

**AN OVERVIEW OF SPEECH-LANGUAGE THERAPY SERVICES FOR  
CHILDREN WITH CLEFT LIP AND/OR PALATE FROM BIRTH TO  
THREE YEARS WITHIN THE KWAZULU-NATAL HEALTH SECTOR**

A Mini Dissertation presented to the Discipline of Speech-Language Pathology  
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in partial fulfilment of the requirements for  
the degree

M. Communication Pathology (Speech-Language Pathology)



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## DECLARATION

I, Marlene Chetty, declare that:

- (i) The research reported in this dissertation, unless where otherwise indicated, is my original work.
- (ii) This dissertation has not been submitted for any degree or examination at any other university.
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Signed: \_\_\_\_\_

Date: \_\_\_\_\_

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*My beautiful sister, Petrina Reddy...* for being the inspiration behind my research in the field of cleft lip and/or palate

*and*

*The children of South Africa...* may this study pioneer further research and development in the levels of care for you all.

## ABSTRACT

A descriptive survey with 19 Speech-Language Therapists from public health and four from private health was used to obtain an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years in the KwaZulu-Natal Health Sector. Results are presented for public health, as none of the four private based respondents worked with cleft lip and/or palate from birth to three years. The number of Speech-Language Therapists (9) working with cleft lip and/or palate (0-3 years) in KwaZulu-Natal appears not to have changed significantly over the past two to three years, similar to the incidence of cleft lip and/or palate births. Reasons for Speech-Language Therapists not working with this population included poor referrals and caseloads comprising of clients older than three years. A team approach to cleft care appears challenging but showing development. There are currently four institutions where professionals function as multidisciplinary teams, consisting mainly of Speech-Language Therapists, doctors and nurses. Speech-Language Therapists' assessments include case history taking, oral peripheral examination, observational feeding assessment and speech-language assessment. Most therapists are consulted within a few days of the birth, which is consistent with international guidelines. Audiological assessment and assessment of resonance were mentioned by a minority of participants. Feeding devices for cleft lip and/or palate are not always available immediately, and hence appears contradictory to the National Rehabilitation Policy. Recommendations include undertaking similar research in other provinces, so as to build a nationwide overview of services for South African children with cleft lip and/or palate.

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## **GLOSSARY OF TERMS**

### **Assessment**

Assessment is a process in which valid, reliable information is collected, and then integrated and interpreted, such that a decision may be made about something. The term 'assessment' may be used synonymously with 'evaluation'. In Speech-Language Pathology, the Speech-Language Therapist conducts an assessment so as to make a professional diagnosis and identify if treatment is warranted, the treatment plan and is the basis for measuring progress. Assessment also warrants referrals to other professionals where necessary. Ultimately, every clinical decision is derived from the process of assessment (Shipley & McAfee, 2008, p. 4).

### **Assistive Devices**

This refers to user friendly devices, utilising appropriate technology, used for the purposes of correcting impairments and limiting the effects of an anomaly or disability (Department of Health, 2000a). With regard to cleft lip and/or palate, assistive devices include modified bottles and teats specific to the condition so as to assist in a more effective feeding process (Wolf and Glass, 1992).

### **Cleft lip and/or palate**

A cleft lip or 'harelip' results from the failure of closure of the primary palate, whereas a cleft palate involves failure of closure of the secondary palate (Gorlin, 1993). A cleft may occur unilaterally or bilaterally, and may affect speech and/or feeding.

### **Craniofacial anomalies**

A craniofacial anomaly refers to a breakdown or malformation of the face, oral cavity and velopharyngeal valve, of which one such craniofacial disorder is cleft lip and palate (Kummer, 2001).

## **Early Intervention**

According to Shonkoff and Meisels (2000), this is intervention that occurs at an early stage in the child's life, which will minimise the impact of a condition (cleft lip and/or palate) on a child's life and prevent further progression. The American Speech-Language-Hearing Association (ASHA, 2008) defines Early Intervention as services that are provided to the birth to three year old population of infants, toddlers and their families.

## **Early Communication Intervention**

Early Communication Intervention refers to a transdisciplinary field, involving the assessment and treatment of children below the age of three who present with or are at risk for a communication, speech, language or oral motor delay or disability as well as their families (ASHA, 2008 and South African Speech-Language-Hearing Association [SASLHA], 2010).

## **Formal Measures**

Formal testing in Speech-Language Therapy usually follows a particular format and has a standardised procedure, with normative data for analysis in terms of standard scores and comparison to same age counterparts, in this case, zero to three years (Beech, Harding & Hilton-Jones, 1993). There is no single test or a set of tests that may be right for all clients. The selection of test material should involve familiarisation and thought in terms of clinical decision making, e.g. age range and languages of standardisation of the test (Shipley & McAfee, 2008).

## **Informal Measures**

Informal measures in Speech-Language Therapy are more descriptive than formal measures. These are usually based in a naturalistic context or situation using observations and are not standardized nor refer to normative data (Beech, Harding & Hilton-Jones, 1993). For example, in the assessment of language in the zero to three year old client, a representative language sample should be obtained in different

naturalistic contexts and be between 50-100 words in length (Shiple & McAfee, 2008).

## **Language**

Language is a form of social tool, a dynamic process used to accomplish a person's goal of communicating. Language involves the "form of language (phonology, morphology, syntax), the content of language (semantics) and/or the function of language in communication (pragmatics)" (Owens, 2004, p. 4).

## **Management**

In Speech-Language Pathology, 'treatment', is a term defined as "the medical and educational connotations of treating and teaching persons with communicative disorders" (Hegde & Davis, 1995, p. 205), as well as their families. In cleft lip and/or palate, management areas include therapy for speech difficulties, language difficulties, velopharyngeal insufficiency and feeding difficulties. For the purposes of this study, the term 'management' for children with cleft lip and/or palate from birth to three years is used synonymously with 'treatment' and 'intervention'.

## **Primary Health Care**

Primary Health Care (PHC) is essential health care, based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self determination (World Health Organisation [WHO], 1978). In 1994, with the establishment of a democratic government in South Africa, the country adopted Primary Health Care as the centrepiece of all its health policies (Schaay & Sanders, 2008).

## **Private Health Sector**

This health sector is responsible for provision of health services to the full paying population, such as those on a medical aid scheme in South Africa (Department of Health, 2000b), or those paying directly to the private institution using private funds (McIntyre, 2010). Currently only 15 percent of the South African population belong to medical aid schemes (McIntyre, 2010).

## **Public Health Sector**

The public health sector is the sector that provides health services to the majority of the South African population. The Department of Health is central to public health and is the main provider for medical services, mainly provided for by Primary Health Care clinics, district, provincial and tertiary hospitals (Department of Health, 2000b). The public health budget flows via intermediaries in the public sector such as the local, national and provincial departments of health (Department of Health, 2000b).

## **Speech**

Kummer (2001) describes speech as a coordination between a number of subsystems, including respiration, phonation, resonance and articulation. Respiration involves adequate inspiration and expiration for phonation, phonation refers to the sound that is produced by the vocal folds as they begin to vibrate, resonance refers to the quality of speech produced by the air travelling through the supraglottic tract (Kummer, 2001). Articulation refers to the alterations in the sound produced by the articulators, i.e. the lips, tongue, teeth, palate and jaw, resulting in the production of vowels and consonants (Kummer, 2001).

## **Speech-Language Therapist**

“A Speech-Language Therapist is a health care and educational professional who assists in the promotion of normal communication, assessment, diagnosis, treatment and management of developmental or acquired speech disorders ... as well as developmental or acquired disorders of language and language processing, and



developmental or acquired disorders of feeding and swallowing in a variety of settings ranging from private practice, private hospitals, government hospitals, rural clinics, tertiary institutions, schools, preschools, industries, communities and home environments” (Health Profession Council of South Africa [HPCSA], 2005, p. 5).

A Speech-Language Therapist may hold a single degree in Speech-Language Pathology, or may have qualified with a dual degree, where he/she is referred to as a Speech-Language Therapist and Audiologist.

### **Speech Sounds**

According to Cardiff (n.d), in English, there are approximately 24 consonants, all grouped into five types, namely plosives, nasals, fricatives, affricates and approximants, classified according to the place, manner of articulation and voicing. Plosives, or stops, are generally produced with a complete constriction in the oral cavity. These are further divided according to the place of articulation, and there are six in total - /p, b, t, d, k, g/.

Nasals also have constriction, as with plosives, except that here air passes through the nose, as in /m; n; N/. Fricatives do not have as much constriction in the oral cavity, but friction occurs at the point of contact. There are nine fricatives, including /f/ and /v/. An affricate is basically a plosive and fricative produced in quick sequence by a single articulator. There are only two affricates in the English language, namely /tʃ/ and /dʒ/. An approximant does not include any friction at all, e.g. /l/ (Cardiff, n.d). The isiZulu language has a much larger phonetic inventory, consisting of 59 consonant sounds and a unique click structure that does not occur in English (Naidoo, 2003).

### **Velopharyngeal Closure**

This refers to the closure of the nasal airway, by elevating the soft palate and contracting the posterior and lateral pharyngeal walls (Peterson-Falzone, Trost-Cardomone, Karnell and Hardin-Jones, 2006).

*Mpho\* is a three month old girl, who was born with a unilateral cleft of the lip and palate. Following her birth, surgeons were called in to evaluate the status of her cleft, after which she was booked in for surgical repair of her cleft lip at three months of age. Three months later, on admission to the hospital for her operation, she is spotted by the resident Speech-Language Therapist during ward rounds. The Speech-Language Therapist is concerned, as Mpho's mum reports nasal regurgitation of her formula since birth as well as other feeding difficulties. Despite her concerns over feeding, she was only given a pamphlet on cleft lip and palate and on feeding by nursing staff. She was not referred to the Speech-Language Therapist, who is at the hospital on a daily basis.*

*Nikiel\* (three months old) was born at a hospital near to that of Mpho, also with a unilateral cleft of the lip and palate. At this hospital, a cleft lip and palate team is in the foundation stages. In his case, the Speech-Language Therapist was called in by the medical doctor soon after his birth. His parents received counselling about feeding as well as about speech and language development and stimulation thereof. His parents were offered a modified teat to assist with bottle feeds initially, until he was fitted with an orthodontic palatal prosthesis. Nikiel's parents are grateful for the early efforts the professionals at the hospital made for his well being.*

The contrast between the above two cases is clear. Where one parent and baby received Speech-Language Therapy support and guidance from the onset, the other knew nothing of Speech-Language Therapy services until her baby was seen by the Speech-Language Therapist in the ward.

Why is it that these differences and disparities exist? Both hospitals have a Speech-Language Therapist present on a daily basis, so ideally both children should have received similar counselling and support at similar times. These thoughts are what led the researcher to consider this research topic – an investigation into Speech-Language Therapy services for children from birth to three years of age within the KwaZulu-Natal health sector.

\* Names have been changed.

## **CHAPTER 1**

### **INTRODUCTION AND ORIENTATION TO THE FIELD OF CLEFT LIP AND/OR PALATE**

The aim and focus of the chapter is to discuss cleft lip and/or palate, in relation to definitions of the condition, statistics relevant internationally and to South Africa, as well as a section surrounding the historical perspectives on cleft lip and/or palate treatment, both internationally as well as in South Africa. The chapter will also provide insight into international as well as national policies and protocols related to early intervention and cleft lip and/or palate within the South African health system. In addition, this chapter will provide a rationale for research into the services provided for children with cleft lip and/or palate within the birth to three years age range.

#### **1.1. INTRODUCTION**

For the majority of parents in the world, the birth of a newborn baby is a time of joy and celebration, a time which usually follows a happy pregnancy as well as a safe labour and delivery process. Following the newborn's entry into the world, the first two years of life involves rapid development in cognition, physical development as well as speech and language (Owens, 2001). However, not all children are born healthy and as a perfect picture (Shonkoff & Meisels, 2000), such as those born with craniofacial anomalies. Craniofacial anomalies are rated as the fourth most common birth anomaly, affecting one in seven hundred live births in the United States (American Cleft Palate Craniofacial Association [ACPA], 2007). Mars, Sell and Habel (2008) report that approximately eighty percent of children with cleft lip and/or palate are born in developing countries, such as South Africa. Of the existing craniofacial anomalies, cleft lip and/or palate is the most common (ACPA, 2007). Furthermore, approximately half of these cleft lip and/or palate children have other associated malformations (Kummer, 2001) and clefting also occurs as a manifestation of many genetic syndromes (Kummer, 2001).

