CHAPTER 6

RESULTS AND DISCUSSION

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

6.1 INTRODUCTION

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

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

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

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

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

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

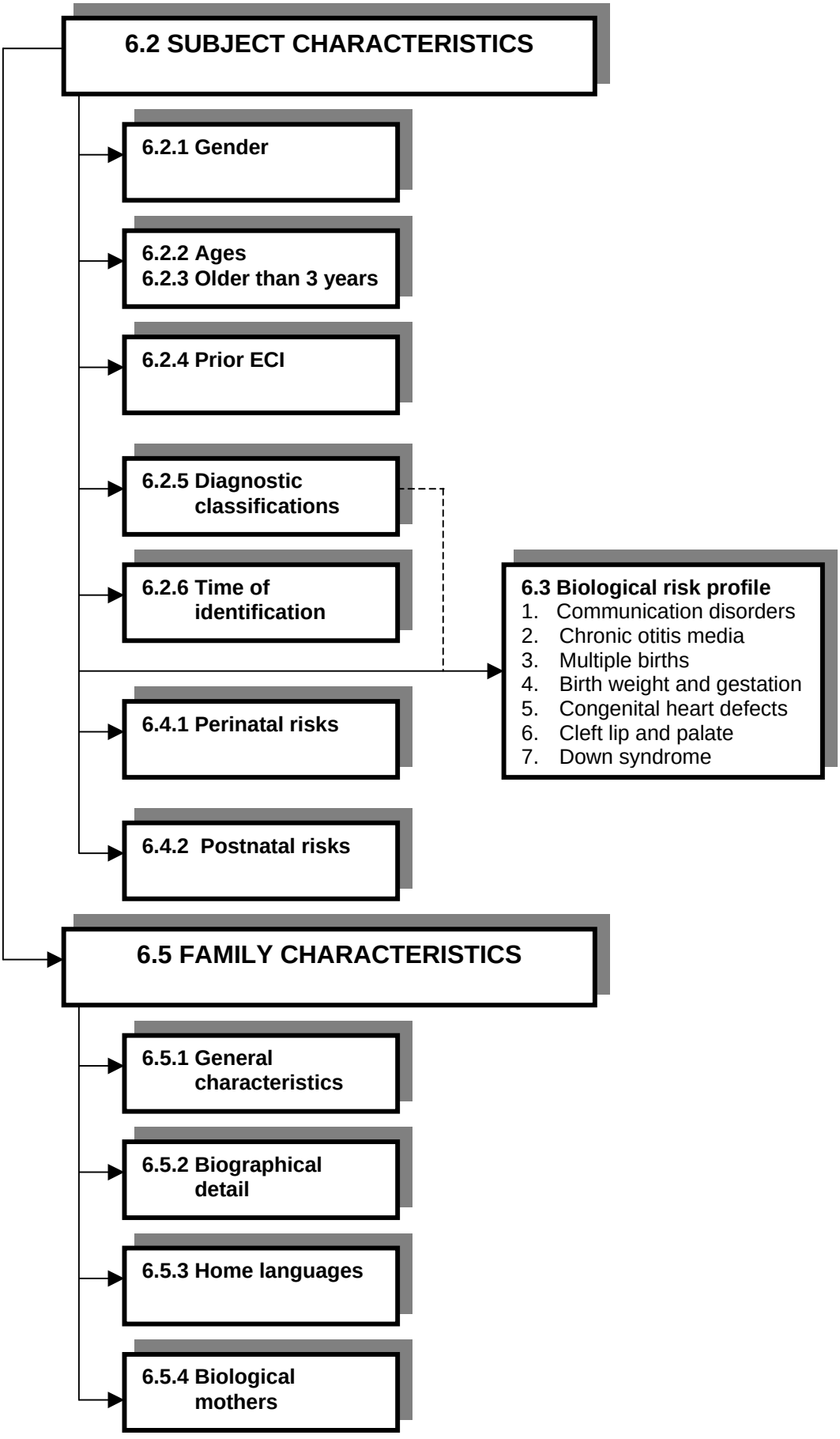

Figure VI.I Overview of results presented in the chapter

6.2 DESCRIPTION OF THE SUBJECTS' CHARACTERISTICS

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

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

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

6.2.1 Gender of the subjects

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

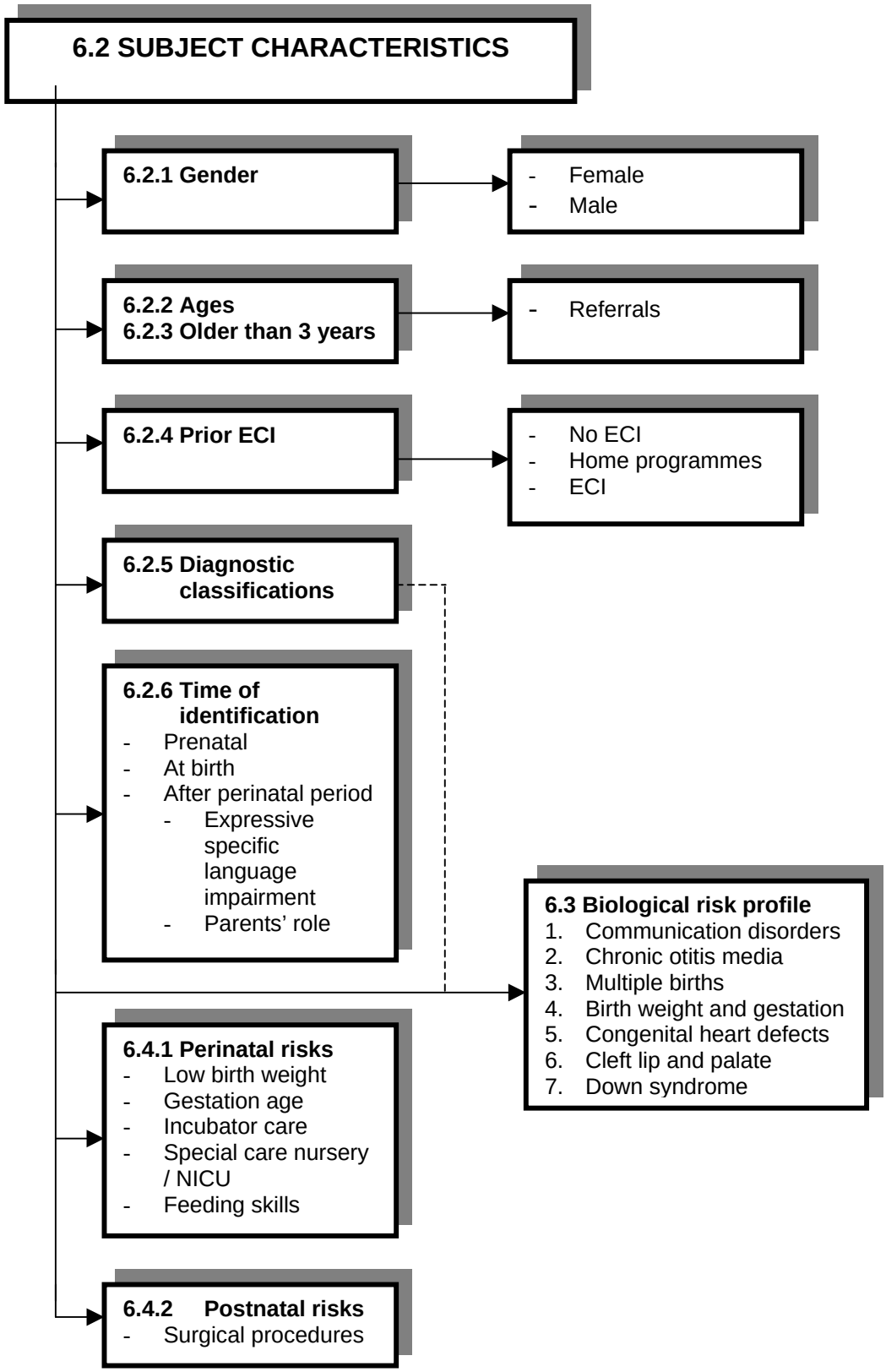

Figure VI.II Outline of results pertaining to the characteristics of the subjects

Table 6.1 Characteristics of subjects (N=153)

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

6.2.2 Age of subjects

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

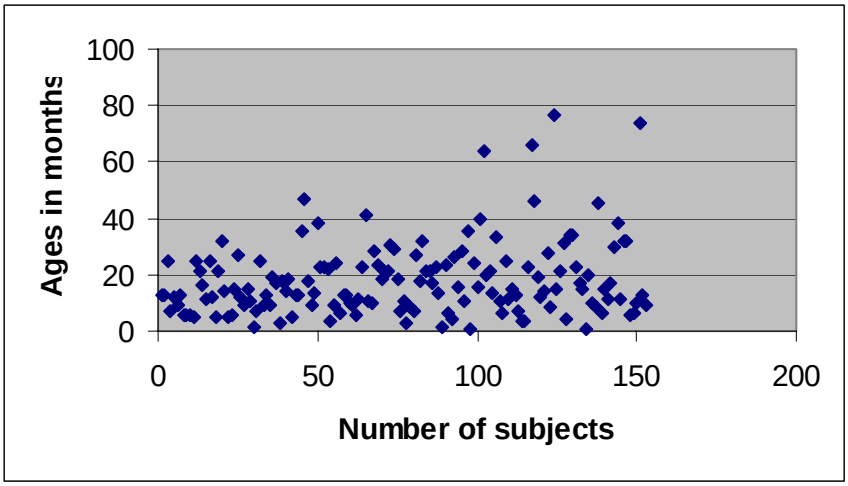

Figure VI.III Scatter graph distribution of subjects' ages (N=153)

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

6.2.3 Subjects older than three years

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

- Two subjects came into contact with ECI services for the first time at the CHRIB assessment and they were subsequently diagnosed with established risk conditions. One subject (CHRIB ID 62) was diagnosed with a moderate hearing loss at the assessment and was referred to CHRIB by the parents themselves while the other subject (CHRIB ID 171)

was diagnosed with a developmental delay associated with microcephaly and was referred to CHRIB by the Down Syndrome Association. As these two subjects had no prior contact with any ECI services and their conditions were identified late, it is of great concern that subjects with conditions which can be identified at birth or early in life, went unnoted.

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

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

Key to table headings

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

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

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

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

The results concerning the relatively high ages of certain subjects also indicate that CHRIB, as a university-based ECI service provider, is recognized by other speech-language therapists and audiologists to provide specialist consultative services in cases of difficult-to-diagnose children or children demonstrating unsatisfactory progress in a treatment programme. Table 6.3 was compiled from the datasheet view of the CHRIB database in *Microsoft® Excel* by applying a filter procedure in order to reveal all the speech-language therapists and audiologists who referred clients to CHRIB for consultative

services. (The CHRIB database table "Persons involved" contains the names of all the professional persons involved in a particular client. See Chapter 5, Table 5.2). The subject's ages were added to the table in a separate column.

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

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

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

Key to table headings and abbreviations

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

6.2.4 Subjects enrolled in ECI programmes prior to CHRIB assessment

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

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

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

professional functions of service delivery, especially those functions involving teamwork and consultation.

