# 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.*

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## 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 21$^{st}$ 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

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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.
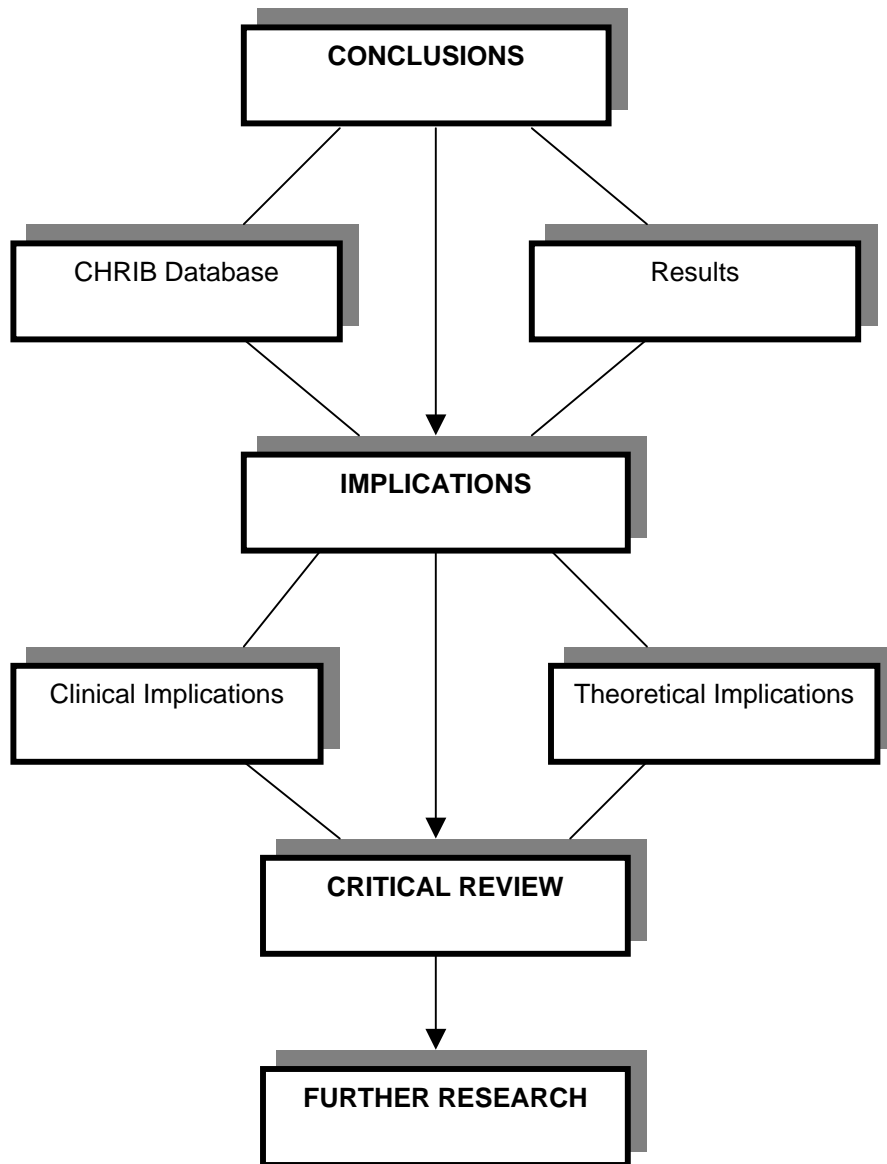
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**Figure VII.I   Outline of chapter contents**