A cleft lip or 'harelip' occurs through the failure of closure of the primary palate, whereas a cleft palate involves failure of closure of the secondary palate (Gorlin, 1993). According to McWilliams, Morris and Shelton (1990), clefts may be either

unilateral, or bilateral and may occur singly or in combination with each other. The etiology of cleft lip and/or palate is not definite, but is linked to genetics as well as the interaction between genetics and the environment (Kummer, 2001). Cleft lip, with or without the presence of cleft palate, and cleft palate in isolation affect approximately one in six hundred babies worldwide (World Health Organisation [WHO], 2000). Therefore, assuming that there are fifteen thousand children born per hour worldwide, a child with a cleft is born every two and a half minutes (World Health Organisation [WHO], 2000). In South Africa, thirty three registered cases of cleft lip with or without cleft palate or isolated cleft palate were reported from 2001 to 2003 (WHO, 2007). The incidence of cleft lip, cleft palate or cleft lip and palate per one hundred thousand births in KwaZulu-Natal was estimated at 25.2 in 2005, 22.4 in 2007, and 30.0 in 2008 (Wilson, L., personal communication, August 14, 2009<sup>1</sup>). These figures appear low at first glance, however in relation to other congenital anomalies such as albinism, anencephaly and clubfoot, cleft lip and/or palate ranks as the third most frequent congenital anomaly in KwaZulu-Natal (Wilson, L., personal communication, August 14, 2009).

The impact of a cleft lip and/or palate affects not only the child, but also the parents. Services for cleft lip and/or palate are required prenatally (if the cleft was detected in utero), through birth, infancy and continuing into adulthood. These services may include, but are not limited to: surgical intervention, feeding intervention, dental and orthodontic management, speech-language assessment and therapy, audiological monitoring, as well as information provision (specific to the condition and age range) for parents. According to Hodgkinson et al. (2005), the pregnancy and birth stages are the earliest stages of intervention, which include working with parents and family as the key facilitators in the intervention process. The next stage of intervention involves the child functioning within the family system as well as external systems, e.g. school. As the child grows, a sense of individuality develops, acknowledging the need for possible psychological intervention during the teenage years, and lastly,

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<sup>1</sup> Lin Wilson is the contact person for the KwaZulu-Natal maternal, child and women's health department, which offers services to promote healthy lifestyles to reduce morbidity and mortality rate, especially in women and children. Due to a lack of published statistical data, it should be noted that these figures are only estimates of those cases which were reported during 2005-2008.

where necessary, further surgical or speech and language related intervention during the stages of adulthood (Hodgkinson et al., 2005).

## **1.2. HISTORICAL PERSPECTIVES ON CLEFT LIP AND/OR PALATE CARE**

A historical perspective on cleft lip and/or palate care dates back as early as the Middle Ages. The first record of surgical repair of a cleft lip dates back to 390 AD, by a Chinese surgeon. In the sixteenth century, Pierre Franco published the first work on surgical repair of cleft lip (Franco, 1561, as cited in Shons, 1993). This was followed by centuries of development in the field, ultimately leading to the technology and experience of professionals in the field today.

In South Africa, the earliest reports of cleft lip and/or palate treatment date back to 1953, with the review of five hundred cases by Penn, Clayden and Bentel (1953). According to Penn, Clayden and Bentel (1953), South African surgeons of the time were 'ignorant' of the nature of the condition, and hence experienced difficulties in approaching the condition in the appropriate manner. Furthermore, the study revealed that a lack of coordination existed with regard to treatments between surgeons, dentists and Speech–Language Therapists (then logopaeditions), as treatment was not a cooperative effort. Of five hundred cases of cleft lip and/or palate repair, two hundred and thirty individuals were having primary surgery for at least the second time. Many repairs had to be 'redone' due to the poor condition of the cleft, previously repaired by "incapable or untrained hands" (Penn, Clayden & Bentel, 1953, p. 484). The authors comment on the well being of the child being the ultimate goal of treatment, as well as constant follow up until the age of ten years. However, the high frequency of secondary deformities following surgical repair of the lip and/or palate indicated a general lack of even basic knowledge and skills of cleft lip and/or palate repair. The conclusion of the study was that, in the 1950's, South Africa's government was urged to take the necessary steps to ensure adequately trained surgeons within the major provincial hospitals in the country.

### **1.3. THE SOUTH AFRICAN HEALTH SYSTEM**

Knowledge of health research policy and systems is crucial to achieve goals and understand the workings of a government system (Ranson and Bennett, 2009), as well as any health organisation. Furthermore, this knowledge assists in attaining global research priorities.

According to Strauss (1999), behind every society's methods of resource allocation lie policies, values and justice, including those resources for craniofacial care. He further states that no condition provokes a more sympathetic response from both the public as well as political forces than visible impairments, such as craniofacial conditions. Furthermore, Mars, Sell and Habel (2008) report that approximately eighty percent of children with cleft lip and/or palate are born in developing countries. It is therefore important that knowledge of South African systems and policies form the backdrop to this craniofacial centred study.

In 1994, with the establishment of a democratic government in South Africa, the country adopted Primary Health Care as the centrepiece of all its health policies (Schaay & Sanders, 2008). According to the World Health Organisation (1978), Primary Health care is defined as:

“Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self determination” (World Health Organisation, 1978).

Primary Health Care is thus important to the field of craniofacial disorders as well as other physical disorders in general, due to the need for universal accessibility. In addition, the majority of South Africa's population live in poverty (Department of Health, 1997) and hence would require essential health care that is cost effective during the different stages of care. This is further discussed by Van Rensburg (2004), who states that South Africa's Primary Health Care package is based on five

components of the Primary Health Care Model. These include that health care needs of every person should be addressed according to how people wish to receive care, that comprehensive health care should be available in rural areas, which in turn will improve service delivery, and that the focus should be on improving the quality of care to improve health in local communities, rather than mere administration of the health service.

The National Health Bill of 1994 sought to establish Primary Health Care in South Africa through the restructuring of the public health care system, i.e. integrating all health services under a single health ministry, establishing a well coordinated district health system and making comprehensive, community-based health care accessible to all South Africans by establishing PHC centres (Kautzky & Tollman, 2008). In addition, President Nelson Mandela, in 1994, announced the introduction of free health care for pregnant and lactating women, as well as children under the age of six (Mhlanga, 2008). Through the principal health status for maternal and child health in South Africa, this contributes to development of all young children, especially those at risk, as well as those mothers and children who live in poverty with their only access to health care being the nearby clinic (Kritzinger, 2000).

Following 1994, the development of South Africa's health system involved the establishment of a number of charters and policies. Of particular interest to services for children with cleft lip and/or palate, are the Charter of the Public and Private Health Sectors of the Republic of South Africa (Department of Health, 2005), the National Rehabilitation Policy (Department of Health, 2000a) and South African Speech-Language-Hearing Association (SASLHA) Guidelines for Speech–Language Therapists in early intervention (Louw, 1997).

### **1.3.1. Charter of the Public and Private Health Sectors of the Republic of South Africa (2005)**

According to Kautzky and Tollman (2008), an obstacle to development and the adequate provision of health services exists as a consequence of the apartheid system of separate health services, the establishment of the private sector, as well as the unequal distribution of health resources and personnel between the private and public

health sectors. The aim of this charter (Department of Health, 2005) was for the parties involved to create a South African health system that is efficient and coherent, as well as cost effective for the entire population, including for cleft lip and/or palate individuals and families. This can be achieved through the optimal utilisation of both public and private health services to benefit the entire country's population. It was agreed upon for the public and private health sectors to establish mutual cooperation, trust and respect, which will in turn improve health care at all levels. However, there are a number of challenges which the South African health system faces, in particular with regard to access to services, financing, equity, and human resources. A strong argument exists that the key challenge facing the health system is not inadequate resources, but rather the inequitable and inefficient application of these resources.

According to Kautzky and Tollman (2008), in 1998 the majority of general practitioners, health nurses and specialists worked in the private health sector, despite the fact that this sector caters for only twenty percent of the population. In 2005, the Department of Health reported that the situation still existed, and that suitably qualified and trained health care personnel are still not equally distributed throughout the national health care system (Department of Health, 2005). Furthermore, the private sector utilises approximately sixty two percent of the national health expenditure to provide for only seven million people, whereas the public health sector utilises only thirty eight percent to provide for approximately thirty five million residents (Kautzky & Tollman, 2008). This is further aggravated by the lack of affordability of belonging to a medical aid scheme, which results in an increasing number of South Africans relying on public health care.

### **1.3.2. National Rehabilitation Policy (Department of Health, 2000a)**

This policy focuses on the standardisation of provision of assistive devices in South Africa, designed for application in the public health sector. Of particular interest to the field of Speech-Language Therapy and Audiology is the provision of assistive devices for communicatively impaired individuals (speech, voice, language disorders, feeding, hearing disorders and deafness) (Department of Health, 2000a). With regard to cleft palate, assistive feeding devices may include specialized feeding bottles or nursers (Wolf & Glass, 1992), which would have to be ordered where necessary. The



policy promotes the development of a budget at provincial and regional or district level for the provision of assistive devices, and states that the assessment and prescription for an assistive device should only be made by the relevant, appropriately trained rehabilitation provider. Thus, in the case of Speech–Language Pathology, the Speech–Language Therapist is the professional who selects, prescribes, issues and trains the individual and their family in the use of the assistive device. In the case of a specialised feeding bottle, the mother would require training. Prescription forms do not have to be signed by a medical practitioner or superintendent, but should be co-signed by individual department heads (Department of Health, 2000a). Furthermore, instant access to assistive devices for infants, children and adults with feeding and swallowing difficulties, e.g. cleft palate, stroke and cerebral palsy, should be guaranteed (Department of Health, 2000a). At the latest, it should be provided on discharge. This is due to the fact that, unlike typically developing infants/neonates, parents of babies with cleft lip and/or palate are required to assist in establishing the suck-swallow breathe feeding pattern for the neonate, via the use of the specialized bottles.

### **1.3.3. SASLHA guidelines for Speech–Language Therapists in Early Communication Intervention**

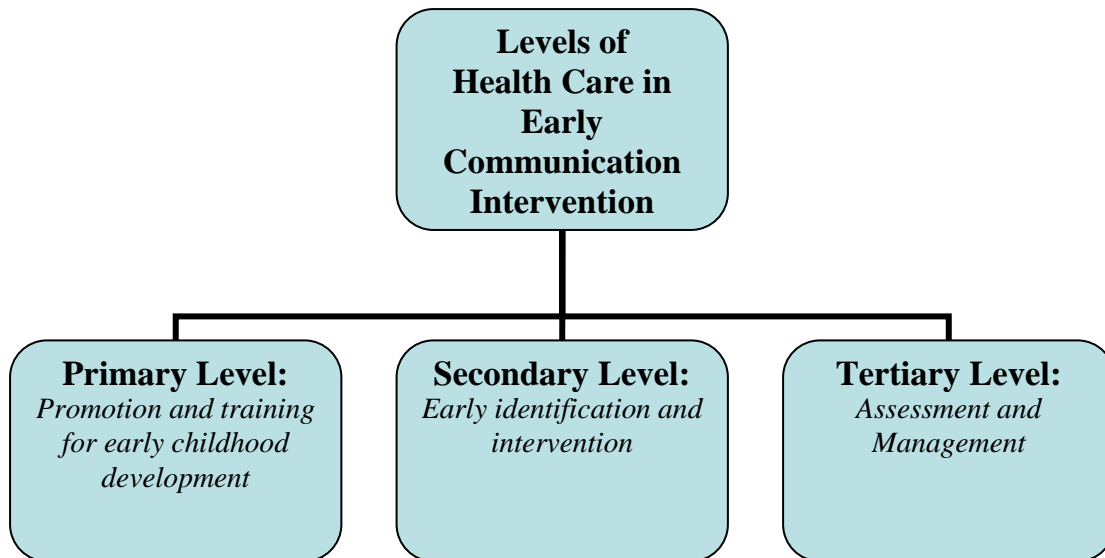
As this study focuses on the birth to three year age range, it is necessary to explore the field of early intervention and early communication intervention in South Africa, as it is this area into which children with cleft lip and/or palate fit.

According to Shonkoff and Meisels (2000), the term *early intervention* refers to intervention that occurs at an early stage in the child’s life, which will minimise the impact of a condition on a child’s life and prevent further progression. There has been much speculation regarding the age range for early intervention services, however in South Africa, it has been established that the first three years of a child’s life is considered the ‘critical’ developmental period, and hence the period in which early intervention services are provided (Billeaud, 2003).