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

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

6.2.5 Main diagnostic classifications of subjects

The next characteristic of the subjects depicted in Table 6.1 (See also Figure VI.II) relates to their main diagnostic classifications according to the *ICD-10 Manual* (CSS, 1996), an international classification system of diseases and related health problems, which was utilized in the CHRIB database. The *International Classification of Impairment, Disability and Handicap* (*ICIDH-2*) (WHO, 1999), a considerably more appropriate classification system for

recording developmental disabilities which the subjects displayed, was not yet available at the time the data was recorded.

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

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

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

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

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

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

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

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

make a decision regarding the necessity of surgery, to determining the devastating effects of agenesis of the corpus callosum on a child's development.

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

6.2.6 Time of identification of subjects' risk conditions

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

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

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

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

Key

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

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

These results not only indicate the high technological prenatal care which resulted in the earliest possible diagnosis in some of the subjects, but also reveal a new role for speech-language therapists (Louw & Kritzinger, 1998), specifically in CHRIB. This role involves the prenatal counseling of families in order to make informed decisions and to be adequately prepared about the developmental risks of the diagnosed conditions in their unborn children and

the importance of commencing with ECI after birth. The advantage is that parents can be prepared prior to the time of active parenting of a child with a risk condition (Louw & Kritzinger, 1998). The results reported in Table 6.4 indicate that prenatal informative counselling (Thomson, 1995) and promoting increased public awareness of ECI services should be seen as important functions in CHRIB. Potential parents' increased knowledge of risk conditions for communication delays can lead to the earlier identification of infants at-risk and eventually to a higher success rate in the prevention of disabilities (Gerber, 1990; Kochanek & Buka, 1995).

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

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

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

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

Table 6.5 continued

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

As the effectiveness of ECI depends on the earliest possible identification of those children requiring the services (Rossetti, 1996), the identification of clients should be viewed on a continuum. Depending on the particular subgroup of children requiring ECI and the nature of the child's communication disorder, early identification is an ongoing process over time and an ECI service provider must be knowledgeable *when* certain subgroups of children can be identified and *who* the likely people are to identify them first. It appears that an early identification model relying on risk factors only will overlook some important subgroups of children requiring ECI. A relevant

model has to afford a key position to parents as it appears that they are uniquely positioned to identify communication delays in their children provided they have the necessary knowledge about ECI. The importance of parents at each stage on the continuum of early identification of risk conditions in their children echoes the centrality already afforded to parents in the entire service delivery process of ECI (Guralnick, 1997; Rossetti, 1996).

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

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

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

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

Key

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

According to Table 6.8 the subjects with communication delay *in the absence of established risk factors* were identified at the average age of 19 months while the subjects *with established risk conditions*, even though they were

identified after the perinatal period, were identified much earlier, at an average age of 10 months. This finding confirms Rossetti's view (1996) that special attention should be afforded to the identification of infants at-risk, as the identification rate of infants with established risks is much higher.

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

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

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

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

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

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

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

In contrast with the high identification rate of communication delay by parents, professionals identified only 32% of the subjects after the perinatal period. In a study on the knowledge of paediatricians in the Gauteng Province of South Africa regarding ECI, Mulder (1998) found that they had adequate knowledge of risk factors which can contribute to communication disorders or delay. The

study (Mulder, 1998) found, however, that the paediatricians lacked knowledge on normal communication development in children, the availability of ECI services and the referral of children to these services. Since 82% of the subjects utilized in the current empirical study are from the Gauteng Province (See Table 5.1, Chapter 5), it can be concluded that some of the paediatricians who may have seen the subjects for medical reasons did not identify and refer these subjects for ECI services due to their lack of knowledge about ECI services and communication development in children.

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

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

In summary, the results of the different stages of identification of risk conditions in the subjects as depicted in Table 6.1 indicate that technology is beginning to contribute to the earlier diagnoses of risk conditions in unborn children, some of whom became subjects in the empirical study. The prenatal

counseling of parents concerning the risk factors for communication development and ECI services identified a new client basis for CHRIB.

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

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

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

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

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

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

6.3 ANALYSIS OF THE DIAGNOSTIC CLASSIFICATIONS FOUND IN THE SUBJECTS

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

6.3.1 Number of diagnostic classifications per subject

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

Table 6.10 Analysis of diagnostic classifications per subject

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

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

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

Table 6. 11 continued

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

Key to table headings

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

As presented in Table 6.10 the mean number of diagnostic classification entries were approximately four per subject, with a minimum of one entry and a maximum of seven entries per subject. The method of multiple diagnostic classification entries per subject resulted in a total of 543 diagnostic classification entries in the CHRIB database (See also Table 6.11). The diagnostic classifications of the subjects were alphabetically organized according to the ICD-10 (CSS, 1996) coding system and presented in Table 6.11 as a complete list of all the different established and biological risk

conditions occurring in the subjects. When a subject presented with different risk factors, the established risk condition (if any) was considered as the main diagnostic classification. In the case of biological risk factors only, the main condition present at birth, such as low birth weight, was entered as the main diagnostic classification of the subject.

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

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

6.3.2 Biological risk profile for communication disorders in the subjects

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

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

.1 Communication disorders

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

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

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

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

Key

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

According to Table 6.12 all four subjects presented with some biological risk conditions associated with communication disorders which warranted an assessment. The subjects were found to present with normal communication

development and recommended for a follow-up assessment if the parents were concerned about their subsequent development.

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

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

.2 Chronic otitis media

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

media is to be expected among the subjects as they represent a high risk population for this disease.

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

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

.3 Multiple births

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

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

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

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

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

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

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

Table 6.13 continued

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

Key

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

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

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

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

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

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

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

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

.4 Birth weight and gestation

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

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

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

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

Table 6.14 continued

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

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

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

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

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

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

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

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

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

recognized in these infants, ECI programmes can be developed to effectively meet the unique needs of infants with cleft lip and palate and their families.

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

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

The subject with hyperactivity and low birth weight is also in agreement with literature findings as attention deficit disorder (ADD) with or without hyperactivity is considered as one of the so called minor disorders associated with low birth weight (Bennett, 1995). Since these infants can be associated with biological risk factors such as low birth weight as in the case of the subjects, it is possible to identify them early. It appears, however, that these

children are often referred for services only when their difficulties cause them problems at school (Plante & Beeson, 1999).

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

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

The classification of small for gestational age (See Table 6.14, *ICD-10* Code P05), measured according to standardized norms (Lubchenco, 1987), and referring to infants weighing significantly less than expected for their degree of maturity at birth (Allen, 1995), is usually regarded as a product of low birth weight and premature birth. Small for gestational age, which reflects poor fetal

growth in utero, resulting in some degree of intra-uterine growth retardation, occurred in 33 (22%) of the subjects with low birth weight and premature birth.

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

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

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

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

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

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

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

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

which is a major determinant of infant mortality and of developmental delay in surviving infants.

.5 Congenital heart defects

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

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

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

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

According to Shprintzen (1997) it has been well established that 10% of all infants with some form of clefting have congenital heart disease as a result of a syndromic association. Cardiac abnormalities are often associated with craniofacial defects as the neural crest cells contribute to both the

development of the heart, the head and the neck during embryogenesis (Sadler, 1995). The results of the current empirical study found that heart defects occurred in the subjects with cleft lip and palate, but at a rate of 6%, thus with a lower prevalence than quoted by Shprintzen (1997). The lower prevalence of heart defects found in the subjects could possibly due to the small sample of subjects in the empirical study.

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

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

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

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

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

Table 6.18 continued

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

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

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

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

Although congenital heart defects occurred in a small percentage of the subjects, the results revealed one of the hidden characteristics of the subjects which occurred in conjunction with different other congenital anomalies as

depicted in Table 6.18. The importance of paying attention to so called minor symptoms is reinforced by Shprintzen (1997) when stating that, in order to avoid poor and ineffective care for a client, it is essential to make a diagnosis when multiple anomalies occur in a child.

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

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

.6 Subjects with cleft lip and palate

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

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

risk factor for communication delay, i.e. recurrent otitis media and was followed up with an assessment and parent guidance.

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

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

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

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

According to Savage (1997) infants with cleft lip and/or palate are biologically at risk for developmental delay. The results of the empirical study indicated that the *risk profile* of the subjects comprises of events which originated at different periods in life and from different but interacting sources, namely:

- Events transpiring in the periconceptual phase which cause various genetic syndromes, muscular dystrophy and multiple pregnancy.
- Abnormal embryogenesis associated with Pierre Robin Sequence, Tessier Type cleft, congenital heart defects, cleft lip and palate and intrauterine growth retardation. Although these conditions found in the subjects originated during embryogenesis, they can be precipitated by genetic disorders (Shprintzen, 1997).
- Central nervous system involvement responsible for petit mal seizures and congenital cerebral cysts.
- Risks during the perinatal period associated with low birth weight and premature birth.
- Risks during the postnatal period and later in life and associated with recurrent otitis media.

The biological risks identified in the subjects with cleft lip and palate therefore involve multiple systems and indicate vulnerable periods when potential damaging events can occur in a so called cascading manner (Shprintzen,

1997) in the subjects. These vulnerable periods for biological risks in children with cleft palate span from conception, through the prenatal period of embryogenesis, the perinatal period, the postnatal period and the later stages of early childhood. Biological risk conditions are, however, not the only risk conditions contributing to the communication disorders of the subjects with cleft lip and palate. The subjects with cleft lip ad palate comprised that largest subgroup of subjects in the empirical study and additional data analysis revealed more of their characteristics and risk conditions (See 6.4.1 and 6.4.2).

The results regarding the subjects with cleft lip and palate indicated that professionals involved in ECI must look beyond the obvious visible established risk of these young children, as they present with a multifaceted disorder which should be described in detail in order to fully understand the nature of their communication disorder.

.7 Subjects with Down syndrome

The last diagnostic classification to be discussed according to Table 6.11, codes Q90.0 and Q90.1 (*ICD-10*, CSS, 1996), concerns the 23 subjects with Down syndrome. This subgroup of consist of 22 subjects with Trisomy 21 and one subject with Down syndrome mosaicism, implying that both the normal number of chromosomes and an extra number 21 chromosome are present in this subject (Thomson, 1995).

Based on Appendix E and by filtering the data, Table 6.19 displays the characteristics of the subjects with Down syndrome.

Table 6.19 Characteristics of subjects with Down syndrome (N=23)

Characteristic	Value / Description	
Age at CHRIB assessment	Average: 9.83 months Range: 0.8 – 26.8 months	
Number of diagnostic classifications entries per subject	Average: 4 entries Range: 2 – 7 entries	
Different diagnostic classification entries apart from Down syndrome found in the subjects	**Description**	**Value**
	1. Speech and language delay	23 / 100%
	2. Congenital heart defects	9 / 39%
	3. Small for gestational age	6 /26%
	4. Recurrent otitis media	6 / 26%
	5. Low birth weight	5 / 22%
	6. Minor prematurity	4 / 17%
	7. Moderate prematurity	4 / 17%
	8. Petit mal seizures	1 / 4%
	9. Duodenal stenosis	1 / 4%
	10. Twin pregnancy	1 / 4%

According to Table 6.19 most of the subjects with Down syndrome were assessed at CHRIB at a young age, some as young as about three weeks of age (0.8 months). Although diagnosed earlier, some of the subjects were assessed for the first time after two years of age and commencing with ECI at that time.

