip and palate, Down syndrome, microcephaly, fetal alcohol syndrome and sensorineural hearing loss (Lubker, 1991; Shprintzen, 1997), some of these subjects were not identified at the earliest possible times. The implications are that intervention cannot start early enough to prevent the sequelae of the condition and the benefits of early intervention elude the child and the family.

Rare congenital disorders, such as fetal *Roaccutane*® syndrome (Briggs, *et al.,* 1994), agenesis of the corpus callosum (Kurtz, *et al*., 1997) and an unconfirmed genetic disorder also presented in the subjects which implies that not all established risk conditions are easily identifiable at birth or later in life. The results further indicated that autism/PDD and expressive specific language delay are also conditions which are difficult to diagnose early, most probably as a result of the subtlety of the initial stages of the communication disorder (Wetherby, *et al.,* 1998). The results indicated it that was not only certain established risk conditions which were difficult to identify at the earliest possible time. Subjects with biological risk conditions for communication disorders such as low birth weight and prematurity, multiple births and hyperactivity were identified early in life, but the risk for communication disorders inherent to their conditions, was disregarded. Since early identification and early commencement with intervention is one of the most important predictors of effective ECI services (Rossetti, 1993), the results of the empirical study emphasized the difficulties experienced in clinical practice to attain the goal of the earliest possible identification of all infants with risks for communication disorders. Suggestions for the improvement of early identification in the subjects were indicated in the results of the empirical study and will now be elaborated upon.

Thirdly, since the results identified parents as key persons in the identification of risk conditions in their children, the implication is that they must be equipped with knowledge of the risks for communication disorders in conditions such as low birth weight, prematurity and multiple births occurring in the infants and how to act on their concerns about the infant's development.

Although parents are ideally placed to identify risks for communication disorders in infants as a result of their continuous involvement in their children (Squires, *et al*., 1996), professionals, assisted by many different technologically based diagnostic procedures, are also present at important times when identification of risk conditions are possible. Different health care professionals are involved at different times in young children's lives, e.g. at the prenatal diagnosis of risk conditions, at birth, during the perinatal period, at primary health care facilities and at family health care practices. Various professionals, equipped with the necessary knowledge about risks for communication disorders, are therefore indispensable members of the extended collaborative ECI team responsible for early identification of risks for communication disorders.

Since ECI has the unique opportunity to intervene at the earliest possible time in an infant's life, early identification of risk conditions is the primary function of the ECI approach. Late identification of infants with risks for communication disorders results in late diagnoses, late referrals and late intervention efforts which compromise the whole process of efficacy of ECI. In order to answer the question to the multifaceted problem of early identification of communication disorders in young children a conceptual framework, which addresses the questions of who must be identified, when and by whom, is proposed in Figure VII.IV.