*Early communication intervention* refers to a transdisciplinary field, involving the assessment and treatment of children below the age of three who present with or are at

risk for a communication, speech, language or oral motor delay or disability as well as their families (American Speech-Language-Hearing Association [ASHA], 2008 & SASLHA, 2010). According to Rossetti (2001), delayed communication development is one of the most common symptoms of developmental delays and disorders. Communicative ability correlates highly with later intelligence and performance at school (Rossetti, 2001). Rossetti (2001) states that early communication intervention services have high probability to make long term, positive differences for children with developmental delays and disorders. Furthermore, as cleft lip and palate is defined as an established risk factor for communication difficulties, i.e. a factor that has the potential to have adverse effects on developmental outcomes (ASHA, 2008), it is clear that early communication intervention (as well as surgical intervention in this case) for this population and their families is vital.

According to Louw (1997), early communication intervention can be implemented as a preventative strategy at primary, secondary and tertiary levels of health care, with the aim of reducing the occurrence as well as severity of conditions (such as cleft lip and/or palate) which have potential to impede communicative development. At the primary prevention level of health care, promotion and training for early childhood development should occur. At the secondary prevention level, early identification and intervention occurs. At the tertiary level of prevention, intervention, which includes assessment and management, occurs (Louw, 1997). The levels are demonstrated below:



**Figure 1.1. Illustration of the levels of prevention within early communication intervention**

In accordance with the announcement of free health services to children under the age of six, SASLHA propagated a nationwide movement toward implementing early communication intervention for disorders, including cleft lip and/or palate in South Africa. These guidelines for intervention stress the following points:

- Developmental gains are greater if intervention begins earlier,
- Intervention should be sensitive to the family's geographical and cultural settings,
- Intervention should be family centred, involving the family directly, and within their daily activity, either based at an institution or at home,
- Intervention can be indirect (e.g. to nursing staff in the neonatal intensive care unit) or direct (to the family),
- Teamwork and the transdisciplinary team is strongly advocated, together with counselling, training and information for caregivers,
- Services should be family centred, including culturally and linguistically acceptable, and

- Services should ultimately promote a child’s participation in their natural environment, services should be part of a coordinated team basis, and be evidence-based (Louw, 1997 & ASHA, 2008)

In addition to the above, Van de Linde (2008, p. 48) discusses the various Primary Health Care programmes in which early communication intervention may be implemented. Those related to cleft lip and/or palate are described in Table 1.1. below.

**Table 1.1.: Primary Health Care Programmes in which early communication intervention may be implemented**

<b>Primary Health Care Programmes</b>	<b>Possible integration of Early Communication Intervention</b>
1. Non personal health services	<ul style="list-style-type: none"> <li>• Promotion of early communication services through mass media presentations</li> <li>• Increasing awareness of normal child development</li> </ul>
2. Prevention and control of diseases	<ul style="list-style-type: none"> <li>• Screening and assessment of young children at risk for developmental delay, e.g. cleft lip and palate</li> <li>• Education about normal communication development, stimulation as well as early literacy development for parents and caregivers.</li> </ul>
3. Maternal, child and women’s health	<ul style="list-style-type: none"> <li>• Screening, assessment and intervention for young children and infants at risk for developmental delays and disorders, e.g. cleft lip and palate</li> <li>• Providing information and training, as well as support for parents and caregivers of infants and children at risk for developmental delays and disorders</li> </ul>
4. Health monitoring and evaluation	<ul style="list-style-type: none"> <li>• Monitoring of the implementation of early communication intervention collaborative activities</li> <li>• Monitoring of case findings</li> </ul>

#### **1.4. RATIONALE FOR CLEFT LIP AND/OR PALATE RESEARCH IN THE DEVELOPING WORLD AND SOUTH AFRICA**

Craniofacial anomalies, such as cleft lip and/or palate incur considerable costs related to morbidity and health care, social and employment issues, as well as personal issues in families and society (World Health Organisation [WHO], 2000). In the developed world, there have been great advances in medical care. In developing countries such as South Africa, challenges exist mainly due to issues such as limited resources. According to Mars, Sell and Habel (2008), approximately eighty percent of children with cleft lip and/or palate are born in the developing world, where cleft care services may not always be adequate. With regard to Speech-Language Pathology, Speech-Language Therapists in the developing world are required to take responsibility for highlighting their own role on the early intervention team for children with cleft lip and/or palate (Eurocran Speech Project, 2000). This is due to the limitations in availability of these professionals as well as services being only recently introduced in some countries. A clear example of this, according to Van de Linde (2008), was that in 2005, only one Speech-Language Therapist and Audiologist serviced the entire Ditsobotla sub-district in the North West Province of South Africa, hence little attention was paid to early communication intervention due to the increased workload. This could have resulted in ‘missing out’ on those children at risk for communication delays.

The majority of South Africa’s population live in poverty, where early intervention services, especially those required for communication, are scarce (Fair & Louw, 1999, as cited in Kritzinger, 2000). Three problems relating to the provision of early intervention services in South Africa are highlighted below:

- In South Africa, there exists an increased number of children with or at risk for communication delays and disorders, hence indicating the need for proper early communication intervention services (Kritzinger, 2000).
- As the majority of South Africans reside in rural and poverty-stricken areas where there are fewer health facilities and fewer early intervention facilities

(Kautzky & Tollman, 2008), identification of children for such services is difficult and complicated.

- The above mentioned scarcity of early intervention facilities may lead to health care workers in the existing facilities having poor knowledge of the importance of referrals to Speech-Language Therapists in the case of cleft lip and/or palate, which further undermines the importance of developing early communication intervention in South Africa.

The health of children is therefore largely dependent on the services available and offered to them, and the clinical expertise of the professionals who serve them. Despite much improvement in the services and level of care for children, many children may still receive care that is “substantially inferior to what can or could be provided” (ACPA, 2000, p. 1). In South Africa, an assessment of the healthcare system by the South African Human Rights Commission in 2007 recorded great concern about the levels of access to healthcare services and the quality of care provided in the public healthcare system, despite existing policy and legislation governing this sector (Netcare, 2008). With specific reference to cleft lip and palate, care for these children is challenged in South Africa, as children with clefts present a minority in terms of requirements for health services, compared to other conditions such as HIV/AIDS. Due to these reasons, this research study may advocate for collaboration between parents, patients and healthcare organisations to motivate for the necessary resources for holistic care of the child with cleft lip and/or palate, which may in turn educate political leaders, such as health ministers, to seek stricter legislation for access to quality care (Strauss, 1999). In addition, the future of cleft teams in KwaZulu-Natal and South Africa may be more clearly defined, and the vital role of the Speech-Language Therapist will receive more justification in addition to surgical requirements being a priority.

Investigations into the areas and methods of assessment and management used by Speech-Language Therapists for children with cleft lip and/or palate may be of particular help to those therapists who see only a few children with cleft lip and/or palate, as it will provide information on candidacy for treatment, and, more importantly, the most common methods used which aims to increase confidence for

working with this client group, as this helps to bridge the gap between theory and practice.

While services for cleft lip and/or palate begin at birth and continue to adulthood, the aim of this research study is to investigate the early Speech-Language Therapy services for children with cleft lip and/or palate in the province of KwaZulu Natal.

### 1.5. BRIEF OUTLINE OF CHAPTERS

An outline of the chapters of this research study is presented in Table 1.2. below.

**Table 1.2. An outline of the chapters and content of this dissertation**

<b>Chapter</b>	<b>Title</b>	<b>Content</b>
2	The impact of cleft lip and/or palate, early intervention services, the team approach, and the role of the Speech-Language Therapist in assessment and management of cleft lip and/or palate	<p>Discussion in this chapter surrounds the impact of a cleft lip and/or palate on the child and family, as well early intervention services required by the child with cleft lip and/or palate, relating to surgical intervention, feeding difficulties, speech-language intervention, orthodontics as well as general information for the family.</p> <p>The role of the Speech-Language Therapist and Speech-Language Therapy in cleft lip and/or palate is discussed in-depth. It includes a detailed description of the various aims and methods of assessment and management that form the required standard in cleft lip and/or palate care, which provide the baseline for interpretation of findings of the study.</p>
3	Methodology	The methodology chapter of the dissertation includes a detailed description of the procedure for completion of the research study. Therefore, it highlights the aims and sub-aims of the study, the research design, selection criteria and description of participants, data collection method, data collection instrument, analysis of data as well as ethical and legal considerations as well as details regarding data collection and analysis.

4	Results and Discussion	This chapter focuses on the findings of the study, deduced by the results of analysis. Results are described quantitatively for the closed ended questions, and qualitatively (discussion surrounding the emergent themes) for open ended questions. The results are then interpreted in light of current and previous literature and previous research.
5	Conclusion and Implications	This chapter provides a detailed description of the conclusions deduced from the research study, together with theoretical implications of the study, as well as implications for clinical practice. Recommendations for further research are also outlined. The limitations of the study are presented.

## 1.6. SUMMARY OF CHAPTER

Chapter One provided an overview of the background and rationale to this research study, with specific reference to international and national literature, policies and guidelines. The chapter began with aspects relating to definitions and statistical information for cleft lip and/or palate internationally and in South Africa, and furthermore described the historical perspectives on cleft lip and/or palate care. Cleft lip and/or palate care has shown significant improvements since the 1950's, the decade which it dates back to in South Africa. The South African health care system has also undergone significant change since the introduction of Primary Health Care in 1994, which was also discussed in the chapter. In addition, a description of the South African health system as related to cleft lip and/or palate care, as well as early communication intervention was described.



**CHAPTER 2**  
**CLEFT LIP AND/OR PALATE: IMPACT, EARLY INTERVENTION**  
**SERVICES, THE TEAM APPROACH, AND THE ROLE OF THE SPEECH-**  
**LANGUAGE THERAPIST**

This chapter will provide insight into the impact of a cleft lip and/or palate on the child as well as the family. Discussion in this chapter will focus on the early intervention services required by the child with cleft lip and/or palate, relating to surgical intervention, feeding difficulties, orthodontic management (as these are primary concerns) as well as general information for the family, with an emphasis on speech-language service provision.

The role of the Speech-Language Therapist and Speech-Language Therapy in cleft lip and/or palate will be discussed in depth. It will include a detailed description of the various aims and methods of assessment and management comprising the required standard in cleft lip and/or palate care, which will provide the baseline for interpretation of findings of the research study. This chapter also contains ‘anecdotal’ evidence from various local professionals in the field of cleft lip and/or palate (this information was gathered for a previous assignment in the field, and did not form part of data collection) in order to enhance information from the limited amount of literature reviews available.

**2.1. INTRODUCTION**

Infants and toddlers born with cleft lip and/or palate are at a higher risk for the development of difficulties with feeding, hearing, and communication, as well as possible problems in the caregiver-child relationship (Peterson-Falzone, Trost-Cardomone, Karnell and Hardin-Jones, 2006). Due to the diverse effects of the condition, parameters for ‘best practice’ have been developed by international organisations such as the American Cleft Palate-Craniofacial Association [ACPA] (2000). In addition, it is a standard guideline that the earlier the care for the child with a cleft lip and/or palate, the better the outcome (Kummer, 2001).

## **2.2. THE IMPACT OF A CLEFT LIP AND/OR PALATE**

### **2.2.1. The impact of cleft lip and/or palate on communication**

Communication is vital in a child's development. In children with cleft lip and/or palate, however, there is a higher risk for communication difficulties when compared to typically developing children, and the impact thereof may be seen in the following areas of communication: prelinguistic behaviour, speech (articulation), voice, resonance, language and hearing (Kummer, 2001). These are discussed in detail below.

- **Impact of a cleft lip and/or palate on vocalisations and early prelinguistic behaviours**

As a young child develops, they move toward the production of speech and speech sounds by developing their oral motor control, by vocalising, sensory integration, social interaction, mother-child interaction, as well as interaction with the environment (Owens, 2001). However, in children with cleft lip and palate, there exists a deviance in prelinguistic development.

The impact of the cleft may include delay in the emergence, variations and developing complexity of babbling, reduction in the use of consonants (particularly labial and lingual sounds), with more frequent use of nasal consonants and glottal stops, as well as alterations in mother child interaction, possibly due to psychosocial aspects related to the mother's acceptance of the structural malformation (Albery and Russell, 1994). Furthermore, it is not always possible to determine at this prelinguistic stage whether the lack of plosives is due to velopharyngeal insufficiency or other factors, such as hearing difficulties or a delay in speech sound (plosives) acquisition. However, this is a good indicator for those at risk for deviant and delayed phonological characteristics (Albery & Russell, 1994).