## 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.
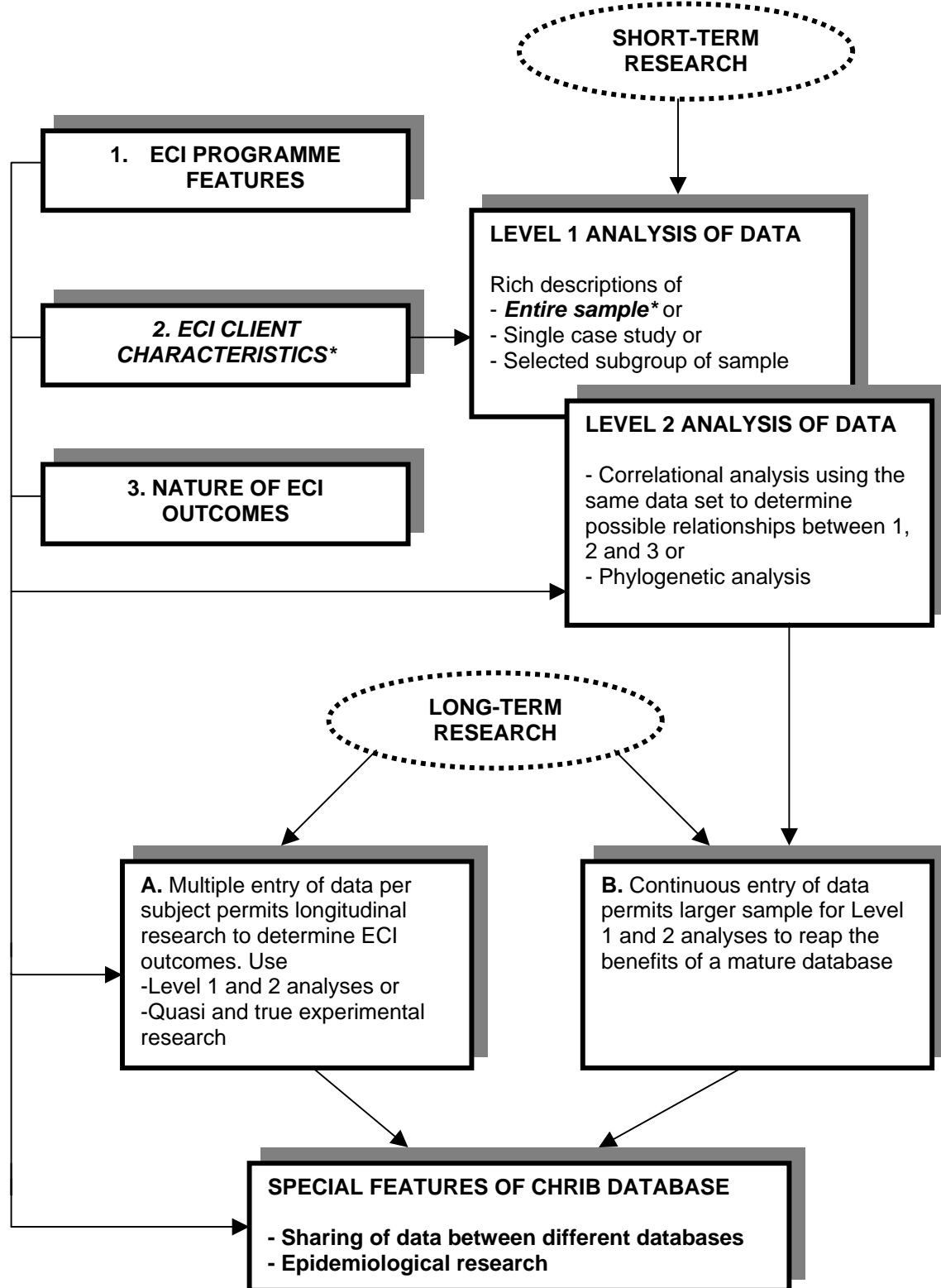
**Figure VII.II  Research capabilities of the CHRIB database**
Conceptualized from: Guralnick, 1997; Kruger, 2000a; Leedy, 1997; Beaglehole, *et al.,* 1993.  **Key\*** Italics indicate the extent of the current empirical study