The characteristics displayed by the subjects in Table 6.19 and coded according to the *ICD-10* (CSS, 1996) are all consistent with the multiple symptoms occurring with an increased prevalence in children with Down syndrome and described in the literature (Van Dyke, 1995). The only exception appears to be seizures which are documented in the Down syndrome population, but do not occur at a higher rate than in the general population (Van Dyke, 1995).

The mean number of diagnostic classification entries per subject is four and similar to those found in the total number of subjects of the empirical study (153) and is displayed in Table 6.10. Since Down syndrome represents a disorder involving almost all organ systems, resulting in a wide spectrum of health and developmental consequences, some of which are life threatening (Spiker & Hopmann, 1997), the use of the *IDC-10* (CSS, 1996) is inadequate to describe the subjects' characteristics. The number of diagnostic classifications in the present study do not distinguish between the subjects

with Down syndrome and those with other conditions, as the mere listing of biological risk conditions does not indicate the severity of risk for communication delay. Since the *ICD-10* (CSS, 1996) does not provide a separate entry for developmental delay, the distinguishing factor for the subjects with Down syndrome is to be found in describing the far reaching implications of the chromosomal disorder itself.

Similar to the syndromes associated with cleft lip and palate found in the subjects, Down syndrome is also a multiple anomaly syndrome, but extends much further than those syndromes. Down syndrome is the most commonly known cause of cognitive impairment and congenital anomalies with a vast complexity of health impairments, developmental delays across all domains and distinctive patterns of communication impairment (Kumin, Councill & Goodman, 1999; Msall, DiGaudio & Malone, 1995; Van Dyke, 1995). Yet, these typical characteristics of the subjects with Down syndrome do not emerge when utilizing the *ICD-10* (CSS, 1996) which only lists the different biological risk conditions in the subjects and does not indicate the severity of the disorder. Another tool is therefore required to adequately describe the characteristics of the subjects with Down syndrome.

In summary, the analysis of the results of the biological risk profiles of the subjects displayed in Table 6.11 revealed a large amount of detailed information. Based on a biological approach to the classification of risk conditions for communication delay in the subjects the following can be concluded:

- The multiple diagnostic entries listed for each subject provided a rich description of the different biological factors impacting on a subject's communication development.
- The different diagnostic classification entries had to be prioritized in terms of the severity of impact of the condition on a subject's communication development. In each subject the established risk factor, if present, was listed first. Using this approach, the subjects with cleft lip and palate and

those with Down syndrome emerged as the two largest distinctive subgroups.

- Although occasional cleft lip and palate has been described in persons with Down syndrome (Shprintzen, 1997) these two conditions were found to be mutually exclusive in the subjects. However, biological risk conditions such as multiple pregnancy, low birth weight, premature birth, small for gestational age, congenital heart defects and otitis media were found to occur in both subgroups of subjects.
- All but four of the 153 subjects displayed delayed communication development, which is the only developmental domain of the subjects which could be coded according to the *ICD-10* (CSS, 1996). Since CHRIB is an ECI facility with a communication-based focus, the results emphasize the importance of such an early intervention approach.
- The approach of multiple listing of biological risk conditions in the subjects, resulted in emphasizing the cascading effect of sequenced biological events from conception till later in postnatal life, which shaped the specific risk profile of the subjects with cleft lip and palate.

In conclusion, the use of the *ICD-10* (CSS, 1996) to categorize the different diagnostic classifications found in the subjects, *proved to be sufficient to comprehensively describe the different established and biological risks* relating to the subjects' communication development. The *ICD-10* (CSS, 1996), however, adheres to a medical approach to the classification of developmental disabilities and communication disorders and only uses the terms *specific developmental disorders of speech and language*, *specific speech articulation disorders* and *expressive language disorder* to describe communication disorders. These three terms are classified under the main category of *Mental and Behavioural Disorders* and the subcategory of *Disorders of Psychological Development*. Although the user is able to add subcategories to accommodate specific needs, the conceptual framework of the *ICD-10* (CSS, 1996) *largely omits communication disorders and other developmental disabilities.* The new classification system released by the

WHO, the *ICIDH2* (WHO, 1999), appears to classify developmental disabilities in a more comprehensive manner and will be used in future.

Notwithstanding the benefits of multiple listing and prioritizing risk factors, as well as indicating cascading effects of biological events to create a risk profile of the subjects, the *ICD-10* (CSS, 1996) therefore proved to be limiting in describing delays in developmental domains other than communication development in the subjects. Moreover, the environment as a powerful force to interact on the subjects' biological risk profiles and to shape their developmental outcomes (Kochanek & Buka, 1995), has been omitted. For this reason the following results will focus on some perinatal and postnatal biological and environmental events which influenced the subjects' communication development.

6.4 CHARACTERISTICS OF THE SUBJECTS IN THE PERINATAL AND POSTNATAL PERIODS

In order to provide a description of the early events and their effects on the subjects' communication development, selected data from the CHRIB database relating to the perinatal and postnatal periods of the subjects' development will be described (See Figure VI.II).

6.4.1 Characteristics of the subjects in the perinatal period

The data relating to the characteristics of the subjects in the perinatal period was obtained from the CHRIB Case History Form (Louw & Kritzinger, 1995a) as completed by the parents and then entered into the CHRIB database. By means of a process of data manipulation the results are now presented in Table 6.20.

Table 6.20 Characteristics of perinatal risk factors experienced by the subjects (N=153)

Characteristic	Category	# Subjects	%
1. Gestation age	-Range	25-44 weeks	-
	-Extreme prematurity	2	2%
	-Moderate prematurity	39	25%
	-Minor prematurity	16	10%
	-Full term	94	61%
	-Post mature	2	2%
2. Birth weight	-Range	760-4200 grams	-
	-Extremely low birth weight	4	3%
	-Low birth weight	35	23%
	-Normal birth weight	105	66%
	-High birth weight	9	8%
3. Subjects in incubator	-Never in incubator	71	46%
	-1-5 days in incubator	48	32%
	-6-84 days in incubator	34	22%
4. Subjects in special care nursery (SCN) or NICU	-Never in SCN or NICU	90	59%
	-1-7 days in SCN or NICU	26	17%
	-8-90 days in SCN or NICU	37	24%
5. Breast feeding, N=34	-Never breast fed	119	78%
	-Breast fed after birth	22	14%
	-Breast fed after 2-7 days	9	6%
	-Breast fed after 8-84 days	3	2%
6. Bottle feeding, N=119	-Bottle fed after birth	19	16%
	-Successful after 2-7 days	49	41%
	-Successful after 8-150 days	51	43%

As indicated in Table 6.20 six perinatal risk factors were selected to provide a perinatal risk profile of the subjects as a group. Although numerous perinatal complications such as those described by Als (1997) and Rossetti (1996) and which occurred in the subjects can be listed, only six perinatal risk factors were selected. The six risk factors listed in Table 6.20 are characteristics of the subjects which parents are likely to remember as they represent markers of progress or transitions in the infant's early life. Knowledge of risk conditions such as respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosis, retinopathy of prematurity, apnea and bradycardia, intercranial haemorrhage and necrotizing enterocolitis (Als, 1997; Rossetti, 1996) occurring in a subject provides valuable knowledge to CHRIB as a service provider, but are often not accurately reported by parents.

The six risk factors are listed in the order of prevalence of occurrence in the subjects. This implies that the least occurring risk factors were low birth weight and prematurity and the most prevalent risk factor experienced by the

subjects during the perinatal period and listed in Table 6.20 was feeding difficulties.

As previously indicated in Table 6.11, and according to Table 6.20, extreme and moderate premature birth occurred in 27% of the subjects and extreme and moderate low birth weight occurred in 26% of the subjects. It was also highlighted earlier (Table 6.15) that these perinatal risk conditions co-occurred in subjects with a variety of conditions, namely in subjects with cleft lip and palate, Down syndrome, multiple births, hyperactivity and fetal *Roaccutane*® syndrome or presented on its own. Since low birth weight and prematurity is considered the most frequently occurring neonatal medical risk complications (Rossetti, 1990b) these conditions represent the basis of the subjects' perinatal risks.

Table 6.20 indicates some further perinatal risk factors found in the subjects. Since only 26-27% of subjects presented with low birth weight and prematurity, which in itself destines a subject for incubator and/or special care/NICU care after birth (Rossetti, 1996), it is surprising that many more subjects, namely 54% and 42% respectively, required incubator care and care in a high care nursery or the NICU. This finding indicates that a substantial number of infants were not ready to cope with the demands of the extra-uterine environment for reasons other than prematurity and low birth weight. These reasons may be attributed to the increased number of congenital anomalies found in the subjects (See Table 6.11).

The results of the last perinatal risk factor listed in Table 6.20 pertains to the feeding difficulties which the subjects experienced after birth. A total of 112 (73%) subjects experienced some degree of feeding difficulties (See Table 6.20, Nr 5 & 6), either with breast feeding or with bottle feeding. Only 14% of the subjects were successfully breast fed since birth while 16% were successfully bottle fed since birth, which implies that the subjects could suck and swallow adequately for sufficient food intake per feed.

Although bottle feeding could have been the mother's choice and may not indicate feeding difficulties in the subject, a large percentage of subjects, 78%, did not breast feed at all, but received bottle feeding only. However, as there is currently a general public awareness of the numerous advantages of breast feeding (Bergh & Bosman, 1995), it could rather have been that the subjects experienced difficulties with breast feeding than that their mothers chose to bottle feed them. Bottle feeding is considered an easier way of feeding in comparison with breast feeding (Wolf & Glass, 1992) and it appears that the subjects' mothers could have resorted to bottle feeding as a result of feeding difficulties in the subjects. Underlying feeding difficulties could therefore have contributed to the high prevalence of bottle feeding found in the subjects.

Since the sample represented infants with numerous risk conditions the results regarding a prevalence of feeding difficulties among the subjects correspond with findings in the literature that almost all types of disabilities are associated with nutrition or feeding problems in infancy (Litchfield, Brotherson, Oakland & McClintic, 1995). The identification of early feeding difficulties in the subjects points to a specific ECI need required by the subjects before they were assessed at CHRIB.

In contrast with the feeding problems experienced by the subjects, an analysis of the subjects who succeeded with breast feeding can provide more insight into the nature of the early feeding experiences of the subjects. Table 6.21 provides the results of the subjects who succeeded with breast feeding.

According to Table 6.21 subjects with a variety of risk conditions succeeded with breast feeding, either from birth onwards, or after two to seven days. The three subjects who succeeded in breast feeding only after an extended period of time, were infants with extremely low birth weight and prematurity. It is remarkable that these subjects could eventually breast feed successfully, as their respiratory insufficiency and subsequent intubation, together with other neonatal medical complications allow them to feed orally only after sufficient growth, maturation and experience have taken place. The subjects' mothers

need to be commended since the successful transition from non-oral feeding methods to oral feeding and breast feeding can only be achieved with support, feeding therapy and much persistence (Wolf & Glass, 1992).