- **Impact of a cleft lip and/or palate on speech**

According to Albery and Russell (1994), following surgery, by eighteen months of age, children with clefts of the lip and/or palate demonstrate development with regard to the production of labial plosives as well as fricatives. Despite this there may still be deviant phonetic behaviours in their early speech patterns. Russell (1993, as cited in Albery and Russell, 1994) reports a close relationship between phonetic and phonological development in children with cleft lip and/or palate, as a delay in phonetic development may cause a delay in phonological development.

According to Trost-Cardomone (2008), cleft palate speech is frequently characterised by maladaptive compensatory articulations. These compensatory articulations may occur as substitutions, where target sounds are replaced as co-productions (a ‘double articulation), as retracted or ‘backed’ productions (e.g. alveolars produced as palatals or velars, or palatal productions produced in the velar or uvular place). These in turn may have a negative impact on the intelligibility of speech.

Thus, the speech errors of the child with cleft lip and/or palate may be placed into two broad categories, namely the obligatory problems (these have a physical basis which Speech-Language Therapists are unable to treat, e.g. obligatory nasal emission due to a fistula) and the learned problems (such as maladaptive compensatory articulations) which form part of the Speech-Language Therapists’ treatment (Trost-Cardomone, 2008).

- **Impact of a cleft lip and/or palate on voice and resonance**

According to Stengelhofen (1990), there exists high evidence of vocal fold pathologies in children with cleft palate, and hence the phonatory characteristics of a child (pitch, loudness and quality) may be affected. Furthermore, disorders of resonance are the major area of concern in children with cleft palate (McWilliams, Morris & Shelton, 1990).

Hypernasality, nasal air emission as well as the presence of facial grimacing are more often than not the resultant impact of velopharyngeal dysfunction or insufficiency (McWilliams, Morris & Shelton, 1990). Hyponasality may be caused by an obstruction in the nasopharynx, or as a result of maxillary retrusion as seen in many syndromic cases (Gopal, 2009). According to Kummer (2001) even children with cleft lip and/or palate who have undergone surgical repair of the cleft may still present with velopharyngeal insufficiency, post operative fistulas as well as incorrect, learned speech patterns.

According to Trost-Cardomone (2008) abnormal velopharyngeal closure leads to abnormal speech patterns, by affecting speech resonance and speech airflow. Excessive nasal resonance is particularly seen on vowels and sonorant consonants (glides and liquids). The presence of excess nasal emission and airflow in place of oral emission and airflow results in weaker oral pressure for those consonants requiring high pressure, such as fricatives, stops and affricates (Trost-Cardomone, 2008). Audible nasal air emission on high pressure targets may occur as substitutions or co-productions (distortions) (Trost-Cardomone, 2008).

- **Impact of a cleft lip and/or palate on language development**

Rossetti (2001) reports that the development of language may be influenced by social interaction, biological capability, cognitive capability and hearing ability. Therefore anomalies, i.e. established risk factors such as cleft lip and/or palate, have a broad effect on the development of language due to the impact of the cleft on development. Furthermore, in developing countries, aspects such as socioeconomic deprivation may play a role in language delays and disorders (Gopal, 2009).

McWilliams, Morris and Shelton (1990) report that even the earliest studies of development of communication in children with cleft lip and/or palate focused on articulation ability and the vocabulary repertoire, with little focus on other aspects of language use. One of the earliest studies of language development was conducted by Sprietersbach et al. (1958, as cited in McWilliams, Morris & Shelton, 1990). This study concluded that children with clefts had a shorter mean length of utterance as compared to typically developing children, however no difference was found in terms

of structural complexity, i.e. syntax and morphology. These children were limited in their use of vocabulary (semantics), however not limited in their recognition of vocabulary.

Many studies originating from that of Sprietersbach et al. (1958, as cited in McWilliams, Morris & Shelton, 1990) found that children with clefts scored lower than their non cleft counterparts in language development tests. However, Horn (1972, as cited in McWilliams, Morris & Shelton, 1990) acknowledged the possible contribution of hearing problems, poor caregiver-child interaction, 'overprotective parents' as well as the inferior modelling of speech to the reported language delays or deviances. McWilliams, Morris and Shelton (1990) stress that as Speech-Language Therapists, it is of utmost importance to remember the possibility of language delays and understand the need for cautious evaluation of language.

- **Impact of a cleft lip and/or palate on hearing**

Dysfunction of the Eustachian tube is a common cause of middle ear disease in children with cleft palate (Stool, 2006). The presence of a cleft palate affects the functions of the Eustachian tube, of which ventilation of the middle ear is most important. This dysfunction may arise as a result of the Eustachian tube being obstructed, or by infection caused through reflux (due to the cleft) from the nasopharynx into the middle ear. Therefore, in the child born with a cleft palate, who may in all probability have some difficulty with speech production, the long term effects of otitis media are far more serious (Stool, 2006). The presence of Eustachian tube dysfunction leads to fluctuating conductive hearing loss, which, in addition to the structural defect, compounds speech and language difficulties (Royal College of Speech and Language Therapists, [RCSLT], 2005). This is due to the importance of consistent auditory input for language development. However, in a child with fluctuating hearing loss, they are likely to be missing out on frequent episodes of language input (McWilliams, Morris & Shelton, 1990).

### **2.2.2. The impact of a cleft lip and/or palate on feeding**

Early feeding difficulties are a frequent occurrence in children with cleft palate, due to the absence of separation between the oral and nasal cavities. In addition, a cleft palate affects the child's ability to create adequate intra-oral pressure to create a suck that expresses milk from the breast or bottle (Peterson-Falzone et al., 2006). Wolf and Glass (1992) also report the possibility of dental and orthodontic difficulties which may affect feeding. In addition to difficulty sucking, problems with regard to poor intake of the feed, nasal regurgitation, choking, gagging, reflux into the middle ear as well as excessive air intake are reported (Wolf & Glass, 1992). This would require adaptations in the presentation of feeding, areas of caution such as proper positioning of the infant, as well as the possibility for using modified feeding teats or bottles, dependant on type (e.g. lip or palate) or combination of cleft (e.g. lip and palate) (Peterson-Falzone et al., 2006).

### **2.3. EARLY INTERVENTION SERVICES REQUIRED BY THE CHILD WITH CLEFT LIP AND/OR PALATE**

Six areas of early intervention for children with cleft lip and/or palate will be discussed. These are early surgical intervention, early feeding intervention, early dental/orthodontic intervention, early audiological intervention, early speech-language intervention as well as general information for the family.

#### **2.3.1. Early Surgical Intervention**

Surgical intervention for the child with cleft lip and/or palate is vital within the first year of his/her life (Lazarus, 2009). However, the surgery required may be confounded by the physical growth and development of the oral structures. A parallel relationship exists between surgery and development, as the surgery may profoundly affect growth, and, similarly, growth may profoundly affect the seemingly 'perfect' surgical results (Shons, 1993). For this reason, cleft lip and/or palate requires essential, long term follow up until the age of twenty, where the final results of numerous surgical procedures can be appreciated (Shons, 1993). According to the ACPA (2000), the primary surgery required by the child with cleft lip and/or palate is

the closure of the lip and palate. Surgical repair of the cleft lip should be undertaken in the first six months of life, i.e. as early as possible that is safe for the infant. The repair of the palate should be completed by the age of eighteen months, preferably earlier if possible (ACPA, 2000).

The guidelines for surgery in both public and private health sectors in KwaZulu-Natal are similar in nature. This includes a lip repair at three months of age, palate repair at nine months of age and an alveolar bone graft at eight to eleven years of age (Madaree, A., personal communication, July 24, 2009<sup>2</sup>). However, different centres utilise different protocols, which generally follow the required standard (Singh, S., personal communication, August 1, 2009<sup>3</sup>). These standards (ACPA, 2007) with regard to the timing of surgery by all surgeons in public and private health are clearly delineated, as well as the need for dental and speech-language intervention. Families may be provided with choices through the collaborative nature of intervention; however, ultimately the timing for each form of intervention adheres to strict schedules (Berkowitz, 1999). According to Lazarus (2009), a private plastic surgeon in Cape Town, intra-uterine surgery for those clefts detected in utero is a possibility that carries far too many risks, such as miscarriages or severe bleeding. This is therefore not considered an option in surgical intervention. Usually in the private sector, the child is seen shortly after birth, where counselling and reassurance is given to the parents by the professionals involved (Lazarus, 2009). A palatal plate may be made by the orthodontist, and discussions on treatment are held. The repair of the lip and/or palate is completed at six to nine months of age, utilising general anaesthesia and strong painkillers following surgery (Lazarus, 2009). The child is usually discharged from the high care unit a few days after surgery, after which regular Plastic Surgeon, Orthodontist, Audiology, and Speech–Language Therapy ‘check ups’ occur. After this early surgical intervention, later surgery may be indicated in the case of a cleft of the gum (alveolus), bone transplants and minor corrections of previous surgery may occur at nine years of age, and corrective surgery for the jaw or nose may be completed in the late teen years (Lazarus, 2009).

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<sup>2</sup> Head of plastic and reconstructive surgery at the Nelson Mandela School of Medicine, 2009

<sup>3</sup> Orthodontist in public and private health, 2009

Interestingly, in the case of a child born with a cleft lip and/or palate as part of a syndrome, the orofacial defect is not always the primary surgical concern. Many children born with syndromes present with more severe conditions such as heart defects, hence heart surgery, as one would expect, is considered a priority (Speech-Language Therapist 1., personal communication, October 19, 2009<sup>4</sup>).

On the topic of early surgical intervention, it should be noted that cultural influences and diversity play a major role in the stages at which a child may receive intervention, as the South African context is unique, one that is a vibrant mixture of races, languages and culture (de Jager, Fouchè & Majozi, 2008). The South African population consists of four race groups, comprising approximately 79.6% African, 9.1% White, 8.9% Coloured, and 2.5% Indian/Asian (South Africa. Info, 2007). Each of these individuals is primarily a South African; however they belong, within their racial groups, to different religions, cultures and systems, and each has their own personal identity. For example, the belief by certain families that the cleft is ‘God’s will’ or that traditional healing is best may hinder the family’s beliefs in the need for surgery and modern medicine (Dagher & Ross, 2004).

### **2.3.2. Early Feeding Intervention**

Early feeding difficulties are a frequent occurrence in children with cleft palate, due to the absence of separation between the oral and nasal cavities. In addition, a cleft palate affects the child’s ability to create adequate intra-oral pressure to create a suck that expresses milk from the breast or bottle (Peterson-Falzone et al., 2006). The importance of feeding is reported in a study by Young, Riordan, Goldstein and Robin (2001), where parents viewed feeding information as critical, possibly as this was the earliest difficulty they experienced.

In 2002, the World Health Assembly (WHA) adopted the Global Strategy for Infant and Young Child Feeding. Through the review of this international document, the South African National Department of Health was prompted to develop the National Infant and Young Child Feeding Policy (Department of Health [DOH], 2007a). In

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<sup>4</sup> Speech-Language Therapist in private practice in KZN in 2009 (Name has been excluded to ensure confidentiality)



1991, the Baby Friendly Hospital Initiative was launched globally. In South Africa, 140 of the 480 maternity facilities were declared baby friendly by 2004 (Department of Health, 2007b).

The baby friendly approach supports the adoption of exclusive breastfeeding practices in health facilities, followed by sustained breastfeeding for two years, with the introduction of safe complementary foods at six months of age (United Nations Children's Fund [UNICEF] & WHO, 2006). This baby friendly approach is supported, as evidence suggests that exclusive breastfeeding compared to mixed feeding results in reduced incidence of diarrhoea, respiratory infections as well as allergies. There is also strong evidence to suggest that exclusive breastfeeding reduces the risk of obesity and chronic diseases such as cardiovascular disease (UNICEF & WHO, 2006).

In addition to benefits of exclusive breastfeeding for infants up to six months of age, the high prevalence of Human Immunodeficiency Virus (HIV) in South Africa must be considered. As breastfeeding is considered to be the causal factor for half to one third of HIV infections in African countries (Swanepoel, 2004), allowing a baby with a cleft lip and/or palate, where possible, to feed via breast would increase the risk of mother to child transmission of HIV. This can therefore be seen as a major critique of the Baby Friendly Initiative, as, in a country which holds one of the world's highest infection rates of HIV (Guinea, 2008), exclusive breastfeeding, despite its advantages, may place the newborn at risk for further complications by contracting the virus. Furthermore, where hospitals adopt a baby friendly approach, it may be problematic for infants requiring specialised teats to have access to these due to the exclusive breastfeeding approach. However, despite such controversy there is significant information that exclusive breastfeeding has a lower risk of mother to child transmission of HIV than does mixed feeding, and hence the policy can be seen in a positive light (UNICEF & WHO, 2006). In addition, there is minimal risk of only four percent of postnatal transmission of the virus in the instance of exclusive breastfeeding, whereas infant mortality in the first three months of life is almost double when replacement feeding is used (UNICEF & WHO, 2006).