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.
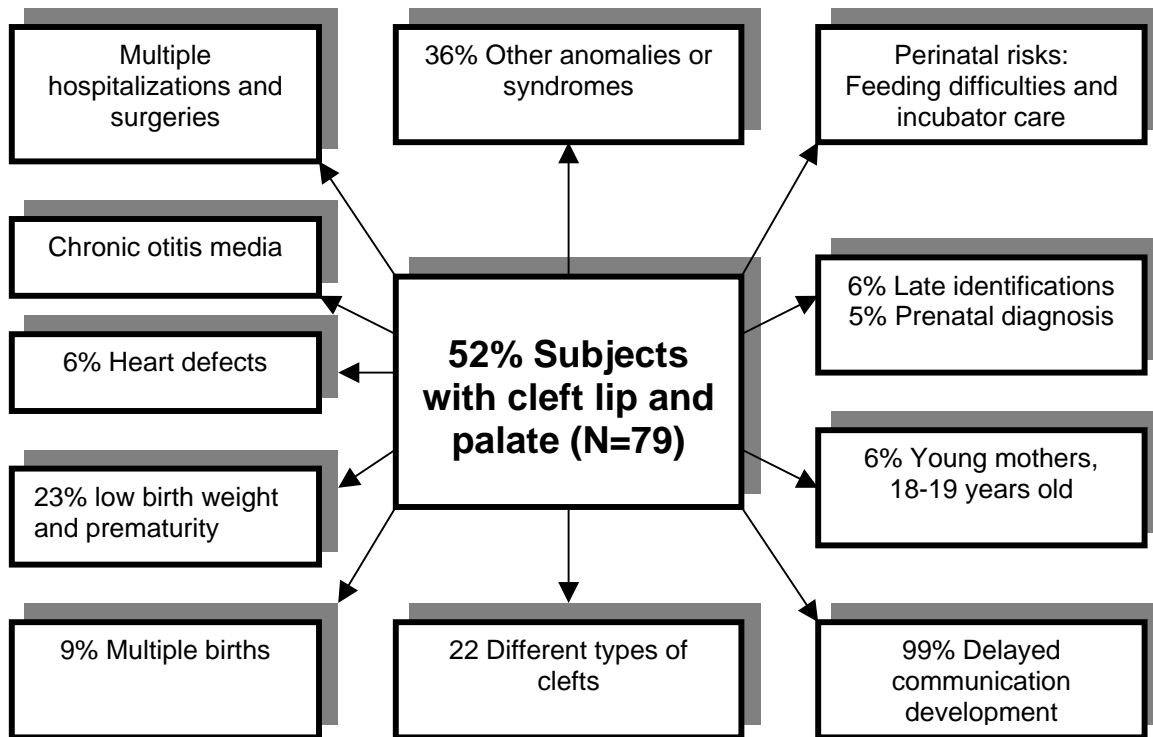
| | | |
|---|---|---|
| Multiple hospitalizations and surgeries | 36% Other anomalies or syndromes | Perinatal risks: Feeding difficulties and incubator care |
| Chronic otitis media | | 6% Late identifications 5% Prenatal diagnosis |
| 6% Heart defects | **52% Subjects with cleft lip and palate (N=79)** | 6% Young mothers, 18-19 years old |
| 23% low birth weight and prematurity | | |
| 9% Multiple births | 22 Different types of clefts | 99% Delayed communication development |