Table 6.21 Subjects who succeeded with breast feeding (N=34)

Subject's condition	# Subjects	% of condition
1. Down syndrome	13 of 23	57%
2. Expressive specific language impairment	6 of 9	67%
3. Autism/PDD	3 of 4	75%
4. Low birth weight and prematurity (after 8-84 days only)	3 of 52	6%
4. Subjects with acquired conditions	2 of 2	100%
5. Multiple pregnancy and communication delay	2 of 23	9%
6. 40% cleft of the soft palate	1 of 79	1%
7. Hyperactivity	1 of 2	50%
8. Fetal alcohol syndrome	1 of 1	100%
9. Microcephaly	1 of 1	100%
10. Tongue tie	1 of 1	100%
Total	**34**	N/A

As further indicated in Table 6.21, the groups of subjects who were the least successful with breast feeding were the subjects with cleft lip and palate, low birth weight and prematurity and multiple pregnancy. The difficulties with breast feeding found in the different subgroups of subjects can be related to the following:

- Only one of the 79 subjects with cleft lip and palate could succeed with breast feeding. As very few instances of successful breast feeding in infants with cleft palate have been reported in the literature, Wolf and Glass (1992) explain that an infant may develop adequate compression and suction to form and position the nipple if the cleft is minor. Since the subject with cleft palate had a 40% cleft of the soft palate only, it appears that he was the only subject with cleft palate who could compensate sufficiently to breast feed successfully.
- As a result of the interrupted caretaking by the mother when the infant is in the NICU and medical complications in the infant, breast feeding is often not successful in infants with low birth weight and prematurity (Morris & Klein, 1987; Wolf & Glass, 1992). It appears that these factors could have

contributed to difficulties with breast feeding found in the group of subjects with low birth weight and prematurity.

- As a result of the extra care involved in infants from multiple pregnancies and differences in timing of feeds and feeding needs of the infants, it appears that sustained breast feeding is often not successful (Bergh & Bosman, 1995). The reports from literature concerning breast feeding in twins validates the finding that only two subjects from a group of 23 could breast feed successfully.

As further indicated in Table 6.21 the subgroups of subjects who were more successful in breast feeding were the subjects with Down syndrome, expressive specific language impairment, autism/PDD and those with acquired disorders. The following explanations are offered to interpret the results:

- Although feeding difficulties as a result of low muscle tone and heart defects in infants with Down syndrome have been reported extensively (Baird, Ingram & Peterson, 1998; Wolf & Glass, 1992), breast feeding is strongly advocated in this group of infants (Van Dyke, 1995). It could be that the subjects with Down syndrome experienced less adverse conditions which could prevent breast feeding or that the parents of these subjects received feeding therapy and support and persisted with breast feeding in spite of feeding difficulties as they were aware of the health benefits of breast milk and the opportunity for early parent-infant attachment associated with breast feeding.
- No specific feeding difficulties during the perinatal period are reported in the infants with expressive specific language impairment in the literature (Rescorla & Goosens, 1992), but the sample size of nine subjects is too small to draw further inferences.
- In the case of the subjects with autism/PDD the sample size also does not allow further interpretation of the results. Amato and Slavin (1998), however, found oro-motor deficits which included chewing difficulties and abnormal oral sensitivity to food texture in young children with autism.

These findings could relate to the early feeding difficulties found in one of the subjects with autism/PDD in the present study.

- The subjects with acquired disorders did not display any risk conditions prior to the event causing their disorder and could therefore breast feed successfully.
- Successful breast feeding in the other groups of subjects indicated in Table 6.21 can also not be explained further as the sample sizes are limited.

In contrast with the groups of subjects who displayed successful breast feeding, Table 6.22 provides an analysis of the 51 subjects who experienced the most feeding difficulties as indicated by the time period before they could feed successfully by means of a bottle (See Table 6.20 Nr 6).

Table 6.22 Subjects with successful bottle feeding only after 8–150 Days (N=51)

Subjects' condition	# Subjects	% of Condition
Cleft lip and palate	35 of 79	44%
Down syndrome	5 of 23	22%
Low birth weight and prematurity	5 of 52	10%
Multiple pregnancy	3 of 23	22%
Subjects with an unknown condition	2 of 2	100%
Delayed language development and developmental delay	1 of 1	100%
Total	**51**	**N/A**

According to Table 6.22 a substantial number of subjects with cleft lip and palate experienced feeding difficulties of a serious nature as they only succeeded to feed successfully by means of a bottle after a period of time. The fact that only one subject with cleft palate could breast feed successfully (See Table 6.21), further emphasizes the finding that most of the feeding difficulties found in the subjects occurred in those with cleft lip and palate, as could be expected (Savage, 1997).

The following results in Table 6.22 serve to indicate the broad spectrum of feeding skills which were found in the subjects. While Table 6.21

demonstrated that some subjects with Down syndrome, low birth weight and prematurity and those from multiple pregnancies could display adequate feeding skills to breast feed successfully, Table 6.22 disclosed that the same groups of subjects could also display serious feeding difficulties. The analysis of feeding skills found in the subjects indicated both *a high prevalence* of feeding difficulties and *a large variation* in feeding skills, which ranged from successful breast feeding to serious feeding difficulties within some of the subgroups of subjects. The results also reiterate the statement by Bu'Lock, Woolridge and Baum (1990) that feeding difficulties make up a major proportion of problems which are found in fullterm as well as preterm infants. Since effective feeding is a prerequisite for the survival of newborn infants (Bu'Lock, *et al.,* 1990) it was an important risk factor to identify in the subjects, not only for their wellbeing and growth, but also for their development.

The importance of feeding difficulties in the perinatal period as a predictor of communication delay in infants with low birth weight and prematurity has been indicated in a previous study (Kritzinger, 1994). This study found that, in comparison with other perinatal risk factors such as low birth weight, prematurity, perinatal infections, gender, low Apgar scores and the length of time spent in the incubator, the subjects' feeding difficulties best predicted their communication development at 12 months. The longer the time lapse before the infants could feed successfully, the more delayed their communication development was at 12 months. Since the results of the present study already indicated a communication delay in 98% of the subjects (See Table 6.11) it is clear that the feeding difficulties experienced by most of the subjects in the perinatal period must relate to their communication delay. The feeding difficulties experienced by clients and subsequent appropriate intervention and support to parents are therefore important facets of ECI.

Feeding difficulties during the perinatal period can be viewed as a product of an infant's functioning during that time and provides a more descriptive manner of defining the infant's condition than just a statement such as low birth weight or prematurity. Moreover, it is postulated that feeding difficulties could be a more sensitive indicator of future communication development in

low birth weight and premature infants than the number of days an infant spent in the incubator or in a special care nursery or the NICU. The period of time the infant spends in the incubator or in the special care nursery/NICU may not only depend on the infant's response to the extra uterine life, but could also depend on exogenous factors such as a decision made by the medical team involved. As the study cited (Kritzinger, 1994) only relates to low birth weight and premature infants and the present study also included other groups of infants at risk for communication delay, ongoing research is necessary to determine the factors predicting their communication development. However, it appears that a description of the feeding difficulties in the subjects succeeded in emphasizing a prevalent risk factor in the perinatal period.

The perinatal risk profile of the subjects, of whom approximately 80% display established risk conditions (See Table 6.1), is that a significant number of the subjects spent some time in an incubator, an additional number spent time in a special care nursery/NICU while still an additional number experienced feeding difficulties. The results serve to illustrate the concept of continuum of risk as proposed by Rossetti (1996). The beginning point of communication delay in the subjects is not the time they fail to utter their first words at an age appropriate phase of development. The origins of the communication delay in the subjects may be traced back to biological or environmental influences relating to events earlier in life. (Rossetti, 1996). The concept of continuum of risk does not only elucidate the subjects' past, but also points to their continued risk in the postnatal period and the future.

In order to illustrate this concept further, selected characteristics of continued risk factors in the subjects' postnatal period will be presented.

6.4.2 Characteristics of the subjects in the postnatal period

A key feature of the subjects during the postnatal period was selected to provide a description of some of the environmental risks experienced by the subjects during this developmental phase. The number of surgical procedures

performed on the subjects during the postnatal and later stages, instead of illnesses, were selected to illustrate the continuum of risk factors for developmental delay which the subjects experienced.

In order to assure reliable results, it was postulated that the subjects' parents were more likely to accurately remember details about surgical procedures than details about all illnesses in their young children. An analysis of the surgical procedures experienced by the subjects was therefore carried out and presented in Table 6.23. The data was originally obtained from the CHRIB Case History Form (Louw & Kritzinger, 1995a) completed by the parents and entered into the CHRIB database.

According to Table 3.23 a total number of 93 (61%) of the subjects underwent a total of 187 surgical procedures at the time of the CHRIB assessment and data collection. This implies that each of the 93 subjects had an average of two surgical procedures, with a minimum of one and a maximum of seven surgical procedures per subject. The results also indicate that the majority of surgical procedures were performed on the subjects during their first year of life, with the peak period for surgeries between the ages of five to eight months in the subjects.

As depicted in Table 6.23 a total number of 22 different surgical procedures were performed on the subjects, of which ten different procedures directly relate to the 79 subjects with cleft lip and palate. The surgical procedure most prevalent in the subjects was, however, the insertion of ventilation tubes for the treatment of otitis media with effusion and relates to the prevalence of otitis media in 55% in all the subjects (See Table 6.11). The peak period of five to eight months for surgeries performed on the subjects could relate to the surgical protocol of the Facial Deformities Clinic where the majority of the subjects with cleft lip and palate were treated (Bütow, 1995) and the peak period of seven to twelve months for acute otitis media in children (Plante & Beeson, 1999). The other surgical procedures listed in Table 6.23 serve to illustrate some of the health concerns of the subjects which warranted surgical

intervention and could pose a subsequent risk for delayed language development.

Table 6. 23 Type and number of surgical procedures performed on the subjects (N=93)

Category	Value
- Number of subjects who underwent surgery - Number of subjects without surgery	93 (61%) 60 (39%)
- Total number of surgical procedures performed - Number of surgical procedures on each client	187 Range: 1-7 Average: 2
- Number of surgical procedures per age group	0-4 months: 33 5-8 months: 96 9-12 months: 24 13-18 months: 18 19-37 months: 16 **Total: 187**
Type of surgical procedure	**# Surgical procedures**
1.Ventilation tubes inserted	46
2. Soft palate repair*	43
3. Lip and hard palate repair	22
4. Hard and soft palate repair	21
5. Lip repair	8
6. Columella lengthening	7
7. Hard palate repair	5
8. Hernia repair	5
9. Circumcision	4
10. Lip and soft palate repair	3
11. Strabismus repair and other eye surgery	3
12. Heart surgery	3
13. Neurosurgery	3
14. Foot operation	3
15. Tonsillectomy	3
16. Oro-facial surgery	2
17. Lip, hard and soft palate repair	1
18. Submucous cleft repair	1
19. Frenulum cut	1
20. Adenoidectomy	1
21. Mastoidectomy	1
22. Pilorotomy (stomach surgery)	1
Total	**187**

Key*
- Surgical procedures typed in bold indicate procedures related to cleft lip and palate

The multiple surgical procedures experienced by a subject could impact both on the subject's emotional and communication development as well as on the family. Eiserman, *et al.* (1996) state that hospitalization for surgery, separation from the family and restrictions of physical activity following the surgery were some of the most salient stressors not only for the family with a child with cleft

lip and palate, but also for the child's own development. Surgical procedures, characterized by increased family concern about the infant and accompanied by periods of hospitalizations, can be interpreted as added stressors for families with infants at risk for disabilities. According to Guralnick (1997) the stressors for families created by the child's disability add to the factors influencing the developmental outcomes for young children.