Despite the National Rehabilitation Policy (Department of Health, 2000a) stating that immediate access to feeding and swallowing assistive devices (such as those which may be needed by infants with clefts of the lip and/or palate) be guaranteed, this is not always the case in the public setting. At certain public institutions, the application for a non stock item (NSI), which includes assistive devices for feeding, requires approval and a signature from the medical superintendent, before being submitted to a cash flow committee where the decision to purchase the item will be made (Speech-Language Therapist 2, personal communication, July 1, 2009<sup>5</sup>). This procedure, in contrast to the policy of ‘instant access’, takes approximately three to four weeks.

This is of concern, as this may lead to the mother and infant with cleft lip and/or palate being discharged from the hospital before receiving the required assistive device, or before receiving related information and skills. In addition, the National Rehabilitation Policy states that a signature from a medical superintendent is not necessary, which is in contrast to the actual hospital practice. In more rural based public hospitals, advice is given to the mother of the infant, and the onus is upon her to purchase the teat at the nearest pharmacy or store to the area (Speech-Language Therapist 3, personal communication, August 14, 2009<sup>6</sup>).

However, in certain hospitals, the provision of assistive feeding teats is not viewed as a major obstacle, and in severe cases, a nasogastric tube is inserted (Speech-Language Therapist 4, personal communication, July 28, 2009<sup>7</sup>). However, the insertion of a nasogastric tube, which is common in settings where feeding intervention is unavailable, is of concern. According to Peterson-Falzone et al. (2006), nasogastric tubes bypass the oropharyngeal mechanism, hence inhibiting the development of an adequate suck-swallow-breathe pattern. The prolonged use of such a tube may cause even greater, long-term feeding and swallowing problems (Peterson-Falzone et al., 2006). It is therefore recommended that such methods are reserved for emergencies and only for severely compromised infants.

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<sup>5</sup> Speech-Language Therapist in the public health sector of KZN in 2009 (Name has been excluded to ensure confidentiality)

<sup>6</sup> Speech-Language Therapist in the public health sector of KZN in 2009 (Name has been excluded to ensure confidentiality)

<sup>7</sup> Speech-Language Therapist in the public health sector of Western Cape in 2009 (Name has been excluded to ensure confidentiality)

Despite the importance of the Speech–Language Therapist in the early feeding care of the infant with a cleft lip and/or palate, this professional may not always be available at the required time (Speech-Language Therapist 2., personal communication, July 10, 2009). The Speech–Language Therapist is usually responsible for developmental or acquired disorders of feeding and swallowing assessment and intervention (HPCSA, 2005), as the anatomy used in both feeding and speech is the same (Peterson-Falzone et al., 2006). However, many families may receive feeding counselling from their individual practitioner (such as the plastic surgeon or paediatrician) who is not always prepared to give information and advice on feeding (Peterson-Falzone et al., 2006). In the majority of settings, this could be attributed to staff shortage or inadequate referral. The result of this may be that infants with feeding difficulties may be compromised, and follow up appointments need to be arranged on discharge. Furthermore, referrals may be received at a time when the Speech-Language Therapist is not present at the particular institution, resulting in the patient being discharged before consultation.

In certain settings, such as a public institution in Gauteng where a cleft lip and palate team clinic is present, the provision of modified teats for cleft palate infants is easily accessible, as these assistive devices are regularly ordered and kept as ward stock items. In this case, the initial teat is given to the family, with instructions that, in the case of a new teat being needed it may be purchased at the family's own cost (Speech-Language Therapist 5, personal communication, October 21, 2009<sup>8</sup>). However, according to findings by Dekker (2007), four of the seven Speech–Language Therapists who participated in her study felt that local material and apparatus such as feeding bottles should be more readily available to improve service delivery.

### **2.3.3. Early Dental/Orthodontic Intervention**

As a result of the medical condition, many children with cleft lip and/or palate from birth to three years of age will require specialised dental care, not only on a primary level, but as routine maintenance throughout their lifespan (ACPA, 2000).

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<sup>8</sup> Speech-Language Therapist in Gauteng Department of Health in 2009 (Name excluded to ensure confidentiality)

In many cleft centres, the orthodontist is usually a vital member of the team, responsible for both regular dental care, as well as special prosthetic needs such as a palatal obturator (Peterson-Falzone et al., 2006). However, in South Africa, the provision of a palatal obturator at birth for more efficient feeding at hospitals is not always funded, and is often voluntarily funded by the orthodontist involved (Singh, S. personal communication, August 4, 2009).

In addition to the possible need for prosthetic appliances, the American Academy of Paediatric Dentistry (2008) report on the importance of monitoring of dental and facial growth, monitoring for malocclusion, as well as close monitoring for possible dental or periodontal disease.

### **2.3.4. Early Audiological Intervention**

Dysfunction of the Eustachian tube is a common cause of middle ear disease in children with cleft palate (Stool, 2006). The presence of Eustachian tube dysfunction leads to fluctuating conductive hearing loss, which, in addition to the structural defect, compounds speech and language difficulties (RCSLT, 2005).

Speech–Language Therapists working in the public sector in South Africa have reported that referrals for audiological evaluations occur where necessary, i.e. when a hearing difficulty is suspected, or via a medical referral (Speech-Language Therapist 6., personal communication, August 19, 2009<sup>9</sup>). However, in certain rural hospitals, audiological equipment is unavailable, and the therapist relies on report and informal observations to determine the need for a referral for an audiological evaluation (Speech-Language Therapist 7., personal communication, September 27, 2009<sup>10</sup>). It therefore appears that the trend in the public sector is for the Speech-Language Therapist to monitor the child regularly and refer for audiological evaluations. This could also be related to their knowledge that cleft palates are frequently associated

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<sup>9</sup> Speech-Language Therapist in KZN Department of Health in 2009 (Name excluded to ensure confidentiality)

<sup>10</sup> Speech-Language Therapist in KZN Department of Health in 2009 (Name excluded to ensure confidentiality)

with middle ear infections, hence the need for regular audiological evaluations (Speech-Language Therapist 8., personal communication, October 19, 2009<sup>11</sup>).

Despite certain institutions running weekly neonatal audiological screening clinics for high risk infants, babies born with clefts are not always referred for the screening. The breakdown thus appears to be at the level of the actual birth, as all other high risk babies, such as those born prematurely, are regularly referred (Speech-Language Therapist 8., personal communication, October 19, 2009). This appears to be in contrast to the private sector, where all babies placed on a high risk register are screened at the hospital in the ward, and, if referred, are usually seen every ten weeks for screening purposes (Speech-Language Therapist 1., personal communication, October 10, 2009). On consultation with an audiologist in the private sector, it was reported that, in the area of KwaZulu-Natal, the number of children with cleft palate attending regular audiological evaluations has decreased. This may be due to the low incidence of this condition, or that few plastic surgeons specialising in cleft lip and/or palate work in the private sector in KwaZulu-Natal. Many of these patients therefore travel to Gauteng, where certain public institutions also cater for the private or medical scheme funded patients (Speech-Language Therapist 1., personal communication, October 19, 2009).

Further feedback from professionals in the field is that, in the case of infants referred to hospitals, where a monthly cleft lip and/or palate clinic is held, infants are regularly screened by the Audiologist at monthly clinics as part of the cleft lip and palate protocol utilised at this institution (Speech-Language Therapist 9., personal communication, September 29, 2009<sup>12</sup>). At a public hospital in Gauteng, a cleft lip and palate clinic is held monthly, where Audiology bookings are regularly made for children where necessary (Speech-Language Therapist 5., personal communication, October 21, 2009). However, where neonatal screening is required, neonates born with clefts are referred elsewhere as the necessary equipment is unavailable (Speech-Language Therapist 5., personal communication, October 21, 2009). Dekker (2007)

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<sup>11</sup> Speech-Language Therapist in KZN Department of Health in 2009 (Name excluded to ensure confidentiality)

<sup>12</sup> Speech-Language Therapist in KZN Department of Health in 2009 (Name excluded to ensure confidentiality)

found that follow up services for children with cleft lip and/or palate are based on speech rather than hearing or education, which is of concern as the frequency of middle ear pathology with cleft palate is a significant factor requiring appropriate referral and follow up (ACPA, 2007).

### **2.3.5. Early Speech-Language Intervention**

According to the World Health Organisation (1978), speech, language, hearing and dysphagia/feeding programmes should be provided along a continuum of care, from primary through to secondary and tertiary levels of intervention (SASLHA, 2008). Children born with craniofacial anomalies such as cleft lip and/or palate are at risk for developing speech-language disorders, which form part of the secondary level of intervention where the ‘disease’ has already been identified (De Haan, 2001).

According to Witzel (1991), approximately 25% of children who had undergone repair of the palate developed normal speech spontaneously, whereas the remaining 75% percent required Speech–Language Therapy in childhood as well as adolescence. The etiology of these speech problems may lie in a number of factors, including “abnormal oronasal structure and function, abnormal oronasal structure and growth, abnormal neuromotor development or abnormal or disturbed psychosocial development” (Hodgkinson et al., 2005, p. 19). It should also be noted that a proportion of children with cleft lip and/or palate may also exhibit the same developmental language and phonological disorders exhibited by typically developing children (Hodgkinson et al., 2005). The Speech–Language Therapist is therefore a vital member of the transdisciplinary team involved in cleft care, with the responsibility of assessing and monitoring the child’s speech and language from birth to the culmination of treatment efforts, which usually spans up until the age of twenty years (Hodgkinson et al., 2005). With the possible exception of isolated cleft lip, the Speech–Language Therapist also holds the responsibility of compiling speech–language records annually up until the age of four years (American Cleft Palate Craniofacial Association, 2000). However, at certain public institutions, at the birth of a baby with a cleft lip and/or palate, the Speech–Language Therapist is only called to the ward in the case of a feeding difficulty. Where a difficulty with feeding is not present, the neonate is referred to the institution’s cleft lip and palate clinic, where he

or she will be seen on a monthly basis, or referred to their nearest institution offering Speech–Language Therapy services as per the institution’s catchment area policy (Speech-Language Therapist5, personal communication, October 21, 2009).

Van de Linde (2008) reports that developing countries such as South Africa need to determine priorities, including that assessment and management services for young children with impairments (such as cleft lip and/or palate) should be developed. The absence of Speech-Language Therapists in the cleft team or at the health institution therefore leads to service delivery that appears fragmented, as all functions of the Speech-Language Therapist are not optimally utilised. These functions occur at two stages, namely assessment and management (RCSLT, 2005). The assessment phase involves early monitoring, assessment of speech and language, collaboration with audiologists (in the case of concerns regarding hearing) and assessment of velopharyngeal function. The management phase involves the Speech-Language Therapist playing an early advisory role to parents, partnership with parents, feeding support, as well as management of phonological, articulatory and the speech consequences of velopharyngeal dysfunction (RCSLT, 2005). However, according to Hodgkinson et al. (2005), in the absence of the Speech–Language Therapist, the institution nurse or ward nurse may be trained to provide necessary information.

Overett and Kathard (2006) conducted a study to document the outpatient profiles of Speech–Language Therapy and Audiology clients at a public tertiary hospital in the Western Cape. The motivation for the study was that, in South Africa, although health services are essential, these services fail to reach many South Africans due to a lack of resources. The demographics in South Africa are such that many Speech–Language Therapists are based in urban areas, with few venturing into practice in rural areas. The study reports that many parents have been told by health professionals ‘not to worry’ about their child’s communication difficulties, as they would ‘grow out of them’. This is what leads to many children missing out on early intervention services and only being discovered at school level, particularly due to communication difficulties being less visible as compared to physical handicaps (Overett & Kathard, 2006). This could be related to the fact that the zero to six year age group made up only 7.58% of the Speech-Language Therapy and Audiology department’s clientele.

However, in the case of cleft lip and/or palate, the condition is visible and one hopes that this would lead to children with cleft lip and/or palate receiving intervention as early as possible, and continuing as long as necessary. Reasons for poor attendance of the zero to six year age group for Speech-Language Therapy may be due to language barriers, as the therapists at this hospital were mainly English or Afrikaans speaking, resulting in limited provision of services to the Xhosa speaking population (Louw, Shibambu & Roemer, 2006). Cultural reasons may also be a reason for services not being accessed, as different cultural groups vary in their perceptions of disorders and therapeutic interventions (Louw, Shibambu & Roemer, 2006). In the case of cleft lip and or/palate, a reason for not attending therapy may be that the cleft is repaired and the child presents with little or no speech difficulties related to the cleft. Due to this, many children who still present with general phonological delays may be ‘missed out’.