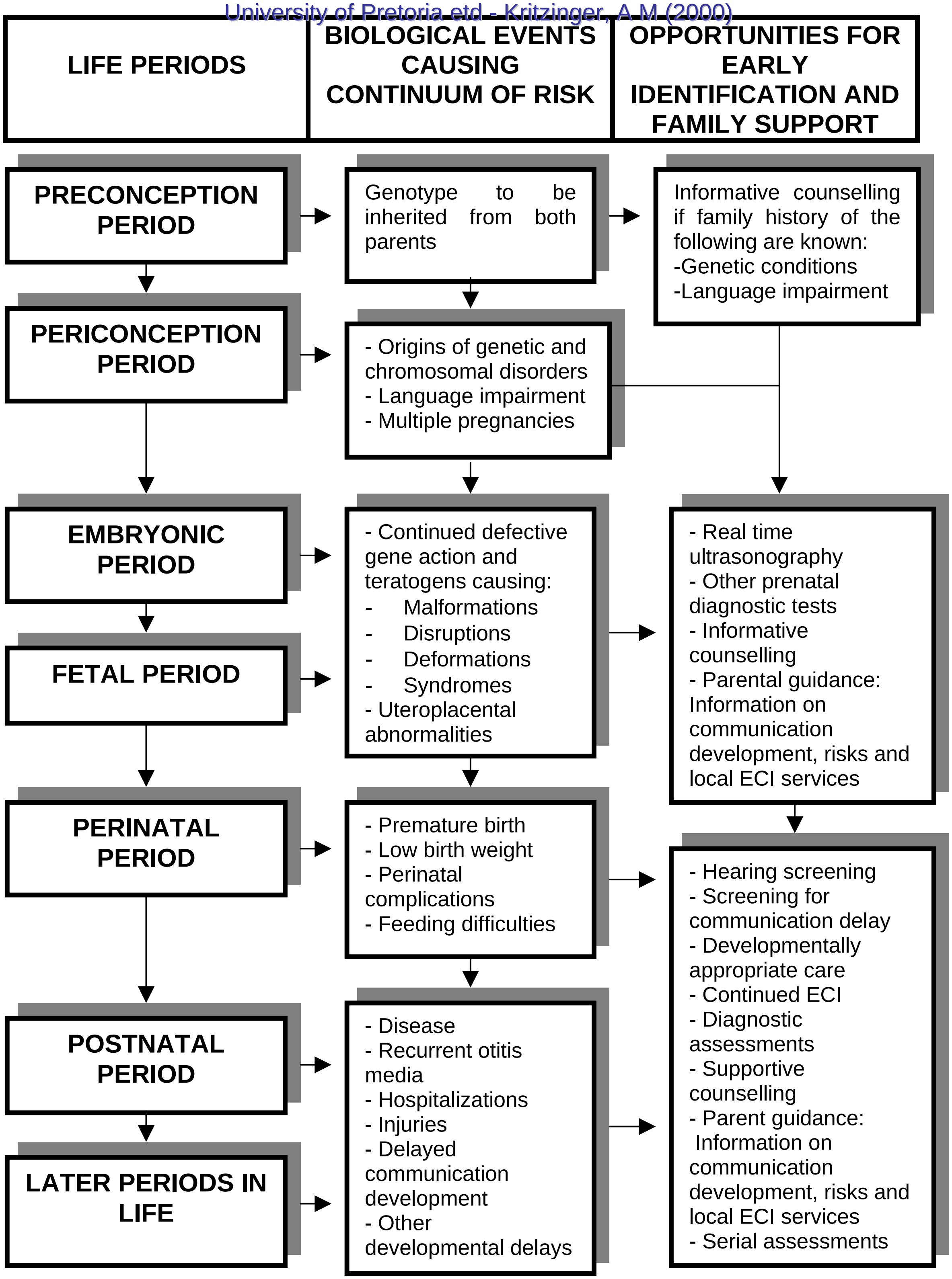

Figure VII.IV Conceptual framework for the early identification of risks for communication disorders

Conceptualized from: Allen, 1995; Glascoe, 1995; Louw & Kritzinger, 1998; Rossetti, 1996; Rubin, 1995; Sadler, 1995; 1999; Shprintzen, 1997; Thomson, 1995; Tomblin, 1989.

As illustrated in Figure VII.IV the conceptual framework for early identification of risks for communication disorders is proposed as a guideline for best practice to assist the ECI service provider to identify the critical times of cascading biological events which can negatively impact on the young child's communication development and to identify these events as possible opportunities for the identification of risks for communication development in the young child concerned.

Technological advances now allow the prenatal diagnosis of certain risk conditions in children which also affords the ECI service provider the opportunity to provide informative counselling and support to parents. The conceptual framework also demonstrates the continuum of risk throughout a young child's life and indicates the different professional roles of ECI during these periods. The different roles, executed by different professionals involved in the early identification process, include the following:

- Informative and supportive counselling to prospective parents, raising public awareness about risks for communication disorders and ECI during the prenatal period.
- Hearing screening, screening for communication delay, assessment, intervention in the form of developmentally appropriate care and information to parents about risks for communication disorders during the perinatal period.
- Serial assessments, followed by treatment by means of parent training, continued parent support and guidance during the postnatal period and later in the child's life.

The conceptual framework for early identification of risk conditions for communication delay is proposed as a guideline for the ECI service provider to be an active participant, directly or through transdisciplinary action, throughout the critical periods of possible harmful biological and other events in a young child's life. The aim of the framework is therefore to assist CHRIB in identifying key periods where the identification of risk conditions is possible and to develop essential steps to address parents' information needs thereby establishing a responsive ECI facility.

The conclusions regarding the establishment of the CHRIB database system and the most salient findings of the empirical study, emphasize the value of an in depth investigation which would not have been possible without the database approach to research.

7.3 IMPLICATIONS

In order to add value to the results, the clinical and theoretical implications of the CHRB database and results derived from its data will be discussed.

7.3.1 Implications for clinical practice

The establishment of a database system, designed to meet the current requirements of an ECI service provider, implies the availability of a powerful tool exclusive to the use of the ECI facility to increase the effectiveness of its clinical activities. According to theoretical and clinical guidelines to increase the effectiveness of ECI service delivery which were gleaned from a literature survey in Chapter 2, a set of 14 parameters on a continuum of efficacy were identified and can now be applied to guide the discussion of the clinical implications of the CHRIB database and results of the empirical study (See Chapter 2, Figure II.IV).