Rossetti (1996) adds an emotional dimension to the different stressors impacting families which can be applied to families of infants with cleft lip and palate. The lack of opportunity afforded to parents to provide care while their child is hospitalized, reduces attachment and interaction and could affect caregiver involvement in later intervention (Rossetti, 1996). Wolf and Glass (1992) emphasize the emotional effect of hospitalizations on infants and describe the difficulties in maintaining trustful relationships the child may experience when needs for comfort and food are not met.

The emphasis on surgical procedures as a postnatal risk factor for communication delay added to the continuum of risk evidenced in the subjects which can be traced from the prenatal period, through the perinatal, postnatal and later periods of life. The demonstration of risk conditions experienced by the subjects throughout their short lives points to the responsibility of CHRIB to meet the needs of families by providing a responsive presence during the periods when events can occur which can contribute to communication delays later in life.

The needs of families, however, can only be adequately met if an analysis of their characteristics are carried out.

6.5 CHARACTERISTICS OF THE SUBJECTS' FAMILIES

According to Guralnick (1997) individualized ECI programmes for young children and their families have been a centrepiece of EI services from the start, but limited empirical information is available to clinicians to adapt programme features to fit the unique profiles of children and families. The analysis of family circumstances is therefore an important component of the current empirical study.

Since the groundbreaking longitudinal studies of Escalona (1982; 1987) of young children with low birth weight and living in poverty, the influence of adverse family circumstances on the development of children at risk for developmental delays has been widely accepted. Escalona (1982; 1987) found a dramatic downward trend in the cognitive development of infants with low birth weight in the second year of life. Moreover, infants found to be at the greatest risk for early death and compromised developmental outcomes in the USA, are those raised by mothers who are black, single, adolescent, abusing drugs, uneducated and with a low income (Rossetti, 1998).

Figure VI.IV was compiled to provide an outline of the chronological order in which the results regarding the main characteristics of the subjects' families will be presented.

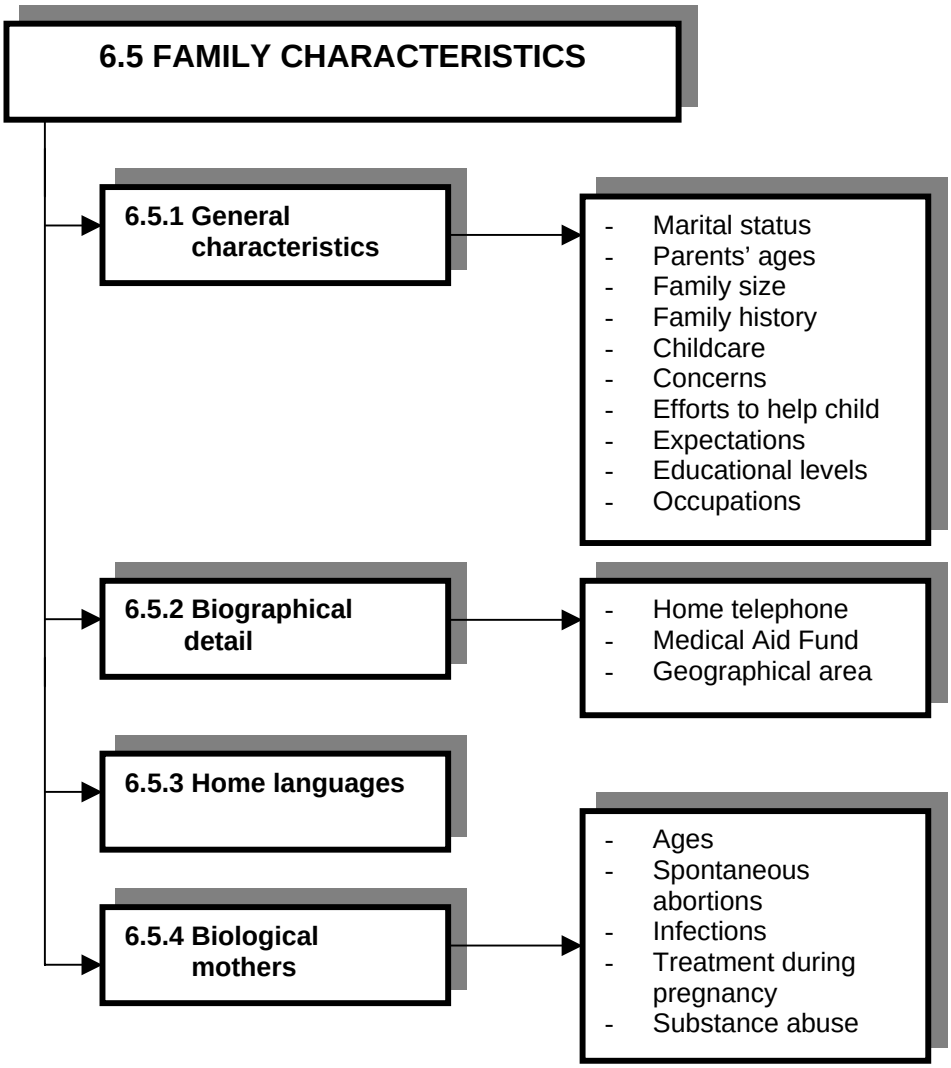

Figure VI.IV Outline of results regarding the characteristics of the subjects' families

In order to identify possible risks in the subjects' families a description of the main characteristics of the 145 families, retrieved from the CHRIB database, is presented in Table 6.24. A total of only 145 families as opposed to 153 children were involved in the empirical study as the families of twins and triplets were only counted once.

Table 6.24 General characteristics of the subjects' families (N=145)

Characteristic	Category	# Subjects	%
1. Marital status of parents	Married Divorced Separated Never married	134 5 4 2	92% 4% 3% 1%
2. Caregiver's relationship to subjects	Biological parents Adoptive parents Grandparents	143 1 1	98% 1% 1%
3. Mother's age at assessment of child 4. Father's age at assessment of child	Range Average age Range Average age	20-52 years 30 years 22-62 years 33 years	- - - -
5. Family size	I Child 2 Children 3 Children 4 Children 5 Children 6 Children	50 62 19 9 4 1	34% 43% 13% 6% 3% 1%
6. Persons with speech, language or hearing problems in family	Yes No	36 109	25% 75%
7. Other children with developmental disorders	Yes No	6 siblings 139 siblings	4% 96%
8. # subjects in daily child care facilities and nursery schools, N=153	Yes No	89 64	58% 42%
9. Mentioned concern about subject's general development, N=153	No concern Unsure Concerned	97 20 36	63% 13% 24%
10. Mentioned concern about child's communication development, N=153	No concern Did not mention Concerned	7 8 138	5% 5% 90%
11. Reported efforts to help child, N=153	Reported No efforts mentioned	134 19	88% 12%
12. Listed family expectations of assessment, N=153	Listed Did not state	140 13	92% 8%
13. Parents' educational level (M= Mother; F= Father) *Fathers' educational levels: 5 missing values of one-parent families	**Category** No Schooling Primary school High school Matric Certificate Diploma Graduate Postgraduate **Total**	**# M** 3 1 16 65 1 18 30 11 **N=145**	**# F** 0 1 18 51 0 25 32 13 **N=140***	**%M** 2% 1% 11% 45% 1% 12% 20% 8% **100%**	**%F** - 1% 13% 36% - 18% 23% 9% **100%**

14. Parents' occupations	Category	# M	# F	% M	% F
	-Full time mother	58	-	40%	-
(M= Mother; F= Father)	-Professional & technical	36	75	24%	54%
*Fathers' occupations: 5 missing values of one-parent families	-Managerial	18	34	12%	23%
	-Secretarial	11	-	8%	-
	-Clerical & sales	20	7	14%	5%
	-Artisan	-	12	-	8%
	-Self employed	1	7	1%	5%
	-Domestic worker	1	1	1%	1%
	-Not employed	-	6	-	4%
	Total	**N=145**	**N=140***	**100%**	**100%**

6.5.1 General characteristics of the subjects' families

According to Table 6.24 the majority of subjects were from intact families and living with their biological parents. Only 11 (8%) subjects were raised by single mothers, one subject was adopted and one subject was living with her grandparents. Since 88% of the subjects are from white families (See Table 5.1), the results can be compared to divorce rates among this population group in South Africa. The divorce rate among whites is high and approximately 65% of minor children affected are white, 27% are coloured and 7% are Indians (Patel, 1994). In a survey conducted in 1993 (Barberton & Woolard, 1998) it was estimated that only one third of African children were growing up with both parents present in the household. The results 92% of intact families found in the subjects are therefore not representative of the South African situation, especially in the light of the AIDS crisis, estimated to orphan 250 000 children during 2000 (Bridgraj, 1999). It appears that CHRIB, a tertiary based ECI provider, attracts clients who are mostly white, but not representative of the white community concerning family intactness.

The average ages of the parents at the time of data collection were 30 years for the mothers and 33 years for the fathers. The upper margins of the parents' ages are high, 52 and 62 respectively, but refer to the two grandparents raising their grandchild, the one pair of adoptive parents and a few parents over 36 years.

Upon further analysis of Table 6.24 (See Nr 5) most of the subjects (90%) are from small families of three and less siblings. Only 10% of the subjects are from families of four to six siblings, indicating possible risks for family stress as parenting and financial resources have to be shared among a larger number of siblings, one of whom making more demands on these resources as a result of a disability (Ostfeld & Gibbs, 1990). The findings that 90% of the subjects are from relatively small families and that 92% of the subjects are from two parent families indicate that these subjects did not experience the stressors related to large families and disrupted family life as a result of divorce.

The following family characteristic concerns the presence of communication disorders in the nuclear family and/or extended family. In Table 6.24, Nr 6, 25% of families have a history of communication disorders of which 4% occur within the nuclear family (See Table 6.24, Nr 7). These results could relate to the possible genetically inherited basis of some of the disorders occurring in the subjects, such as cleft lip and palate and sensorineural hearing loss (Shprintzen, 1997). The results of a familial concentration of communication disorders in the subjects can also be compared with the results of Tomblin (1989) who found a strong familial association for developmental language disorder and that the likely mode of transmission appears to be genetic. The results indicate that a positive family history of communication disorders can be regarded as a risk factor for communication disorders and may be used to identify communication disorders in children. If parents among the general public are aware that communication disorders in their family pose a risk for communication disorders in their children, there is a possibility that these children can be identified and treated earlier.