With regard to private versus public provision of Speech–Language Therapy services, Roulstone et al. (2004, as cited in Overett & Kathard, 2006) found that nearly 18% of public sector appointments were cancelled, whereas Klop (1998, as cited in Overett & Kathard, 2006) found that only two of her sixty four private based clients dropped out of therapy. This example illustrates the possible influence of contextual factors on service provision. Interestingly, due to the low incidence of cleft lip and/or palate births in KwaZulu-Natal, some private Speech–Language Therapists have reported that they have not had cleft lip and/or palate clients, despite many years of practice (Speech-Language Therapist 10, personal communication, October 6, 2009<sup>13</sup>).

The specific roles and duties of the Speech-Language Therapist in the assessment and management of children with cleft lip and/or palate from birth to three years of age will be discussed later on in this chapter.

### **2.3.6. General Information for the family**

Informing the parents and family about the young child with a cleft lip and/or palate is a difficult process for most professionals; however it is nonetheless crucial to provide

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<sup>13</sup> Speech-Language Therapist (private practice) in KZN in 2009. Name has been excluded to ensure confidentiality.



them with clear, precise and easy to understand information (Bellardie and Harris, 2008). Providing leaflets about cleft lip and/or palate to the parents also increases their retention of information (Bellardie and Harris, 2008).

In South Africa, public and private hospitals consulted have reported that, where necessary, information on cleft lip and/or palate is available. The structure and content of information packages vary between settings, from merely a discussion with parents, to simple pamphlets through to booklets of information. At certain institutions, diagrammatical information is used in the initial explanation of the condition to the parents (Speech-Language Therapist 3, personal communication, September 10, 2009), whereas in institutions where a cleft lip and palate clinic is held (such as one public institution in Gauteng), the book 'Michael has a cleft lip' is distributed (Speech-Language Therapist 5, personal communication, October 21, 2009). According to Young, Riordan, Goldstein and Robin (2001), the provision of written or diagrammatical information increases levels of parental satisfaction with health care professionals, and the level of dissatisfaction with their initial medical consultation lessens.

Young, Riordan, Goldstein and Robin (2001) reported that, typically, during the baby's first day of life (i.e. early intervention), parents felt that basic information about cleft lip and/or palate is needed, and that the more complicated information could wait. They also felt that information on etiological aspects, genetic basis and actual repair of the palate ranked low in importance, whereas feeding information was viewed as critical. In the optimal setting of a craniofacial clinic, the 'checklist' for information to cover with parents includes using the correct terminology (i.e. cleft lip and/or palate and not lay terms), feeding difficulties, demonstrations of breast and bottle feeding, demonstration of the baby's positive physical features, explanations that the cleft is not the fault of the parents, reassurance that their child is in no form of pain, information on the signs and symptoms of illness, as well as the arrangement of follow up appointments with the necessary specialists for issues that may be deferred in the newborn period (Young, Riordan, Goldstein & Robin, 2001).

In a recent study by Bellardie and Harris (2008), eleven percent of parents of a child born with a cleft at the Red Cross Children's hospital in Cape Town felt that they had

not been given adequate information during the first few days. Eighty eight percent of parents appreciated the reassurance they received with regard to treatment of the condition. Interestingly, some parents interviewed suggested that real photographs of other children should be used instead of diagrams. Parents also suggested that the information leaflet given should include more information on genetics as well as counselling and support groups (Bellardie & Harris, 2008).

A study by Louw, Shibambu and Roemer (2006) investigated cleft palate team participation of culturally diverse families in South Africa. The study showed the importance of consultation, as prior to team consultation the majority of participants had no prior knowledge of cleft lip and/or palate. For those participants who still displayed limited knowledge following consultation, this was attributed to much of the information being verbally presented with written material scarcely available in African languages. An implication of this study was that language and literacy barriers be overcome through the use of visual sources such as diagrams and pictures, and that families are reminded of their importance in the cleft palate team, and encouraged to voice their concerns or queries.

#### **2.4. THE ROLE OF TEAMS IN EARLY INTERVENTION FOR CLEFT LIP AND/OR PALATE**

According to Peterson-Falzone, Hardin-Jones and Karnell (2001), Peterson-Falzone et al. (2006) and the ACPA (2000), the only manner in which the impact of a cleft palate on a child may be effectively managed is through a multidisciplinary team approach to intervention. Of importance is that early surgical repair of the cleft is associated with the best possible outcome for speech development (Peterson-Falzone, Hardin-Jones and Karnell, 2001). However, in a developing country such as South Africa, a major challenge may be the coordination between early surgical repair and the availability of an interdisciplinary team (Gopal, 2009). The actions of various non profit organizations, such as Operation Smile and The Smile Train allow for international or national surgeons to visit developing countries and perform surgery in the public sector (Gopal, 2009), thus helping to alleviate such challenges.

The application of a team approach to cleft lip and/or palate intervention improves the level of care provided for the child, as well as the preparedness of different team members to pool their thoughts and efforts in a multidisciplinary team (Berkowitz, 1999). The cleft team includes, but is not limited to, craniofacial surgeons, plastic surgeons, orthodontists, ear nose and throat specialists, speech-language therapists, audiologists, paediatricians, dieticians, as well as social workers (Berkowitz, 1999). In addition, as the psychological care of a patient with a cleft lip and/or palate begins with diagnosis, the involvement of a specialist psychologist is becoming increasingly apparent in the field (Hodgkinson et al., 2005). Furthermore, although the exact etiology of cleft lip and/or palate is largely unknown, there are over four hundred syndromes which include the condition as a primary or secondary component (Hodgkinson et al., 2005). The presence of a syndrome with a genetic basis therefore requires the involvement of another professional, the geneticist. This is further emphasized by Hofstee, Kors and Hennekam (1993), who report that all multidisciplinary cleft teams require the expertise or membership of at least one person to undertake a full examination into features for dysmorphism or genetic occurrences. With the institution of a team approach, the plan for care is generally more cost effective, including better follow up care and monitoring aspects.

According to Dekker (2007), many South African universities have attached to their facilities multidisciplinary cleft units or centres. These include: The University of Kwa-Zulu Natal at Grey's Hospital and Inkosi Albert Luthuli Hospital; the University of Witwatersrand at Johannesburg General Hospital; the University of Limpopo in Garankua; the University of Pretoria at Die Tand en Mond Hospitaal; the University of Stellenbosch at Tygerberg Hospital as well as the University of Cape Town at Red Cross Children's Hospital. The first team to be established was in 1958 in the Western Cape, which indicates that cleft care in South Africa has come a long way, with much chance for further development (Dekker, 2007).

Further investigation into the cleft teams of South Africa by Dekker (2007) found that cleft teams in the country have approximately four hundred new patients and one thousand seven hundred follow-up patients annually, indicating a significant number of children with cleft lip and/or palate in the country. However, these teams are urban based and only in four provinces of the country, which negatively affects service

delivery, as much of South Africa resides in more rural areas, and hence travel quite a distance to receive services (Dekker, 2007). It should be noted, however, that the teams in these four provinces service patients from all nine provinces as well as from neighbouring countries.

The composition of these cleft teams in South Africa is in accordance with the American Cleft Palate Association guidelines (Dekker, 2007), with the Speech–Language Therapist included in every team. Four of the teams have interpreters as important members, which thus caters for cultural and linguistic differences. Intervention is provided in six of South Africa’s eleven official languages. However, the interpreter is not always available. This therefore indicates that the language difference is an important barrier which may hinder the effective provision of Speech–Language Therapy services for population with the cleft lip and/or palate.

All therapists consulted with regard to the involvement of other professionals in the care of infants with cleft lip and/or palates have reported that referrals to these professionals occur as and when necessary, such as to Audiologists. This appears practical as in most institutions the primary members of the ‘ideal’ team are consulted when a birth of an infant with a cleft lip and/or palate occurs. At certain institutions, following the initial Speech–Language Therapy consultation, the patient may be kept on as a regular outpatient or referred to the nearest public service Speech-Language Therapy department for follow up care (Speech-Language Therapist 5., personal communication, October 7, 2009).

## **2.5. THE ROLE OF THE SPEECH-LANGUAGE THERAPIST IN THE ASSESSMENT AND MANAGEMENT OF CHILDREN WITH CLEFT LIP AND/OR PALATE FROM BIRTH TO THREE YEARS OF AGE**

### **2.5.1. Assessment**

The Speech-Language Therapist plays a vital role on the multidisciplinary team, with specific focus on the assessment of communication (speech and language), oral motor function and feeding. The results of the assessment provide baselines for the evaluation of management efforts, the outcome of treatment as well as for clinical

audits (ACPA, 2000). The table below shows the areas and stages of communication assessment.

**Table 2.1.: Areas for assessment of communication and the stages at which each area may be assessed in the 0-3 year age range**

Area/s	Stages		
	Neonatal (0-1 month)	Infancy (1-12 months)	Toddlerhood (12-36 months)
Case history	*	*	*
Feeding	*	*	*
Hearing/Listening	*	*	*
Communication interaction and pragmatics	*	*	*
Emergent literacy	-	*	*
Oral motor examination	*	*	*
Speech and language	-	*	*

*Adapted from Gopal (2009, p. 62)*

*Key: \* requires assessment at this stage*

*- does not require assessment at this stage*

According to Gopal (2009), the areas of assessment remain largely the same for the three stages of assessment, however, the methods, level and manner of assessment should be adapted for each age range, or rather, for each child. The areas specific to the Speech-Language Therapist's role are discussed below.

### **2.5.1.1. Case History**

The case history is a standard procedure, usually the first stage of assessment for the child at any age. The typical areas included in the case history are: pre and post natal development, medical history, hearing history, feeding and swallowing history, family history and family dynamics, socio-emotional history, educational history,

early literacy, speech-language history as well as information on previous assessment and therapy where required (Hegde & Davis, 1995). Of particular importance to cleft lip and/or palate should be questions related to medical and surgical intervention, feeding, hearing history, family history and genetics as well as speech and language.

#### **2.5.1.2. Hearing Ability**

The ACPA (2000) states that the assessment of hearing status in children with cleft lip and/or palate is vital, secondary to the high incidence of middle ear disease in these children (Stool, 2006). Furthermore, as hearing loss may impact on speech-language development, a differential diagnosis of hearing loss is required. According to Gopal (2009), at the neonatal stage, the ears should be examined for physical features such as atresia by the medical or health professional, and newborn hearing screening should be conducted by an Audiologist or Speech-Language Therapist and Audiologist. In the infant stage, bilateral hearing sensitivity should be investigated. From the infant stage continuing into the toddler years the Audiologist should ensure regular monitoring of the child's hearing status as well as middle ear functioning due to the high possibility of recurring middle ear infections. Furthermore, the ACPA (2000) recommend annual hearing evaluations.

#### **2.5.1.3. Oral motor examination**

An insufficient velopharyngeal mechanism, oronasal fistulas, dental and occlusal problems (all of which are common in children with a cleft palate) as well as any other structural deficits may place the child at a considerable disadvantage in terms of speech development (Stengelhofen, 1990).

Orofacial structures, i.e. the client's face, jaw and teeth, lips, tongue, pharynx and hard and soft palates should be examined (Shipley & McAfee, 2008). Furthermore, details on the cleft itself should be ascertained. These include the type of cleft (lip and/or palate), adequacy of cleft repair (good/fair/poor), the absence or presence of other facial abnormalities, the presence or absence of a submucosal cleft, presence or absence of, location and patency of fistulas (labiodental, alveolar, palatal or velar), perceived length of the velum, perceived depth of the nasopharynx, the shape of the

alveolar ridge (notched/wide/cleft/collapsed), as well as the possible presence of a bifid uvula, or absent uvula (Peterson-Falzone et al., 2006). Tonsil size and position should also be observed in case of possible obstruction (Peterson-Falzone et al., 2006).

In addition to the above, Gopal, (2009) suggests the evaluation of orofacial structures and oral motor function, at the neonatal, infant and toddler stages of life. During the neonatal stage, the Speech-Language Therapist who forms an important part of the team assists in obtaining a baseline description of the type and severity of the cleft lip and/or palate, the possible impact of the cleft on later speech production as well as feeding difficulties the child may encounter. This assessment may occur slightly later than at birth where the doctor or midwife may screen the neonate's facial features (Gopal, 2009). During the infant stage, Gopal (2009) states that the Speech-Language Therapist should describe the facial features of the infant which may link to a possible genetic syndrome, hence collaborating with the geneticist, paediatrician or neonatologist where indicated. Repair of the cleft may also be undertaken at this stage, hence the Speech-Language Therapist should note the accuracy and adequacy of the cleft repair post operatively. An evaluation of oral motor structures and function should also occur at the toddler stage, as well as factors that may require further surgery, e.g. a palatal fistula. The table below summarises the aspects of an oral motor examination for a child with a cleft lip and/or palate.

