CHAPTER 1

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

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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

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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;

INCREASED PREVALENCE OF INFANTS REQUIRING ECI

Poor access to ECI facilities

Scarcity of ECI facilities

Limited referral system

Limited teamwork

Paucity of EC Interventionists

Limited knowledge about the benefits of ECI

Problem areas

LIMITED EPIDEMIOLOGICAL AND OTHER RESEARCH DATA ABOUT YOUNG CHILDREN WITH DISABILITIES AND AT RISK FOR COMMUNICATION DISORDERS

Poor ECI planning and service delivery

Consequences

Limited early identification and treatment of infants who require ECI

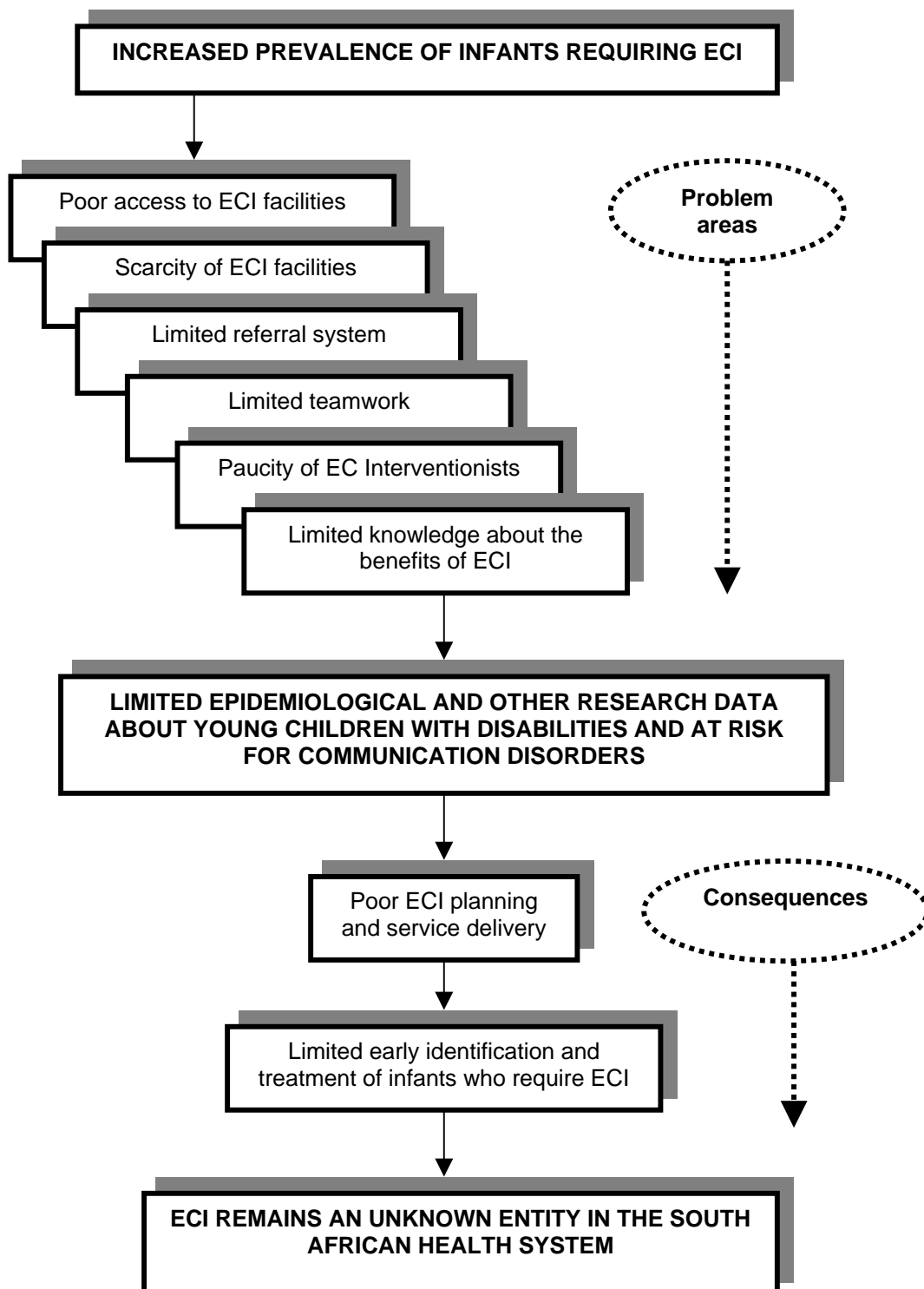**ECI REMAINS AN UNKNOWN ENTITY IN THE SOUTH AFRICAN HEALTH SYSTEM**

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

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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

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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).

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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

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University of Pretoria etd – Kritzinger, A M (2000)

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.

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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).

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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.