Table 6.24 Nr 8 indicates that 58% of the subjects attended some form of daily child care facility, such as a day mother or a crèche, or an early educational facility such as a playgroup or a nursery school. A substantial number of subjects (42%) were at home with their mothers. The finding that so many subjects are full time in the care of their mothers, indicates positive outcomes for the subjects' communication development (Oren & Ruhl, 1997). Since all the subjects presented with risks factors which can negatively impact

on their communication development, there is so much more opportunity for their mothers to provide “contingent, encouraging, affectively warm, non-intrusive, appropriately structured, discourse-based and developmentally sensitive patterns of caregiver-child interactions” to optimize their children’s development (Guralnick, 1997: 6). The finding emphasizes an ideal situation for effective ECI in CHRIB provided that the mothers of the subjects are trained and supported to establish routine patterns of optimal parent-child communication interaction which will facilitate their children’s development.

The results also indicate the possibility of decreasing the incidence of otitis media in some of the subjects as research has shown that children in group day care settings and crowded living conditions are at an increased risk for middle ear disease (Plante & Beeson, 1999). The use of daily childcare facilities in 58% of the subjects can therefore contribute to the chronic middle ear disease already found in 55% of the subjects. The number of subjects in childcare facilities also relates to the mothers’ occupational status to be discussed later under Nr 14 (Table 6.24).

Table 6.24 Nr 9 to 12 relate to the parents’ concerns about their child’s development and their involvement in the child’s communication problem at the time of the CHRIB assessment. The results indicate that in only 24% of instances, parents were concerned about the subjects’ general development, but that in 90% of instances the parents were concerned about the subjects’ communication development. This indicates that parental focus was on the child’s main problem area which is also confirmed by the next result. An equally high percentage of subjects’ parents (88%) reported on their efforts to assist their child in acquiring communication skills. These efforts ranged from applying the home programmes received at the Facial Deformities Clinic to reporting on talking, reading and pronouncing words clearly to the subjects. It is clear that a high percentage of parents displayed a high degree of awareness of, and involvement in, their child’s communication problems, as their focus is directed specifically at the area of communication development. Since all but 4 of the 153 subjects displayed some form of communication delay or disorder (See Table 6.11), the results of high parental involvement in

their child's communication problems therefore indicate that the subjects' parents were in touch with their child's most prevalent needs. The results indicate a positive attitude toward ECI in the subjects' parents, which increases the possibility of effective services since a high degree of parental involvement is one of the main factors determining the effectiveness of ECI (Rossetti, 1996).

The family's expectations of the CHRIB assessment also confirm the high degree of involvement of the parents in their child (See Table 6.24, Nr 12). A total of 92% of parents listed their expectations of the assessment. An analysis of the parental responses to the question about expectations of the assessment (See Appendix B), which was entered into the CHRIB database as text data, revealed that they had specific information needs. Although most parents only listed one need they wanted to be addressed during the CHRIB assessment, collectively their needs centered around the following four themes:

- The cause(s) of their child's communication problems.
- The current level of their child's functioning.
- What to expect of their child and his/her communication problems in future.
- What they, as parents, can do to improve their child's communication problems.

Although the parents demonstrated a high degree of awareness and involvement in their child's communication problems, it should not be assumed that they have sufficient information about their child's communication disorder. The parents clearly stated their needs in a logical set of responses, stating that they wanted to know about the past, present and future of the subjects' communication problems and what their role as parents should be in the intervention process.

The collective pattern of information requirements of 92% of the subjects' parents emerging from the results can be related to what Guralnick (1997, p 8) refers to as the "crisis of information about the child's health and development families often experience". Guralnick (1997) identified almost the same type of questions which families ask about their child's health and development. These questions relate to parental needs on how to interpret their child's behaviour, which implies that they wanted to know whether their child's functioning is age appropriate. According to Guralnick (1997) parents also want to know what can be changed in order to help their child and what the future developmental expectations of the child is. Lastly, parents ask questions regarding the nature and effectiveness of therapeutic services. It is interesting to note that the last question posed by Guralnick (1997) was not raised by the parents in the current study. This finding correlates with previous results which indicated that the parents lacked knowledge about ECI services and when to commence with the services (See Tables 6.7, 6.8 and 6.9).

The need to know about the cause of the communication problem was clearly stated by the subjects' parents in the current study, but not mentioned by Guralnick (1997) as a source of information need. The finding that the subjects' parents required knowledge about the causes of communication disorders in their children must be addressed in CHRIB as it could indicate limited public awareness about communication disorders. According to Rossetti (1998) parents frequently ask questions about the cause of their child's problem and the inquiry can reveal some degree of guilt which the parents may experience. It may be that a request by parents for clarification of the cause of the problem could specifically relate to communication disorders as children with specific expressive language disorders or autism/PDD for example display no physical anomaly to which the problem could be attributed to.

Whatever the questions parents ask, Guralnick (1997) states clearly that information needs created by the child's disability are very important and he regards it as one of the potential stressors for families which can negatively affect child developmental outcomes.

As the results of the empirical study have already identified other information needs of the subjects' parents, the present results only underscores the importance of meeting parents' information needs in CHRIB since it is one of the environmental risks which can negatively affect the programmes' outcomes. The need to act on parents' concerns about their child's development has already been identified as one of the elements on the continuum of parameters for effective service delivery in ECI (See Figure II.IV).

The last set of family characteristics depicted in Table 6.24 (See Nr 13 and 14) refer to the parents' educational level and their occupations. The results indicate that the majority of parents had a high level of education with only a small percentage of parents not completing their high school education. The results indicate an exceptionally high percentage of parents with tertiary levels of education, with 50% of the subjects' mothers and 40% of the subjects' fathers with diploma, graduate and postgraduate qualifications. According to Patel (1994) only 16% of the white population in South Africa has some form of tertiary education. In a study on education and poverty, Woolard and Barberton (1998) found a strong correlation between education attainment and standard of living in South Africa. The high educational levels of the subjects' mothers in the current study should also be emphasized, since it is widely accepted that a child's health is directly related to the mother's level of education (Sanders, 1999). In the light of these findings, it is clear that most of the subjects could be raised in homes with an adequate to a high standard of living as only 14% of mothers and 14% of fathers did not finish high school education or grade 12.

The analysis of the parents' occupations revealed that only 4% of fathers were unemployed. Approximately half of the fathers have a professional or technical training and are employed as such. A total of 40% of the mothers are full time at home and the results relate to Nr 8 (Table 6.24) which revealed that 42% of mothers did not make use of daily care facilities for the subjects. The difference of 2% in the results could relate to mothers making use of

domestic workers or extended family members to look after their children while they are at work. Similar to the fathers, it appears that the largest group of mothers who are employed, hold professional or technical positions in their occupations. Since the majority of the subjects' parents is employed and does not experience financial stressors associated with unemployment, the subjects' home environments appears optimal for their development which can contribute to positive ECI outcomes (Guralnick, 1997).

In summary, the results of selected characteristics of the subjects' families demonstrated that stressors, such as divorce, single parents, very young mothers, large families, families with more than one child with a disability, low educational levels and unemployment occurred in less than 10% of the families. It should be noted that the characteristics of most of the families discussed thus far indicate that the subjects' families represent an advantaged group which is not even typical of the white population in South Africa. It is also important to note that only 8-12% of the families did not state any concern about the subjects' communication development, did not mention any efforts to help the subject thus far and listed no expectations regarding the CHRIB assessment. As no statistical analysis was carried out to determine a possible relationship between the degree of family involvement in the subject and levels of stress the families experienced, no reasons for the presumed low family involvement in this minority group of subjects can be provided. By far the majority of subjects did not experience adverse environmental risks in their homes, which can positively impact on the subjects' development and effectiveness of ECI services provided to them. The finding of the limited family stressors identified in the subjects could imply greater family involvement in the intervention process, a critical component for effective ECI.

It is, however, important to note that adverse familial circumstances did occur to a certain extent in the population of infants with communication disorders served by CHRIB and that there were families who could not articulate their involvement in the subjects. The implication is that the CHRIB programme must provide in the special needs of families with very diverse characteristics,

ranging from unemployed parents with low levels of education to highly educated professional parents.

Furthermore, it should be borne in mind that the characteristics used to describe the subjects' families in Table 6.24 are only crude indicators and do not measure family functioning, stress and adjustment. Each of the subjects' families has a child with a certain degree of communication disorder and almost all families expressed their concerns about the child (See Table 6.24, Nr 10). According to Ostfeld and Gibbs (1990) the birth of an infant with a disability exerts unexpected stresses and demands upon the family system and places the family as a whole as well as individual members at increased risk for ineffective coping. The results therefore only provide a superficial analysis of the different stressors relating to the subjects' families. It is therefore important to investigate the specific risks of each family during an assessment if individualized family-centered intervention wants to be carried out.

6.5.2 Biographical detail of the subjects' families

The following data, extracted from the CHRIB database and presented in Table 6.21, serves to provide some biographical and personal detail in order to give additional data on the living standard of the subjects' families.

Table 6.25 Biographical detail of the subjects' families (N=145)

Feature	Category	# Subjects	%
Home telephone	Yes	138	95%
	No	7	5%
Belong to a medical aid fund	Yes	109	75%
	No	36	25%
Geographical area of residence	-Pretoria Region	84	58%
	-Gauteng excluding Pretoria	41	28%
	-Northern Province & Mpumalanga	5	3%
	-North West Province	5	3%
	-KwaZulu Natal	4	3%
	-Free State	4	3%
	-Turkey	1	1%
	-Zimbabwe	1	1%
	Total	**145**	**100%**

According to Table 6.25, only 5% of the subjects' families do not have a home telephone, which can relate to a low-income status of the family. The use of telecommunication indicates a family has access to sources of information, support and facilities and can be contacted. This implies that the subjects' families can establish communication networks and can be contacted for ECI arrangements. The finding correlates with earlier results that the majority of subjects' parents are employed.

The results in Table 6.25 indicate that 75% of the subjects' families belong to a medical aid fund. The results compare well with health care statistics in South Africa which indicate that 76% of white families belong to medical aid funds (Soal, 1999). Since the majority of the subjects are from white families it appears that the subjects are representative of white South Africans regarding membership of a medical aid fund.

A total of 25% (36) of the subjects' parents do not belong to a medical aid fund, which does not assist them in the payment of the families' medical expenses. Since membership of a medical aid fund is dependent upon monthly contributions deducted from a member's salary, unemployed people are usually not able to sustain their contributions and medical aid fund membership is terminated. As indicated in Table 6.24, only 4% of fathers of the subjects were unemployed, but 25% (36) of families do not belong to a medical aid fund. Upon further analysis of the data in the CHRIB database it appears that a number of parents chose not to belong to a medical aid fund and make use of their own income to pay for medical expenses or make use of the state aided health services. The possible reasons for parents not belonging to a medical aid fund are outlined in Table 6.26.