**Table 2.2.: Oral motor examination for a child with cleft lip and/or palate (Summary)**

<b>Stage</b>	<b>Method (may vary dependant on therapist)</b>	<b>Equipment (includes but is not limited to)</b>
Neonatal	<ul style="list-style-type: none"> <li>• Observations of the lips, tongue, palate and respiratory system to determine the presurgical status of the cleft, as well as its type and severity</li> </ul>	Gloves, penlight torch, tongue depressor, laryngeal mirror
Infant	<ul style="list-style-type: none"> <li>• Observations of the cleft following repair</li> </ul>	Gloves, penlight torch, tongue depressor,

	<ul style="list-style-type: none"> <li>• Imitation of movements of oral structures and non-speech tasks</li> </ul>	laryngeal mirror
Toddler	<ul style="list-style-type: none"> <li>• Observations of the cleft following repair</li> <li>• Imitation of oral movements</li> <li>• Non speech tasks such as smiling and blowing kisses</li> <li>• Speech tasks such as diadochokinetic rates or the ability to coordinate syllable sounds</li> <li>• Testing for hypernasality and nasal emission</li> </ul>	Gloves, penlight torch, tongue depressor, laryngeal mirror, mirror to test nasal emissions

#### 2.5.1.4. Feeding Evaluation

Following the assessment of oral motor skills, the Speech-Language Therapist should conduct an assessment of the child’s feeding abilities, dependant on the child’s age. The Speech-Language Therapist plays an important role, together with the nurses and medical doctor in evaluating the child’s ability in terms of feeding. Children with clefts are at risk for difficulty with feeding, especially before repair of the cleft. Children with cleft palate may have problems with feeding as the normal anatomy of the oral cavity is compromised (Stengelhofen, 1990).

“Early feeding difficulties and pre-surgical orthodontic treatment will influence the intra-oral physiology which is the basis for later speech development” (Stuffins, 1984, cited in Stengelhofen, 1990, p. 65). According to Arvedson and Brodsky (2002), the evaluation of feeding should occur at three stages, namely the neonatal stage, infant stage and toddler stage. All aspects of feeding should be considered at all stages, in addition to the difficulties commonly seen in cleft lip and/or palate, such as increased feeding time. As the child grows, other aspects such as self feeding are considered (Wolf & Glass, 1992). During the assessment of feeding at the neonatal stage, the clinician should evaluate oral sensory-motor development, the availability of nutritional food as well as parent-child interaction. Uys’s (2008) feeding evaluation



for the at risk infant looks at the following areas: medical history, current state and behaviour of the infant, physical examination, oral feeding history, mother and child interaction during feeding, oral structures at rest, as well as the functioning of the oral structures during the oral and pharyngeal stages of swallowing, particularly with regard to non nutritive and nutritive sucking. Observations regarding the oesophageal stage of swallowing are also included. With regard to cleft lip and/or palate, of particular importance is the ability to maintain a latch and seal during breast or bottle feeding, and the possibility of nasal regurgitation secondary to the cleft of the palate (Wolf & Glass, 1992).

At the infant stage, children are usually progressing from breastfeeding or bottle feeding to the puree/soft diet (Arvedson & Brodsky, 2002). This stage requires an evaluation of the infant's tongue movements, pre-chewing skill, as well as the ability to propel the bolus from anterior to posterior.

During toddlerhood, evaluation of feeding and swallowing should include assessment of lip closure, chewing function, anterior-posterior propulsion of the bolus as well as the pharyngeal stage of swallowing (Arvedson & Brodsky, 2002). The evaluation of feeding and swallowing should always consider the child's nutritional status, i.e. weight gain, which thereby indicates collaboration with a dietician (Gopal, 2009).

There are a number of protocols for feeding evaluations available commercially, such as McCurtin's (1997) *Feeding Assessment Checklist*. Research studies have also resulted in feeding evaluation resources, such as Uys's (2008) *Feeding evaluation form for at risk infants*. These protocols are developed for general feeding evaluations and are not cleft specific.

In addition to the discussion on subjective instruments above, there exist objective assessments for the infant and toddler, such as fiberoptic endoscopic evaluation of swallowing (FEES) as well as Videofluoroscopy. These may be used either routinely or in exceptional circumstances, dependant on the institution as well as whether equipment and trained personnel are available (Speech-Language Therapist 6., personal communication, August 19, 2009).

#### **2.5.1.4. Communication (Speech, Language, Voice and Resonance)**

##### **2.5.1.4.1. Speech Assessment**

According to Gopal (2009) the assessment of the child with cleft lip and/or palate speech sound system may be either perceptual (subjective) or instrumental.

At the infant stage, the Speech-Language Therapist is usually concerned with the ability of the child to vocalise and babble, and, if so, the repertoire of pre-speech sounds used (Gopal, 2009). During toddlerhood, an assessment of the child's speech sound system generally includes the Speech-Language Therapist eliciting a speech sample, at both word and connected speech levels, and determining the phonetic inventory as well as subjective intelligibility of the toddler. Shipley and McAfee (2008) state that speech samples are especially important in diagnosing disorders of speech production, and conversational samples are more representative of how the child usually speaks in the natural environment. Stimulability testing should also be conducted, to determine whether the client's productions can be improved when given a model, instructed or when prompting of the articulators occurs (Shipley & McAfee, 2008). Stimulability testing also assists when planning therapy. The use of recording, either audio or video, assists when transcribing and analysing the speech sample (Gopal, 2009).

Formal tests for the assessment of speech may also be used where available, however these should be used with caution where not standardised on South African English speakers. This includes the Goldman Fristoe Test of Articulation (2-21 years), (Goldman & Fristoe, 2000), used commonly in the Western Cape (Pascoe, Maphalala, Ebrahim, Hime, Mdladla, Mohamed & Skinner, 2010) and the Clinical Assessment of Articulation and Phonology (2.6 – 8.11 years) (Secord, 2002).

With regard to voice and resonance, the Speech-Language Therapist should observe for disorders of phonation as associated with the velopharyngeal incompetence, commonly seen in children or adults with cleft lip and/or palate. These include hoarseness, soft voice, monotone and strangled voice. Instrumental (objective) assessments are required for all disorders of resonance and/or audible nasal emission (ACPA, 2007). Instrumental assessments allow for the ruling out of any nasal

emission due to velopharyngeal dysfunction as well to identify improvement in velopharyngeal competence following Speech-Language Therapy (Vijapur, 2006). Instrumental speech assessment procedures are not frequently used in South Africa, possibly due to funding reasons or perhaps due to some procedures requiring specialised training. These include videofluoroscopy, nasoendoscopy as well as nasometry (Gopal, 2009).

#### **2.5.1.4.2. Language Assessment**

The ACPA (2000) recommends screening and assessment of children with cleft lip and/or palate at an early stage to allow for early identification of speech-language disorders.

At the infant stage, assessment generally includes observations of parent-child interactions, to determine any effects the cleft may have on the bonding process (Peterson-Falzone et al., 2006). Gopal (2009) suggests an assessment of parent-child interaction, means of communication (e.g. verbal or non verbal), as well as receptive and expressive language skills (in terms of morphology, syntax and semantics). In addition, the use of eye gaze, eye contact and pragmatic skills such as turn taking should be observed (Rossetti, 2001).

During toddlerhood, the Speech-Language Therapist's assessment of language involves a more in-depth assessment of receptive and expressive language skills. Assessment may involve the therapist eliciting a language sample from the child, and then engaging in analysis of the sample via informal measures such as the Language Assessment, Remediation and Screening Procedure (LARSP) (Crystal et al., 1976, cited in Owens, 2004) in the case of English speakers.

A number of formalised checklists and tests also exist for the assessment of language (English) skills from birth to three years, which are listed in the tables below.

**Table 2.3.: Checklists for language development**

<b>Name of Checklist/Inventory</b>	<b>Authors</b>	<b>Year</b>
Communication and Symbolic Behaviour Skills Developmental Profile (6-24 months)	Wetherby and Prizant	2002
McArthur Bates Communicative Development Inventory (8-37 months)	Philip, Dale, Reznick and Bates	2007
Receptive-Expressive Emergent Language Scale (REELS) (0 – 3 years)	Bzoch, League and Brown	2003

**Table 2.4.: Formal assessments/Norm referenced tests of language**

<b>Name of test</b>	<b>Age Range</b>	<b>Author</b>	<b>Year</b>
Early Language Milestones Scales (ELM 2)	0 - 3	Coplan	1987
Test of Early Language Development (TELD)	2 - 7	Hresko, Reid and Hammill	1999
Rossetti Infant Toddler Language Scale	0-3	Rossetti	1990
Preschool Language Scale 4	0 - 6	Zimmerman, Steiner and Pond	1992
The New Reynell Developmental Language Scales	2 - 7	Edwards, Letts and Sinka	2011

## **2.5.2. Therapy/Management**

According to Peterson-Falzone et al. (2006), children with cleft lip and/or palate will, in the majority of cases, require the services of a Speech-Language Therapist at some point in their lives. The Speech-Language Therapist is therefore involved in “sequenced speech-language intervention” (Peterson-Falzone et al., 2006, p. 105) from birth through the toddler years. Peterson-Falzone et al. (2006) do not focus entirely on nasality issues until the child is three years of age, as before this, the focus is on increasing the child’s phonetic repertoire. It is, however necessary to encourage simple activities such as blowing on lightweight items, e.g. cotton balls, or blowing out a candle with gentle occlusion of the nares where necessary (Peterson-Falzone et al., 2006). These and other intervention techniques are described below.

### **2.5.2.1. Management Stage: Early Monitoring**

Ideally, the Speech-Language Therapist should first be meeting the parents and baby at the birth, or when the baby is no more than three months of age (Peterson-Falzone et al., 2006). At this stage, he/she would discuss with the parents the possible expected impact of the cleft on speech and language development from birth to three years of age, or perhaps from birth to a year. They would obtain a baseline of the child’s current pre-linguistic development and begin monitoring the baby, whilst providing suggestions to the parents on stimulating their child’s early communicative functions. They also play an important role in answering any questions the parents may have with regard to speech and language development, as well as feeding (Peterson-Falzone et al., 2006).

At five to six months of age, the Speech-Language Therapist is interested in ensuring that the child’s receptive language as well as early communicative repertoire is developing appropriately. They would provide more specific information to the parents to assist the child with vocal development, as well as help the parents to understand why they are required to stimulate their child’s receptive and expressive language (Peterson-Falzone et al., 2006).

It can therefore be seen that, at this stage, the Speech-Language Therapist is involved more as a secondary facilitator, with the caregiver or parent being the primary facilitator, i.e. family centred intervention (Owens, 2004). It is therefore important that another aim of management at this stage is to determine those parents and children who may benefit from more direct intervention with the Speech-Language Therapist.

#### 2.5.2.2. Management Stage: Intervention with the Prelinguistic Child

According to Peterson-Falzone et al. (2006), due to the expected delays in phonetic development of babies with cleft palate, an appropriate goal of therapy is usually to encourage a wider range of vocalisations. The following are suggestions from Peterson-Falzone et al. (2006, p. 107):

- Encourage parents to model different sounds and words, as well as non speech noises during play and daily activities, as well as sounds which their child has not yet learnt to produce
- Utilise motherese, with exaggerated intonation to elicit the attention of their baby
- Use a higher loudness level to ensure the baby is able to hear their vocal play adequately
- Encourage the use of greetings with exaggerated intonation, such as ‘Hi!’ and ‘Bye bye!’.

In addition to the above, other goals of therapy would be to expand the consonant inventory of the child as well as the range of syllable shapes that the child utilises (Peterson-Falzone et al., 2006). These are described below:

- Imitating the baby’s babble productions, i.e. back and forth babbling between parent and child to encourage the development of turn taking skills
- Before the child is due for palatal surgery, encourage more consonant vowel combinations, e.g. ‘mama’, ‘lala’

- Reinforce the baby's attempts to produce the sounds that they have already established, although these may be nasal in nature.

For babies who do not grasp or readily imitate their parent's vocal productions, it may also be beneficial to encourage more bodily movements before actual vocalisations (Peterson-Falzone et al., 2006). These include encouraging larger body movements such as clapping and dancing, then the imitation of facial expressions (e.g. happy, sad), followed by a gradual inclusion of lip and tongue movements, and finally the pairing of these movement with vocalisations.