- Since the *early identification of children* with risks for communication disorders will increase the efficacy of services at CHRIB, the conceptual framework for early identification as illustrated in Figure VII.IV provides a guideline for action. Clinical efforts directed at transdisciplinary work with radiologists, geneticists and nurses involved in the prenatal identification and risk conditions for communication disorders must be explored (Louw & Kritzinger, 1998). In the same fashion, transdisciplinary activities and/or direct involvement by ECI professionals must be initiated during the perinatal period where collaboration with paediatricians, nurses in labour wards, well baby nurseries and special care nurseries can improve the age of identification of infants at risk for communication disorders. The set of professionals involved in the postnatal health care of infants, such as paediatricians, primary care doctors and nurses, in urban settings or community-based primary health care, must also be targeted for early identification. Lastly, health care professionals, such as primary care doctors and nurses, various medical specialists involved in health care of young children with disabilities, trauma and injuries, and persons involved in day care of young children must be equipped to identify risks for communication disorders in young children and refer the families to local ECI services.

- Since *acting on parental concerns about their child's development* can accelerate the commencement of ECI, it is of great importance that health care professionals in contact with families with young children are aware of the reliability of parental concerns and refer parents immediately an assessment (Rossetti, 1996). The results indicated that parental concerns lead to the identification of communication disorders in their young children.
- The results of the empirical study clearly indicated that *holistic partnerships with parents and other professionals,* either by transdisciplinary or interdisciplinary activities will increase the effectiveness of ECI endeavors (Briggs, 1997; Rossetti, 1996). The conceptual framework for early identification can only be applied successfully when strong partnerships between parents and professionals from different disciplines are formed.
- Since the results indicated that many of the subjects are living outside Pretoria and due to staff limitations, *intervention in naturally occurring contexts* of the families (McConkey, 1995a) can only be attained through transdisciplinary work. An example of transdisciplinary work with community

nurses at the Facial Deformities Clinic who are visiting parents in their homes, should be formalized and extended, since it can increase effectiveness of ECI services.

- The multiple risk profiles of individual subjects (See Appendix E) as well as the subgroups of subjects investigated, clearly indicated the necessity of *individualized treatment plans* for young children at risk for communication disorders. The application of individualized treatment plans wherein goals, procedures of reaching those goals and measuring its success is clearly defined (Spiker & Hopmann, 1997) have the potential to increase the effectiveness of the ECI services.
- Since the results of the empirical study indicated risks for communication disorders and subsequent risks for school failure in all the subjects and as these risks were repeatedly disregarded in the subjects when other risk conditions, such as multiple births and low birth weight and prematurity were identified, Rossetti's strong emphasis on a *communication-based intervention plan* (Rossetti, 1996) is validated. The emphasis on communication-based intervention should not only be limited to the individual intervention plans for children and their families, but should also be included in communications to other professionals and the public.
- The results of the characteristics of the subjects' families indicated the importance of recognizing the many assets of the majority of families in the study. The challenge *to identify strengths in all the children and families* served by CHRIB is inherent to the family-centered philosophy to service delivery (Ammerman & Parks, 1998) and should be aimed for, since an asset-based approach can increase the effectiveness of the ECI services.
- Since the parents of the subjects were already identified as key persons in the identification of their children's risks for communication disorders, their continued involvement in the intervention plan is one of the most important determiners of the success of the ECI efforts. Since specific information needs were identified in the subjects' parents, *training parents to facilitate their child's communication development* is one of the most important

intervention activities as it cannot be assumed that parents have the necessary skills when they expressed their willingness to help their child (McConkey, 1995a).