Table 6.26 Characteristics of subjects' parents not belonging to medical aid funds (N=36)

Employment status of main breadwinner in family	Marital status	# Families	Remarks
1. Self employed: Owns own business, farms or works as professional person	Married	17 / 47%	Parents are economically independent and choose not to belong to a medical aid fund
2. Employed as voluntary worker in church	Married	3 / 8%	Income is too low to belong to a medical aid fund

3. Unemployed	Married	3 / 8%	No medical aid fund
4. Unemployed	Single mother	5 / 14%	No medical aid fund
5. Self employed	Single mother	2 / 6%	Income is too low to belong to a medical aid fund
6. Employed: Clerical worker, mine worker, domestic worker	Married	4 / 11%	Income is too low to belong to a medical aid fund
7. Employed: Artisan	Married	2 / 6%	Income is too low to belong to a medical aid fund
Total	**-**	**36 / 100%**	**-**

According to Table 6.26, a total number of 17 families do not belong to a medical aid fund as a result of their own choice, while the remainder 19 families or 13% of the 145 families, have no access to a medical aid fund as a result of unemployment or low income. It is also significant to note that seven of the 12 single mothers in the study (See Table 6.26 Nr 4 and 5) do not have the benefits of a medical aid fund and reiterates the finding in the USA that the variables of single mothers, unemployment and low income often co-occur and poses a risk for optimal child development (Escalona, 1987; Rossetti, 1998).

The last variable in Table 6.21 pertains to the geographical area in which the subjects reside. The results indicate that CHRIB mostly serves a population of infants and toddlers whose families are able to travel if they are not living in Pretoria. The fact that 42% of the subjects' families traveled from outside the Pretoria region, some as far as other provinces and countries, implies that CHRIB is providing a necessary service in ECI to families living in areas where such services are not yet established. Although factors such as the parental preferences can also determine their utilization of a particular ECI facility, the results provide some evidence of the unavailability of ECI services in South Africa. According to Haasbroek (1999) ECI is an emerging service among private practitioners and in the public sector in South Africa, but by far not available in all contexts and towns. The results of the biographical profile of the subjects' families strongly indicate that CHRIB is an important ECI service provider as subjects were drawn from six of the nine different provinces in South Africa, as well as from other countries.

The last characteristic of the subjects' families to be discussed pertains to their home languages.

6.5.3 Subjects' home languages

Table 6.27 provides an analysis of the different languages the subjects are exposed to in their homes based on the parents' responses in the CHRIB Case History Form (Louw & Kritzinger, 1995a).

The results in Table 6.27 indicate that although most of the subjects have Afrikaans or English as a single home language, 18% of the subjects are exposed to two or more home languages. The rich diversity of home languages also reflects the multilingual and therefore multicultural nature of the South African context in some of the subjects.

Table 6.27 Languages spoken in the subject's homes (N=153)

Language	# Subjects	%
Single home language		
Afrikaans	95	62%
English	28	17%
Northern Sotho	3	2%
Portuguese	1	1%
Subtotal	**127**	**82%**
More than one home language		
English* & Afrikaans	11	6%
English & Urdu	1	1%
Afrikaans & English	2	1%
Afrikaans & German	2	1%
Afrikaans & Sotho	1	1%
Portuguese & English	2	1%
Turkish & English	1	1%
Zulu & English	1	1%
Urdu & English	1	1%
Swazi & Zulu	1	1%
Subtotal	**23**	**15%**
More than 2 home languages		
Afrikaans, English & German	1	1%
Portuguese, English & Afrikaans	1	1%
English, Portuguese & Italian	1	1%
Subtotal	**3**	**3%**
Total	**153**	**100%**

***Key:** The first language reported indicates the dominant language of the family

When comparing the results of the subjects' home languages with recent statistics of the distribution of first language in greater Pretoria, it appears that Afrikaans is the most prevalent first language among the residents, with Sepedi and English as the second and third most prevalent first languages, which may partly explain why Afrikaans was found to be the dominant language in the majority of the subjects (Ngwesi, 1999). As indicated in Table 6.25, 58% of the subjects live in the Pretoria region.

The linguistic and cultural diversity in some of the subjects points to the special information needs of their families as all the subjects are already at risk for, or display an array of communication disorders with a subsequent risk for school failure in the future. According to Baker (2000) when one language is better developed it is advantageous to concentrate on developing the stronger language first when delayed or disordered communication development is evident in a child. As 58% of the subjects are already attending a daily childcare facility or a nursery school (See Table 6.24 Nr 8) where the subject's dominant language may not be spoken, the parents of the multilingual subjects must be provided with information regarding their children's present and future educational needs.

The discussion of the results regarding the characteristics of the subjects' families revealed that while most of the families had an adequate standard of living and experienced no serious risks which could interact negatively on the subjects' development, environmental risk conditions were found amongst some of the families. The environmental risks emerging from the results and the corresponding percentages occurring in the subjects' families are summarized in Table 6.28.

Table 6.28 Environmental risks found in the subjects' families

Risk Condition	%
1. Single mothers	8%
2. Large families	10%
3. No concern, efforts to help or expectations listed about subject	10%
4. Low educational levels of parents	14%
5. Low income families	Less than 10%
6. Income too low to belong to a medical aid fund	13%

These environmental risk conditions occurred to a limited extent in the subjects' families and cannot be interpreted as a profile of a certain subgroup of the subjects since correlations between the variables were not determined. It is, however, of importance that these environmental risk conditions occurred in the vulnerable families served by CHRIB. Efforts must be directed to meet the needs of these families in ECI as strong associations are found among stressful family characteristics, family interaction patterns and non-optimal child development outcomes (Guralnick, 1997).

Apart from the environmental risks identified in a minority of the subjects, stressors and informational needs regarding the subjects' communication problems were already identified in more than 90% of the subjects' families (See Table 6.20, Nr 10). The results therefore provide some important guidelines for appropriate ECI service delivery to meet the unique set of needs of each family.

In order to provide a comprehensive analysis of the different risk conditions found in the subjects, specific maternal risks were identified.

6.5.4 Characteristics of the subjects' biological mothers

Selected characteristics of the 145 biological mothers of the subjects are presented in Table 6.29 in order to indicate possible biological risks which could have affected the subjects since the earliest stages of their development. Since the data of the subjects' parents and their biological mothers differ, a description of the subjects' biological mothers is necessary (See 6.5.1). There were 145 biological mothers since the mothers of twins and triplets were counted only once.

Table 6.29 Characteristics of biological mothers of subjects during pregnancy (N=145)

Characteristic	Category	# Subjects	%
1. Mother's age at time of pregnancy	Average Range Mothers 18-19 years old Mothers older than 36 years	27.95 years 18-42 years 5 mothers 5 mothers	- - 4% 4%
2. Spontaneous abortions or stillborn infants	Yes No	24 121	17% 83%
3. Viral infections and other	Yes	16	11%

infections	No	129	89%
4. Health problems	Yes No	72 73	50% 50%
5. Medical treatment	Yes No	67 78	46% 54%
6. Smoking, alcohol or drugs	Smoking Alcohol -*Prozac*® under subscription -*Roaccutane*® to abort fetus -Anticonvulsants for epilepsy	9 1 1 1 1	6% 1% 1% 1% 1%

According to Table 6.29 there were only 4% of mothers between 18 and 19 years old and 4% of mothers older than 36 years at the time of the subjects' birth. Since maternal age is regarded as a critical factor to increase the risk potential of her child (Rossetti, 1986), additional data was retrieved from the CHRIB database and manipulated to be presented as a scatter graph in Figure VI.V.

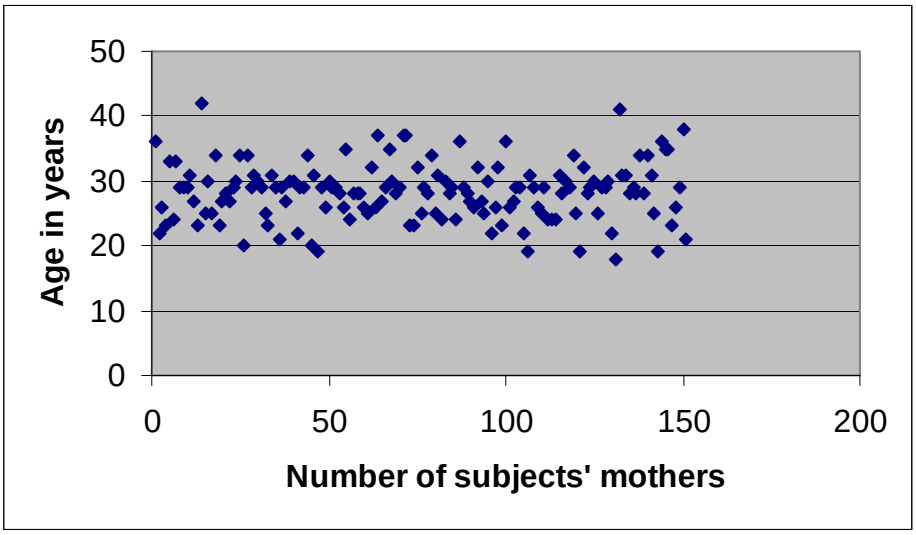

Figure VI.V Scatter graph of ages of subjects' biological mothers at the time of the subjects' birth (N=145)

Figure VI.V displays the ages of the subjects' *biological mothers* at the time of the subjects' birth. According to Rossetti (1986; 1996) mothers younger than 16 years and older than 36 years display a higher risk for a number of conditions such as premature births, repeated miscarriage, cervical incompetence, stillbirth, placental abnormalities, intrauterine growth

retardation, blood group problems, unexplained fetal or neonatal deaths, genetic disease and chromosomal disorders. As depicted in Figure VI.V the average age of the mothers was approximately 28 years and does not indicate a risk factor, but the lower margin of 18 years can pose the particular risks usually associated with adolescent pregnancies. According to Rossetti (1996) pregnant women between 15 and 19 years are likely to be unmarried and not receiving prenatal care before their third trimester of pregnancy.
Upon further analysis of the results in the CHRIB database it appears that all five mothers between the ages of 18 and 19 years gave birth to subjects with various forms of cleft lip and palate (See Appendix E, Subjects with CHRIB ID Nr 58, 124, 140, 152 and 165). Apart from the fact that adolescent mothers as a group give birth to four times as many infants with disabilities as the general population (Gerber, 1990), these interesting results of the current study regarding the young mothers and their cleft lip and palate children cannot be interpreted further. The sample size is too small and no literature support could be found relating maternal age directly to the prevalence of cleft lip and palate (Becker, *et al*., 1998; Gerber, 1990; Sadler, 1995).

Further analysis of the results in the CHRIB database revealed that the five biological mothers who were older than 36 years, gave birth to subjects displaying the following risk conditions: Extremely low birth weight and prematurity, fetal alcohol syndrome, twins with low birth weight and delayed communication development, Down syndrome and cleft palate. Except for the cleft palate and fetal alcohol syndrome, the high ages of the subjects' biological mothers and the corresponding conditions in their children can be associated with the maternal risks described by Rossetti (1986; 1996).

Further results depicted in Table 6.29 (Nr 2) indicate that a total of 24 mothers (17%) experienced spontaneous abortions or gave birth to stillborn infants. Since these conditions are prevalent in 50-60% of all conceptions (Sadler, 1995), it can be expected to occur to some extent in the sample of the current study. Further analysis of the results is presented in Table 6.30.