**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.
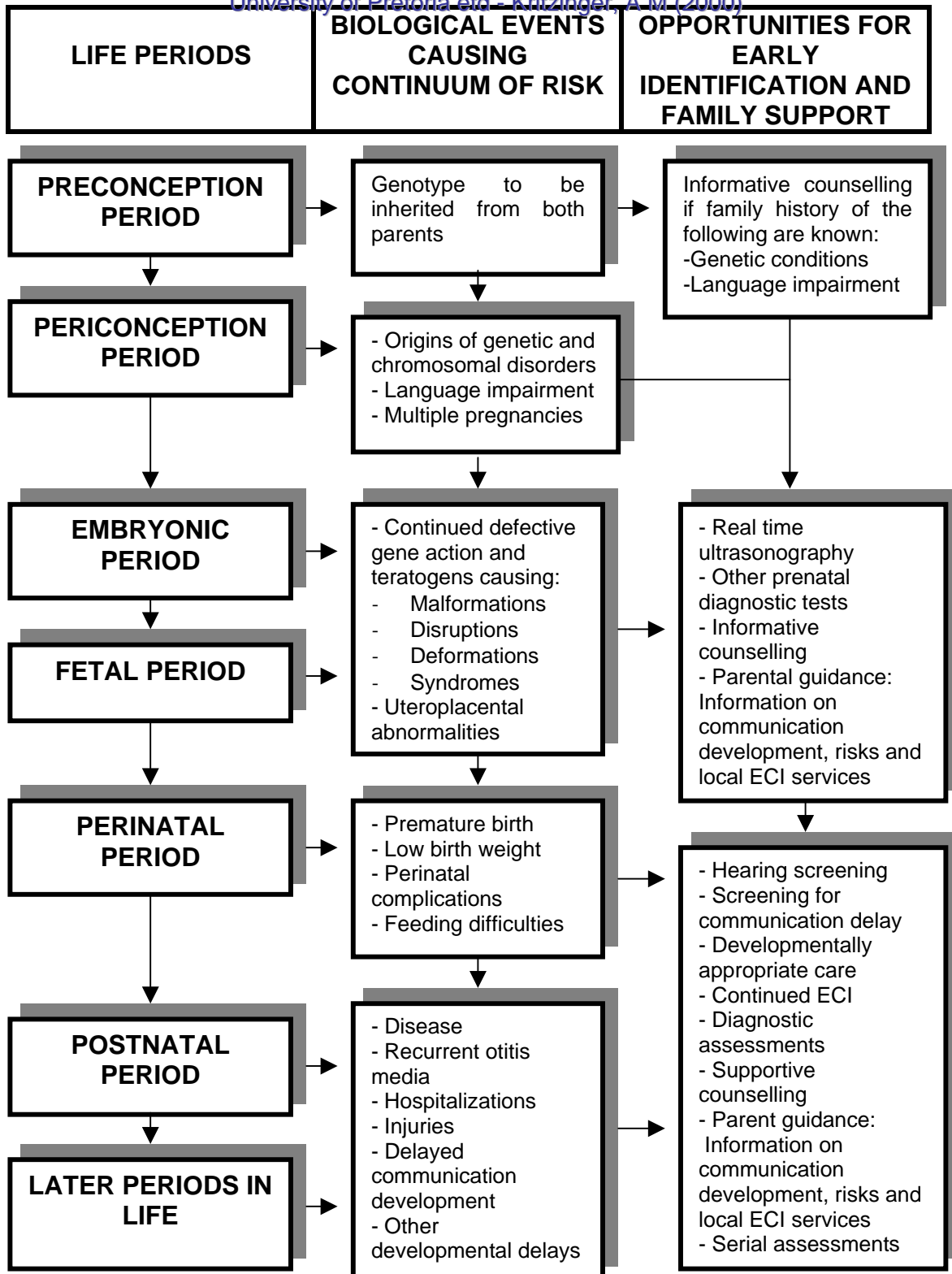
| LIFE PERIODS | BIOLOGICAL EVENTS CAUSING CONTINUUM OF RISK | OPPORTUNITIES FOR EARLY IDENTIFICATION AND FAMILY SUPPORT |
|---|---|---|
| **PRECONCEPTION PERIOD** | Genotype to be inherited from both parents | Informative counselling if family history of the following are known: <br> -Genetic conditions <br> -Language impairment |
| **PERICONCEPTION PERIOD** | - Origins of genetic and chromosomal disorders <br> - Language impairment <br> - Multiple pregnancies | |
| **EMBRYONIC PERIOD** | - Continued defective gene action and teratogens causing: <br> - Malformations <br> - Disruptions <br> - Deformations <br> - Syndromes <br> - Uteroplacental abnormalities | - Real time ultrasonography <br> - Other prenatal diagnostic tests <br> - Informative counselling <br> - Parental guidance: Information on communication development, risks and local ECI services |
| **FETAL PERIOD** | | |
| **PERINATAL PERIOD** | - Premature birth <br> - Low birth weight <br> - Perinatal complications <br> - Feeding difficulties | - Hearing screening <br> - Screening for communication delay <br> - Developmentally appropriate care <br> - Continued ECI <br> - Diagnostic assessments <br> - Supportive counselling <br> - Parent guidance: Information on communication development, risks and local ECI services <br> - Serial assessments |
| **POSTNATAL PERIOD** | - Disease <br> - Recurrent otitis media <br> - Hospitalizations <br> - Injuries <br> - Delayed communication development <br> - Other developmental delays | |
| **LATER PERIODS IN LIFE** | | |

**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

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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.

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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 10$^{th}$ 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

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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 21$^{st}$ 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.

<div align="center">✝✝✝✝✝✝✝</div>
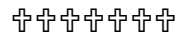
When analyzing the data of the 153 subjects it occurred to the researcher that this number also features in a Bible story. When compared to the account in John 21, there are many obvious differences, but also two similarities.

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.