- Since most of the subjects presented with multiple risks for communication disorders, a *high intensity ECI programme* is recommended in order to gain from time advantage which ECI affords (Rossetti, 1996).
- As the results clearly indicated the needs of the subjects' parents, a comprehensive family-centered approach to ECI must also include *parent support groups*. Parental support groups, especially parent-to-parent programmes can increase the effectiveness of ECI services (Guralnick, 1997; Rossetti, 1996).
- The results of family characteristics indicated that approximately 10% of parents require *resource support* as a result of unemployment, single parents and low income. The implications are that one service provider cannot meet all the different needs of families and coordinated multidisciplinary services to young children, dictated by a national EI policy, is necessary to increase the effectiveness of ECI services in South Africa.
- In order to increase the effectiveness of implementation of a comprehensive ECI programme with a strong underlying philosophy, it is important to *train and supervise ECI clinicians* in their activities. Since CHRIB is a tertiary-based ECI service provider, undergraduate and continued professional education are already important functions of the clinic and can be extended to postgraduate clinical training as well (*White Paper on an Integrated National Disability Strategy,* 1997).
- The results clearly indicated that the population of clients served by CHRIB represent the typical South African characteristic of cultural diversity, although not in the same proportions. The fact that *culturally sensitive ECI services* was identified as one of the parameters determining the effectiveness of services emphasizes the importance of developing clinical expertise in this field (Fair & Louw, 1999).

- The last parameter to include in a comprehensive ECI programme is *the long-term follow-up of the subjects* to improve school readiness. Since CHRIB is one component of the Centre for Early Intervention in Communication Pathology, collaborative follow-up of clients is possible. The second component of the centre, Kommunika, aims to provide continued services to young children at risk for communication disorders and school failure and support them and their families in successful integration in the education system.

The discussion of the clinical implications derived from the results covered the critical aspects of ECI service delivery which can increase the efficacy of the services.

The one aspect, however, not described in the continuum of parameters for effective ECI service delivery, but strongly emphasized in the results, was the information needs of the subjects' parents. These results are confirmed by Guralnick (1997) who identified parental information needs as one of the categories of stressors experienced by families with young children with disabilities. According to Guralnick (1997) information needs, together with needs for social and resource support, are stressors which have the potential to interfere with optimal family patterns of interacting. *Addressing parental information needs* should therefore be viewed as an important component of an ECI programme since disrupted family interaction patterns will also affect the child's development.

Since educating parents and promoting normal communication development are professional functions of clinicians in the field of speech-language pathology and audiology (Uys & Hugo, 1990), clinical activities at CHRIB should be directed to this area of service. Increased public awareness of the different risks for communication disorders in young children and local ECI services has the potential of increasing the effectiveness of early identification of these infants.

Utilizing the continuum of parameters indicating those aspects of service delivery which have the potential to increase the effectiveness of ECI provided clinical standard for the discussion of the clinical implications of the results. Since the clinical implications of the study are supported by theoretical underpinnings, the implications thereof will be discussed.

7.3.2 Theoretical implications of the results

Certain important theoretical implications can be deducted from the results.

The point of departure of the CHRIB database design was a theoretical basis for assessment of infants and toddlers at risk for communication disorders. The holistic assessment model developed by Louw (1986) for the assessment of infants with cleft lip and palate and later adapted and refined as the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b) was utilized to design the database structure and to collect assessment data on the subjects in order to describe their communication functioning. Although the findings of the subjects' communication functioning were not described, as a result of the delimitation of the empirical study, the importance of a comprehensive assessment model, specially designed for the local context is emphasized. The implication is that the contextual assessment model, which was developed locally and utilized in clinical practice over the past ten years in CHRIB, now constitutes the theoretical basis of the CHRIB database. This increases the value of the CHRIB database, not only as a technologically advanced research tool in ECI, but also as a theoretically accountable research tool.

A further theoretical implication to be drawn from the results is the importance of a theoretical framework in ECI to effectively support the families with young children at risk for communication disorders. Samerhoff's transactional model of the continuous change over time between the child and the environment and described by Rossetti (1990a), Guralnick's model (1997) identifying family characteristics, stressors and patterns as influences on the children's outcomes, and the family systems theory, described by Briggs (1997) and Hammer (1998), all contribute to a better understanding of how to deliver effective ECI services to families.

The last theoretical implication pertains to the large number of subjects with established and other risk conditions of which most may have a genetic basis. The results emphasize the importance of knowledge about clinical genetics in the field of ECI. With the current explosion of new knowledge about the genetic basis of clinical syndromes, clinicians are urged to increase their understanding of genetically based communication disorders (Louw & Kritzinger, 1998; Shprintzen, 1997). Knowledge of clinical genetics is therefore of crucial importance to ECI as clinical insight can increase the effectiveness of early identification of risks for communication disorders and further ECI services rendered.

The theoretical implications of the results indicated the importance of accountable theoretical approaches in the field of ECI, without which the advancement of science will not be possible.

In order to conclude the scientific process it is not only the clinical and theoretical implications of the study which must be discussed. In order to provide guidelines for further research, a critical review of the methodology employed in the empirical study and its results must also be presented.