Table 6.30 Risk conditions of subjects whose mothers had spontaneous abortions and stillborn infants (N=24)

Subjects' Condition	# and % of Subjects
Cleft lip and palate (various types)	15 / 63%
Prematurity	3 / 13%
Down syndrome	2 / 8%
Microcephaly	1 / 4%
Unknown syndrome	1 / 4%
Hyperactivity and language delay	1 / 4%
Specific expressive language impairment	1 / 4%
Total	**24 / 100%**

The most salient feature depicted in Table 6.30 is the 15 (63%) subjects with various types of cleft lip and palate whose mothers had spontaneous abortions, some of whom had multiple abortions, and stillborn infants. Again no literature support was found for the results relating to cleft lip and palate. According to Sadler (1995) chromosomal anomalies are responsible for 50% of spontaneous abortions and stillbirths while maternal disease and teratogens can also be contributing factors to these early losses.

The following results in Table 6.29 (Nr 3, 4 & 5) relate to infections, health problems and medical treatment the mothers had during the pregnancy with the subject. A total of 16 (11%) mothers reported infective conditions such as colds, influenza, bronchitis, bladder, kidney, urinary tract, vaginitis and a tooth abscess occurring during their pregnancies. Health problems experienced by 50% of the biological mothers during pregnancy included hypertension, pre-eclampsia, threatened abortions, hyper- and hypothyroidism, kidney stones, low blood pressure, stress, premature rupture of membranes, haemorrhage and epilepsy. A total of 46% of mothers received medical treatment for these conditions just mentioned, which implies that some of those experiencing health problems did not receive treatment for the conditions.

Furthermore, Table 6.29 Nr 6, indicates smoking, use of medication and habits of substance abuse in the subjects' mothers. Nine mothers smoked actively during the pregnancy and five of them had infants with various types of cleft lip and palate. The other conditions occurring in the mothers who

smoked during pregnancy included sensorineural hearing loss, fetal alcohol syndrome and two subjects with specific language impairment. Apart from the drugs used under doctors' supervision for infections during pregnancy and included in Nr 5, other instances of drug usage in the mothers involved the following:

- A mother using alcohol and the subject displayed fetal alcohol syndrome.
- One mother used *Prozac*® during pregnancy and the subject had a general developmental delay.
- Another mother used *Roaccutane*® and the subject presented with fetal *Roaccutane*® syndrome.
- A mother used anticonvulsants to control her epilepsy and the subject displayed a bilateral cleft lip and palate.

Although smoking and use of drugs occurred in only 9% of instances, the results indicate that most of these subjects displayed congenital anomalies. Maternal smoking is known to be associated with cleft lip and palate (Becker, *et al*., 1998; Sadler, 1995) and the use of various anticonvulsants during pregnancy is associated with different congenital anomalies, of which craniofacial anomalies are also described (Sadler, 1995). Although the sample is too small to warrant further statistical analyses, some of the results in Table 6.29 such as maternal infections, health problems and use of substances during pregnancy are in agreement with research results reported in the literature. According to Sadler (1995) poor maternal health (specifically hypertension and renal and cardiac disease), the use of cigarettes, alcohol and other drugs, such as Vitamin A, minor and major tranquilizers, antihypertensive agents, anticonvulsants, aspirin and amphetamines are potentially harmful to the developing embryo and fetus. These conditions and the effects of teratogens, as also indicated in the subjects of the current study, can have various effects, from early death to intra-uterine growth retardation, premature birth and congenital anomalies (Sadler, 1995).

The results concerning the occurrence of cleft lip and palate in the subjects with young mothers, the spontaneous abortions and stillbirths in the mothers of subjects with cleft lip and palate need to be investigated further to determine their significance when more data has been accumulated in the CHRIB database.

The results of biological risks present in the subjects from early in life emphasize the notion to move away from earlier conceptual models which presumed that an increased risk for disability in infants *originate* from adverse circumstances surrounding the birth process (Kochanek & Buka, 1995). The current notion implies that greater significance is now awarded to the cascading effects of gene actions and exogenous factors, interacting with one another during different periods as described by Rubin (1995). These periods in a child's life represent a continuum of vulnerability or risk and include the prenatal period, which is subdivided into the preconceptual, periconceptual, embryogenesis, fetal growth and maturation periods, the perinatal period and postnatal periods (Rubin, 1995). Since the periods when biological events posing risks for communication disorders are likely to occur are known, the possibility of identifying risk factors earlier in life can lead to more effective ECI.

6.6 CONCLUSION

The current study proved that a database as an ECI research tool can be used effectively to provide a rich and detailed description of a sample of the population served by CHRIB, a tertiary based ECI provider. The use of descriptive methodology revealed remarkable detail and unique characteristics of the 153 subjects and their families employed in the empirical study which would not have been possible without a relational database system.

The critical importance of time of identification of risk conditions and commencement with ECI services were illustrated by the results. While very

few subjects were late referrals for ECI, *certain subgroups* of subjects could have been identified earlier as the parents of these subjects were concerned about their children's communication development from an early stage or knew about the risk condition from an early age. It appears that the parents of the subjects with autism/PDD, multiple pregnancies, low birth weight and prematurity, expressive specific language impairment lacked information on risk conditions for delayed communication development, the benefits of ECI and local ECI facilities. The results indicated further limitations in the early identification of the subjects since a number of *subjects with established risk* conditions, who could have been identified at birth, were only identified after the perinatal period. It appears that lack of knowledge about ECI was *not only limited to the subjects' parents*, but that *health care professionals* who came in contact with the subjects at first, also required guidelines for the early identification of risk conditions for communication disorders in the subjects and referral for ECI.

The primary role of parents in the early identification of risk conditions in the subjects was indicated. The results revealed that *parents identified the subjects' risk conditions earlier than the professionals*, thereby confirming results of previous research indicating that parents' concerns about their children's development are mostly accurate and a sensitive indicator of the presence of disability (Rossetti, 1998). The results indicate that parental involvement in ECI should not only be seen as benefiting the effectiveness of the intervention component of the ECI process only, but that their potential in improving on the identification age of risk conditions in their children should be recognized and utilized.

The results also revealed the *different roles of CHRIB* as an ECI service provider in South Africa. A new role for CHRIB is to provide supportive counseling and information to parents whose unborn children have been diagnosed with risk conditions for communication disorders. While technological advances now allow the prenatal diagnosis of certain risk conditions in children, the increased risk for communication disorders in these children, such as those from multiple pregnancies may not be recognized at

that time. The role of CHRIB in providing consultative services to clinicians in the field of EI was clearly demonstrated in the results. The findings of referrals to CHRIB illustrate the recognition of CHRIB as a specialist ECI service provider and indicate that *CHRIB clients* do not only include families with young children at risk for communication disorders, but include professionals in the field of EI as well.

A biological risk profile was presented by using the *ICD-10* (CCS, 1996) diagnostic classification system which indicated that each subject displayed between two and seven different diagnostic classification entries. *The multiple risk profile* was an authentic strategy to describe the different characteristics of the subjects although the *ICD-10* (CCS, 1996) proved to be limiting in describing the different developmental disabilities and communication disorders and to reflect the degree of disability found in the subjects. The diagnostic entries occurring most in the subjects were communication disorders, recurrent otitis media, multiple births, low birth weight and prematurity, heart defects, cleft lip and palate and Down syndrome. The results emphasized the importance of a thorough knowledge about the multiple risk profile of each subject as it contributes to an individualized approach to ECI. The results revealed *interesting findings not extensively described in the literature,* such as the complex nature of the risks contributing to communication disorders found in the subjects associated with multiple births. Additional findings indicated that low birth weight and prematurity were associated with subjects with cleft lip and palate and that low birth weight, prematurity and intrauterine growth retardation of a less severe degree occurred in different subgroups of subjects with congenital anomalies. Furthermore, all subjects with heart defects also exhibited additional congenital anomalies which emphasize a genetic basis for a cascade of early biological events causing congenital anomalies. Results also revealed risk factors for communication disorders in the perinatal period, with feeding difficulties as the most prevalent risk condition in the subjects. The subjects also exhibited a large number of surgical procedures interpreted as environmental risk factors and stressors to the family which can negatively impact on the subjects communication development in the postnatal and later

stages in life. A continuum of risk events were identified in the subjects, indicating critical points for the origins of these events in the subjects.

A recurring theme in the findings of the empirical study was the late identification of risk conditions for communication disorders. The results indicated that the subjects' parents had specific information needs which related to the recognition of the early signs of risk conditions in their children which can results in communication disorders. The parents of the subjects were identified as the key members of the ECI team involved in their young children as they were mostly the first to know about the risk condition, but neither knew how to interpret their knowledge about the child nor how to act upon their concerns about the delayed communication development in their children so that ECI could be initiated as early as possible.

The sample of the empirical study were mostly boys of 18 months with cleft lip and palate, living in the Pretoria region and from white Afrikaner families. Additional analysis of their families revealed that most were intact families with two or three children and that the parents were employed, belonged to medical aid funds and were highly educated. In contrast with the group of families who experienced few life stressors which can negatively impact on the subjects' communication development and the ECI process, approximately 10% of the families had adverse circumstances ranging from single parents, unemployed or low income, low education levels and large families. The characteristics of the subjects' families reveal the diversity of clients requiring ECI services at CHRIB, which also reflects some of the characteristics and diversities of young children and their families requiring ECI services in South Africa.

The results and discussion indicated a continuum of risk events in the subjects which leads to the conclusion that a conceptual framework for the early identification of risk conditions in children must be presented.

The descriptive results of the empirical study were derived from data stored in the CHRIB database and indicated that the CHRIB database is a rich source

of data which can be used in future research. As all the data is available in the CHRIB database further research can now be conducted by using inferential statistics to determine correlations between the different variables. Additional data can be obtained by entering new data into the database, therefore increasing the number of subjects in order to increase the reliability of the results. The CHRIB database has now been established as a viable ECI research tool, using new technology to define ECI in a new century.

6.7 SUMMARY

In order to demonstrate the capabilities of the CHRIB database and the functions of the different software programs linked to one another when used for data manipulation and data analysis, a rich description of selected characteristics of the 153 subjects and their families was provided. The detailed description of the subjects involved the interpretation of results regarding their gender, ages, prior ECI experiences, diagnostic categories, time of identification of their risk conditions, perinatal and postnatal characteristics. The different diagnostic classifications used to describe the risk conditions in the sample revealed a multiple risk profile of the subjects.

A description of the subjects parents followed by interpreting the results regarding their marital status, ages, the family size, family history of disabilities, use of child care facilities, their concerns, efforts to help their children and their expectations of ECI. Further results involved the description of the parents' educational levels, occupations, biographical detail and home languages. Furthermore, the results relating to the subjects' biological mothers were presented and their ages and history of the pregnancies were discussed.

Lastly, the results obtained from the CHRIB database demonstrated the use of computer technology in ECI research in South Africa. The study indicated that the CHRIB database is a viable tool for ECI research in the 21st century which will be driven by technology.