7.4 CRITICAL REVIEW OF METHODOLOGY AND RESULTS

Since results were determined by the methodology employed in the empirical study, a critical review of the methodology is necessary (Leedy, 1997).

The results of the empirical study partly depended on the structure of the CHRIB database, i.e. the number of subjects, the volume, the variety and type of data per subject stored in the database. Limitations in the database design could have compromised the current study and can therefore compromise future research conducted utilizing the CHRIB database as a research tool.

Certain limitations in the CHRIB database were identified during the investigation:

- The table labelled "Medication" could not be used since the data was incomplete. It appeared that the subjects' parents could not supply full details on the different medications the subjects received while ill and hospital reports are not easily accessible retrospectively. The original idea of including a database table for medications used by the subjects is still valid since the use of ototoxic medications is a risk factor for sensorineural hearing loss throughout life (Fowler & Fowler, 1994). The table can therefore only be used when accurate data collection can be ensured.
- The tables labelled "Persons Involved" and "Referring Person" contain useful information for interdisciplinary contact, but the data is not easy to manipulate to create queries.
- The type of information stored in the CHRIB database does not permit an in-depth analysis of the characteristics of the subjects' families regarding the interrelationships and resources. This is considered as a limiting factor since a family-centered approach is advocated in ECI and extensive information on the family is necessary to follow this approach.
- A database system offers many advantages, but is a complex set of software. The initial cost, hardware requirements and training required to use the system must be considered (Ramakrishnan, 1998).
- Lastly, a database system does not appear to be a major time-saving device. Mandeville, *et al*. (1988) confirms this observation and notes that computer

technology offers fast operations, but many more operations are possible, which are efficient but not necessarily timesaving.

The database limitations, however, do not outweigh its advantages and the CHRIB database could be used to produce accountable results. The next aspect of the methodology to be critically evaluated is the choice of a diagnostic classification system in categorizing the risk conditions in the subjects.

The use of the *ICD-10* (CSS, 1996) in the study was found to be an appropriate classification system, but with certain limitations. The *ICD-10* (CSS, 1996) was used as a diagnostic classification system in the CHRIB database (See Appendix E) and to obtain South African infant mortality statistics in Chapter 3. The application of the *ICD-10* (CSS, 1996) proved to useful in the classification and coding of the different risk factors found in the subjects, as some form of classification system had to be used in the CHRIB database. As the *ICD-10* (CSS, 1996), i.e. the 10th revision, was the most frequently used classification system for causes of death and other health information, internationally and locally in the medical field at the time of data collection (Christianson, 1996), the system was chosen in view of the possibility of linking the CHRIB database with other databases.

Moreover, since the South African Central Statistical Service was using this classification system for mortality and morbidity data, health statistics and surveys, which is of great interest to the professional involved in ECI, the choice of the *ICD-10* (CSS, 1996) in the present study was appropriate. The diagnostic classifications and their codes used in South African health statistics and the data in the CHRIB database were therefore reconcilable which assisted in the accurate interpretation of data.

Since the majority of the subjects presented with established risk conditions, the *ICD-10* (CSS, 1996) permitted adequate categorization of confirmed conditions, but were limited in classifying developmental disabilities in general and speech-language disorders specifically. As the role of the environment in contributing to a young child's risk status has found to be particularly relevant in the South African context, it is important to find a systematic way of including environmental risks in a description of a young child's risk profile, a feature the *ICD-10* (1996) does not offer. The environmental risk factors impacting on the subjects' development could therefore not be included in the risk profile of the subjects displayed in Table 6.11.

As recommended by its authors, the new *ICIDH-2* (WHO, 1999) should be used together with the *ICD-10* (CSS, 1996). Since the *ICD-10* (CSS, 1996) represents an etiological framework and provides a diagnosis, the *ICIDH-2* (WHO, 1999) provides a broader picture by describing the health status of people in terms of body functions and structure, activities at the individual level and participation of the person in society. It appears that the *ICIDH-2* (WHO, 1999) provides a much improved system of classification of conditions by differentiating between functional states of persons with the same condition. The *ICD-10* (CSS, 1996) provides the cause of a condition, but is not sufficient to explain the resulting impairment and loss of function in an individual. It is therefore recommended that the *ICIDH-2* (WHO, 1999) be used as an extension of the *ICD-10* (CSS, 1996) in the CHRIB database, since it attempts to integrate the medical and social models of disability and provides an improved classification of communication disorders. It is, however, not clear how applicable the *ICIDH-2* (WHO, 1999) will be for the description of developmental disabilities, since it appears to address disability from an adult perspective. The classification system, of which the final version is to be published in 2001, is still undergoing systematic field trials and is subject to further consultation. Since the authors encourage field testing of the document, its use make a valuable contribution to the CHRIB database, opening new possibilities for further research.

The critical review of the methodology and results of the empirical study indicated that the CHRIB database generated the necessary data to analyze and present as the results according to the aims of the study. Since the aims of the study were successfully accomplished, guidelines for further research can be indicated.

7.5 RECOMMENDATIONS FOR FURTHER RESEARCH

As illustrated in Figure VII.II the CHRIB database is a powerful research tool offering the researcher a variety of research designs to execute further ECI research projects. Since numerous research possibilities were already indicated in Figure VII.IV a few recommendations for future research, promising the most valuable contribution to the field of ECI in South Africa, were selected. Based on the results of the empirical study the following recommendations for further utilization of the CHRIB database in research are made:

- In view of long-term and epidemiological research employing large samples, it is recommended that data collection of clients assessed at CHRIB be continued under the same stringent data collection procedures as applied during the empirical study. This implies that that the sample can increase with approximately 40 subjects per year. At the conclusion of the current research project the total number of subjects in the CHRIB database is already 185 which implies that this method of data collection can continue as part of the weekly activities of CHRIB, thereby ensuring the systematic maturation of the database. This method ensures a steady increase of data and maturation of the CHRIB database, with the advantage of immediately available data for further research.
- As indicated earlier, the interesting results of the subjects with cleft lip and palate illustrated in Figure VII.III must be investigated further, but utilizing a different approach to data analysis. The same data set can be used for a phylogenetic analysis (Kruger, 2000a). This type of analysis, not to be

confused with an analysis of genetic inheritance *per se*, aims to identify patterns of similarities in subjects by process of generalization in order to categorize specific instances. According to Kruger (2000a) the available data of the subjects with cleft lip and palate can be analyzed according to multiple inheritance trees if the necessary computer software packages can be obtained. By way of example this type of analysis may be able to indicate whether the different types of clefts occurring in the subjects can be associated with different characteristics described. By implementing alternative methodologies of data analysis new ideas may be established in the field of ECI.

- The same type of analysis can also be conducted to further describe the subjects with expressive specific language impairment. Since the phylogenetic analysis can be conducted when sparse empirical data are available, this approach may indicate interesting patterns of correlation in this subgroup of subjects.
- Since the data of the 153 subjects' communication functioning has already been analyzed, data presentation and interpretation can be carried out to describe the subjects' level of functioning according to the CHRIB Assessment Protocol (Louw & Kritzinger, 1995b). This will continue the current empirical study and will enable the researcher to compare the subjects' risk profiles with their level of functioning.
- Since the study of different populations requiring ECI in South Africa is of great importance (Fair & Louw, 1999), further research will contribute greatly to the field of ECI. Since the CHRIB database permits entry of data collected in different contexts, the increased populations of infants and toddlers at risk for communication disorders in South Africa, such as those with fetal alcohol syndrome (Viljoen, 1999), low birth weight and prematurity (Kritzinger, *et al*., 1995), HIV infection (Bobat, *et al*., 1999), Down syndrome (Venter, *et al.,* 1995), cerebral palsy (Molteno & Arens, 1991) and prenatal Rubella exposure (Christianson, 1998) and their families from developing communities can be included.

- Since the importance of parents in the ECI process were repeatedly indicated in the results of the empirical study, the investigation of different populations of caregivers, such as adolescent mothers, mothers who are diagnosed with HIV/AIDS, fathers, adoptive parents and parents from developing communities can greatly increase the knowledge base of ECI in South Africa.

The recommendations for further research indicate the continued utilization of the CHRIB database, but moreover, indicate that the CHRIB database approach to research is essential to keep abreast of the demands of the 21st century.

7.6 CONCLUSION

John 21 verse 1-14
Adapted from the *Good News Bible, Today's English Version*

Jesus appears to seven disciples

…… Jesus appeared once more to his disciples at Lake Tiberias. This is how it happened …….

The seven disciples went out on a boat to fish, but all that night they did not catch a thing. As the sun was rising, Jesus stood at the water's edge. Then he asked them, "Haven't you caught anything?"

"Not a thing", they answered.

He said to them, "Throw your net out on the right side of the boat, and then you will catch some".

So they threw the net out and could not pull it back in, because they had caught so many fish.

……. They dragged the net ashore full of big fish, *a hundred and fifty three in all; even though there were so many, still the net did not tear*. Jesus said to them, “Come and eat”.
This, then, was the third time Jesus appeared to his disciples after he was raised from death.

✞✞✞✞✞✞✞

When analyzing the data of the 153 subjects it occurred to the researcher that this number also features in a Bible story. When compared to the account in John 21, there are many obvious differences, but also two similarities.

The one similarity is that the net did not tear. The CHRIB database was adequate to capture the data of the 153 subjects and can capture many more in future. Representatives of the different groups of infants and their families requiring ECI in South Africa can be found in the subjects who were investigated. If these infants are found in due time, the CHRIB database will be able to accommodate them all.

The second similarity is that when involved in ECI, Jesus is waiting *in cognito* on the shore. The risen Christ is deeply concerned about attempts to intervene in the lives of the little ones of society. *They are the children of the new century whose future depend on committed researchers, clinicians and their parents equipped with the knowledge that ECI can make a difference in their lives.*

7.7 SUMMARY

The chapter provides the final conclusions to the entire study. The use of the CHRIB database system as an established ECI research tool with its vast possibilities to contribute to second generation research in EI is discussed. The conclusions to the findings of the empirical study were presented, emphasizing the risk profile of subjects with cleft lip and palate as an example of a subgroup of subjects requiring further investigation. A conceptual framework for the early identification of risks for communication disorders was proposed and its clinical applications discussed. The clinical implications of the study were presented within the framework of a continuum of parameters which can increase or decrease the effectiveness of ECI. Lastly, the theoretical implications of the study indicated that knowledge of clinical genetics has become most important in ECI. Finally a critical review of the methodology and results are presented and further research is indicated.

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Appendix E Subjects and their *ICD-10* (CSS, 1996) Classifications

ClientID*	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10
10	Q35.5.1	F80	H65	P05			
13	Q37.4	F80	P05				
14	F80	H65					
15	Q86.8.1	P07	P05	F80			
16	Q37.7	O30.0	P07	P07.3	F80	H65	
17	Q37.3	F80	H65				
18	Q36.0	F80	H65				
19	O 30.1	P07	P07.3	F80	H65		
20	O 30.1	P07	P07.3	F80			
21	O 30.1	P07	P07.3	P05	F80		
22	Q90.0	F80					
23	Q90.0	F80	H65				
24	Q35.5.4	O30.0	P07.1	F80			
25	P07.2	P07	P05	F80	H65		
26	Q35.5	P07.3	F80				
27	Q37.3	F80.0	H65				
28	Q37.7	O30.0	G40.7	P07.3	F80	H65	
29	Q35.5.2	G71.0	P07	P07.3	F80		
30	F80	H65					
31	Q35.5.1	F80	H65				
32	Q35.5.1	F80	H65				
33	Q90.1	F80					
34	Q90.0	F80	P05				
35	Q35.3	P07	P05	F80	H65		
36	F80	H65					
37	Q35.5.4	F80	H65	Q21.0			
38	Q37.7	P07.1	F80	H65			
39	Q35.3	F80	H65	P05			
40	Q35.5.1	F80					
41	Q90.0	P07.1	F80	Q21.0			
42	Q90.0	P07	P07.1	P05	F80		
43	Q37.7.2	F80	H65				
44	Q37.7	F80	H65				
45	Q37.5	F80	H65				
46	Q90.0	F80	P05				
47	Q37.3	F80	PO8				
48	Q37.7	F80					
49	Q90.0	P07	P07.1	F80	H65	Q21.0	
50	Q90.0	F80	H65	Q21.0			
51	Q35.3	P07.1	F80	H65			
52	P07.3	F80	H65				
53	Q90.0	F80	Q21.0	P05	Q41.0		

Appendix E continued

Client ID	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10
54	Q35.3	O30.0	P07	P07.1	P05	F80	H65
55	Q90.0	F80	P08				
56	Q37.4.1	P07	P05	F80			
57	F84.0	F80					
58	Q37.5.1	P07	P07.3	P05	F80	H65	
59	Q35.7	P07	P07.3	F80	H65		
60	Q37.5	F80	H65				
62	H91.2	F80	H65	P05			
63	O 30.1	P07	P07.3	F80			
64	O 30.1	P07	P07.3	F80			
65	Q35.5.1	F80					
66	Q90.0	P07.3	F80				
67	Q90.0	P07.3	F80				
68	P07	P07.1	P05	F80			
69	Q90.0	P07	P07.1	P05	F80		
70	Q37.7	O30.0	P07.3	F80	H65		
72	O30.0	P07.3	F80	H65			
73	Q37.5	F80	H65				
74	Q35.3	F80	H65				
75	Q90.0	F80					
76	Q37.4	F80	H65				
77	Q86.0	F80					
78	F84.01	F80					
79	Q37.7.1	P07.1	F80				
80	Q35.3	F80	H65				
81	P07	P07.3	F80				
82	F80	H65					
83	Q37.4	F80	H65	P08			
84	O30.0	F80	H65	P05			
85	O30.0	P07	F80				
86	P07	P07.3	F80	H65			
89	S06.6	F80.1					
90	Q37.4	F80	H65				
91	Q35.3.1	F80					
93	P07.2	P07	F80				
94	P07.3	P07					
95	Q37.4	F80					
96	Q35.3	F80					
97	Q90.0	F80	Q21.0	Q21.1			
98	Q37.5	F80	H65	P05			
99	F90.8	P07.3	F80	H65	PO8		
100	O30.0	P07.3	P07	G80.01	F80	H65	
101	O30.0	P07.3	P07	F80	H65		

Appendix E continued

Client ID	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10
102	Q37.5	F80	H65	PO8			
104	Q35.5.1	F80	H65				
105	Q35.5.1	F80	H65				
106	Q37.5.2	F80	H65				
108	Q37.4	F80	H65	P08			
109	Q89	H91.2	F80	Q13.0	Q21.3	Q30.0	
110	P07.3	F80					
111	F80						
112	Q37.4	P07	P05	F80	H65		
113	Q35.5.1	F80	H65				
114	Q37.1.1	Q30.9	F80				
115	F84.0	F80					
116	Q90.0	P07.3	F80	Q21.9			
117	F80	H65	P08				
118	Q90.0	F80	Q21.9				
119	F80	H65					
120	Q35.5.1	F80	H65	Q21.9			
121	Q90.0	P07	P05	F80	H65		
122	Q89	P07	P07.3	F80	H65	Q21.9	
123	Q37.5	P07	P07.3	F80	H65	Q21.9	Q04.6
124	Q37.4	F80	H65				
125	Q37.5	O30.0	F80	H65			
126	Q90.0	G40.7	F80	H65	Q21.0	Q25.0	
127	F80	H65					
128	Q35.5.4	O30.0	F80	H65			
129	Q37.5	P07	P07.3	P05	F80		
130	Q35.5.1	F80					
131	Q35.3	F80					
133	Q35.5	G71.0	P07.1	F80			
134	Q37.7	F80					
135	Q90.0	P07.1	F80	H65	Q21.0	Q21.1	
136	Q35.5.8	P07.1	F80.0	H65			
137	Q35.5.1	F80	H65	P05			
138	P07.3	P07	F80				
139	Q90.0	O30.0	P07.3	P07	P05	F80	H65
140	Q38.3	F80.0	PO8				
141	Q37.7.2	F80	H65				
142	Q37.7	F80	H65				
143	Q37.7	P07	P05	F80.0	H65		
144	Q35.3	F80					
145	Q04.0	F80	H65	P05			
146	F80	H65					
147	Q37.5.5	Q75.0	P07.3	P07	F80		

Appendix E continued

Client ID	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10	ICD-10
148	O30.0	P07.3	F80				
149	O30.0	P07.3	F80				
150	F80	H65	P07.1				
151	O30.0	H91.2	P07.3	F80			
152	Q37.5.3	P07.3	F80				
153	Q90.0	F80	P05				
154	F90.8	H65	P08				
155	Q35.5	F80	Q21.1				
156	Q35.3	F80	P05				
157	F84.0	F80	H65				
158	Q37.4	P07.3	P07	P05	F80	H65	
159	Q37.7	F80	H65	P05	Q21.9		
160	Q37.2	F80	H65				
161	Q35.5	F80	H65				
163	F80						
164	Q37.4	F80.0	H65				
165	Q35.5.1	P07.1	F80	H65			
166	O30.0	P07	P07.3	F80			
167	O30.0	P07.3	F80				
168	P07.3	P07					
169	Q37.7	P07.1	F80				
170	Q37.5	F80					
171	Q02	F80	P05				
172	Q35.3	P07	P05	F80	H65		
173	Q37.1.1	H65					

Client ID*

Missing client ID numbers do not indicate miscalculations, but relates to initial mistakes in the data entry. The mistakes were corrected but the CHRIB database allocated a new number to the corrected entry.