#### 2.5.2.3. Management stage: Intervention for phonetic, lexical and phonological growth after surgery

Following palatal surgery and the complete, appropriate healing of the repaired palate, Peterson-Falzone et al. (2006) recommend that parents should be encouraged to keep a diary of all the new words as well as consonants that their child produces. Toddlers who have severely limited vocabularies frequently have delayed phonological skills as well, and one thus hopes that where improvements are seen in the semantic, syntactic and pragmatic functions of language that similar improvements will be seen in phonology as well. Activities the parent or therapist may use to stimulate new consonants may include the following (Peterson-Falzone et al., 2006, p. 112):

- Sitting side by side in front of a mirror and modelling lip and tongue movements, whilst encouraging the child to imitate
- Puffing up the cheeks with air, and then tapping the cheeks repeatedly to let air pass through the oral airstream in short bursts
- Modelling specific speech targets, such as /pa/ and /da/, i.e. CV syllables
- Using play activities to stimulate specific sounds, e.g. blowing bubbles for bilabials, singing /lalala/ to a simple song, and using animals to associate with speech sounds, e.g. /s/ for snake

Furthermore, the following activities may be used to teach production of stop consonants with oral airflow, i.e. eliminating hypernasality:

- Using a prolonged /p/ to move a cottonwool ball across the table
- Whispering /pa/ to lift a feather or light piece of paper off the hand
- Use lightweight toys to encourage oral airflow. Initially it may be necessary to gently squeeze the nares to assist with identification of airflow.

According to Peterson-Falzone et al., (2006), one may facilitate early words for those toddlers with language difficulties or delays with the following guidelines:

- Begin training words with those sounds already in the child’s phonetic inventory
- Initially words should be those which place little demand on the velopharyngeal system, such as ‘mommy’, ‘more’, ‘night night’
- As the phonetic inventory expands to include more stop consonants, words with those consonants should be added, e.g. ‘ball’, ‘bye bye’.
- Relational words as well as nouns should be included, such as words for rejection, recurrence and location
- Words must be functional.

The following table describes some approaches for increasing early vocabulary:

**Table 2.5.: Approaches to increase early vocabulary**

<b>Intervention Approach</b>	<b>Description</b>
1. Child Centred Approach (Paul, 2001)	<ul style="list-style-type: none"> <li>• Elicit target words by providing opportunity during play</li> <li>• The therapist models the target words</li> <li>• The child may not necessarily be expected to imitate the therapist, however, they should be praised whenever they try to</li> </ul>
2. Hybrid approaches	
2.1. Milieu Teaching	2.1. In this approach, the natural environment is



<p>(Paul, 2001)</p> <p>2.2. Script Therapy (Paul, 2001)</p>	<p>organised such that the child has to request an object in order to receive it, and the therapist follows the lead of the child</p> <p>2.2. Here, the target words for therapy are used within a verbal routine, such as activities that are social and frequent in which the child engages and needs to communicate. The therapist may manipulate the routing so as to elicit the need for functional communication from the child.</p>
<p>3. Clinician Directed Approaches</p> <p>3.1. Drill (Paul, 2001)</p> <p>3.2. Drill Play (Paul, 2001)</p> <p>3.3. Modelling (Paul, 2001)</p>	<p>3.1. Here, therapy is highly structured, with the therapist providing the child with the expected sound or word to be produced.</p> <p>3.2. This type of therapy involves the inclusion of a motivating event into the drill approach described above.</p> <p>3.3. Here, the child listens to a model of the desired response produced by a third person, about what is happening in a picture. The child is required to imitate the model, i.e. modelling and imitation.</p>

*Adapted from Paul (2001)*

In addition to enhancing lexical and phonological growth, McWilliams, Morris and Shelton (1990) discuss disorders of phonation as associated with velopharyngeal incompetence, commonly seen in children or adults with cleft lip and/or palate. These include hoarseness, soft voice, monotone and strangled voice. They further state that children with cleft palate and hoarseness, as well as velopharyngeal incompetency

should not be subjected to the stress of hypernasality treatment. This is due to the possibility that they “may compensate laryngeally” (McWilliams, Morris & Shelton, 1990, p. 250). Furthermore, Kummer (2001) states that between the ages of birth to three years, parents should be told to focus on their child’s phonetic development as a priority. Where voice problems such as hoarseness are encountered, it is vital to refer the child for medical investigations into the cause of the disorder (Kummer, 2001). This is due to the majority of vocal problems in cleft palate being related to problems with velopharyngeal valving.

#### 2.5.2.4. Management practices for feeding difficulties

##### 2.5.2.4.1. Positioning

The Speech-Language Therapist assists with positioning, where the baby should always be positioned in an upright position with the head always higher than the stomach. This allows for a downward flow of milk to the stomach, hence avoiding the possible backflow of milk into the nasal area/Eustachian tube (Arvedson & Brodsky, 2002). Mothers should be advised by the Speech-Language Therapist that a baby with only a cleft lip may succeed at breastfeeding and sometimes babies with both clefts of the lip and palate may also breastfeed successfully (Sydney Children’s Hospital, 2004).

##### 2.5.2.4.2. Delivery of Milk

With typically developing babies, a suck then breathe pattern is followed when feeding. With babies with a cleft of the palate the parent is required to imitate this pattern for their baby, via specialised teats or nursers. These guide the delivery of milk using the baby’s cues (Wolf & Glass, 1992). The specialised teats or nursers are decided upon and issued by the appropriately trained rehabilitation provider (Department of Health, 2000a), in this case, the Speech-Language Therapist.

The following are types of specialised nursers (The Children’s Hospital at Westmead, 2011) available in South Africa for babies with a cleft of the palate:

- The **Mead Johnson Cleft Palate Nurser** is a soft, squeezable bottle, where milk is delivered to the baby by squeezing the bottle. The nipple of the teat is long, so as to direct the flow past the cleft. The bottle can also be squeezed in relation to the baby's suck swallow pattern, hence overcoming the need for a vacuum-suck motion from the baby. The baby's jaw compressions should be observed for in order to approximate the normal feeding pattern/delivery of milk to the baby.
- The **Haberman Feeder** has a large squeezable nipple, with a slit instead of a cross cut. The bottles contain markings at the base of the soft teat to indicate the position of the slit relative to the baby's mouth. There is a one way valve that keeps the milk in the teat, allowing for the feeder to control the speed of the flow of milk.
- The **Pigeon Bottle** has a Y-cut teat, which is larger and more bulbous than others. It is firm at the top and soft at the bottom, allowing for easy tongue compression. It also contains an air valve that prevents the teat from collapsing while the baby is sucking. By tightening or loosening the collar on the bottle, one can control the speed of milk flow. There is also a stopper, which prevents milk from flowing back into the bottle from the teat, hence reducing the amount of air the infant swallows. This bottle works well for slightly older infants as it has a slightly faster flow than other bottles.
- In South Africa, the **NUK** brand has also developed a specialised cleft lip and a specialised cleft palate teat (Engels, S., personal communication, May 24, 2011<sup>14</sup>).

Where the suck-swallow-breathe pattern is compromised, such as when a standard bottle with modified nipple is used, there have been reports of excessive 'splashes', coughing, possibility of choking, nasal regurgitation as well as swallowing of air in gulps (Wolf & Glass, 1992). It is therefore important that the Speech-Language

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<sup>14</sup> NUK Representative in KwaZulu-Natal, South Africa

Therapists, especially with babies with clefts of both the lip and palate, ensure and advise on frequent burping or winding.

With regard to breastfeeding, babies with a cleft palate tend to have a weak suck, and hence expressing of milk may need to occur more often to ensure milk is available for the next feed. The mother is required to massage the breast to stimulate the passage of milk, hence making it easier for the baby. She can also place the nipple into the baby's mouth, and apply pressure to the areola area to assist in compensating for a lack of suction (Sydney Children's Hospital, 2004).

#### 2.5.2.4.3. Timing of Feeds

With particular reference to breast feeding, the compression of the nipple is of primary importance. However, as the flow rates for breast and bottle feeds differ, it may take up to two entire minutes of sucking to initiate the 'let down' of milk. Thus, for the mother of an infant with cleft lip and/or palate, due to sucking difficulties feeding may be time consuming as well as frustrating (Wolf & Glass, 1992). The Speech-Language Therapist would need to advise and counsel the mother regarding the timing of feeds.

#### 2.5.2.4.4. Nutritional Considerations

According to Wolf and Glass (1992), initial feeding management for the child with a cleft of the lip and/or palate needs focus on ensuring adequate weight gain for the purposes of surgery. In addition, slow weight gain is an issue frequently reported in this condition (Wolf & Glass, 1992).

Wolf and Glass (1992) further report that, where infants with craniofacial anomalies have not mastered oral feeding of fluids, the introduction of small boluses of semi solids via spoon should be encouraged, however all the while ensuring adequate fluid intake. It is therefore always important to remember the possibility and sometimes necessity for non oral feeds as supplementary to oral feeds in this population (Wolf & Glass, 1992).

## **2.6. SUMMARY OF CHAPTER**

Chapter two provided discussion regarding the impact of a cleft lip and/or palate on the child and family, as well early intervention services required by the child with cleft lip and/or palate and his or her family, relating to surgical intervention, feeding difficulties, speech and language intervention, orthodontics as well as general information for the family. The role of the Speech-Language Therapist and Speech-Language Therapy in cleft lip and/or palate was also discussed.

## **CHAPTER 3: RESEARCH METHODOLOGY**

This chapter will precisely describe the planning and execution of the research study. Therefore, it will highlight the aims and objectives of the study, the research design, selection criteria and description of participants, data collection instruments, ethical and legal considerations as well as details regarding data collection and analysis.

### **3.1. AIM**

To investigate Speech-Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu-Natal

### **3.2. OBJECTIVES**

- 3.2.1. To determine the current levels of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years in the public and private health sectors of KwaZulu-Natal
- 3.2.2. To determine the types and composition of teams and team services that exists in the public and private health sectors of KwaZulu-Natal
- 3.2.3. To determine the total number of children with cleft lip and/or palate from birth to three years seen by Speech–Language Therapists in the public and private health sectors of KwaZulu-Natal, as well as levels of consultation with Speech-Language Therapists
- 3.2.4. To determine the existence, and if applicable, the nature of policies or protocols for children with cleft lip and/or palate in the public and private health sectors of KwaZulu-Natal
- 3.2.5. To provide an overview of the aims of and methods utilised for assessment of children with cleft lip and/or palate from birth to three years used by Speech–

Language Therapists in the public and private health sectors of KwaZulu-Natal

3.2.6. To provide an overview of the speech, language and feeding management services for children with cleft lip and/or palate from birth to three years provided by Speech–Language Therapists in the public and private health sectors of KwaZulu-Natal

3.2.7. To provide a description of the views of Speech–Language Therapists in the public and private health sectors of KwaZulu-Natal with regard to the services for children with cleft lip and/or palate within the age range birth to three years

### **3.3. RESEARCH DESIGN**

A research design allows for the most accurate, valid answer to the research question, whilst utilising the most appropriate method of enquiry (Leedy & Ormrod, 2005).

A descriptive survey research design, utilising both qualitative and quantitative approaches (Leedy & Ormrod, 2005) was utilised in this study. According to Fouche and De Vos (2005), the integration of research with practice advocates for a combination of qualitative and quantitative research methods. Furthermore, Creswell and Clark (2007) state that the use of both approaches allows for a better understanding of the aspect being investigated, as opposed to utilising only one type of data. The utilisation of both quantitative and qualitative approaches allowed for the collection of quantitative information, which would be further supplemented and understood by the qualitative experiences of the participants. The study design allowed for both qualitative and quantitative information to be gathered and for the results to be analysed either quantitatively or qualitatively. Information gathered from quantitative and qualitative analyses could then be integrated. This type of study design complements one type of research with another, by relying on the presentation of data through words, i.e. qualitative and statistical results represented by numbers, i.e. quantitative. Within a qualitative research approach, the aim is to understand social relationships, as well as the meaning that human beings attach to their daily

lives in their own words and values (Fouche & De Vos, 2005). Babbie and Mouton (1998) further describe this approach as viewing the world through the people's eyes, which helps increase understanding. On the other hand, a quantitative approach aims to present data obtained through numbers and statistics, which allows for a more objective, controlled and formalised analysis of data (Fouche & De Vos, 2005). According to Leedy and Ormrod (2005, p. 187), survey research “involves acquiring information about one or more groups of people – perhaps about their characteristics, opinions, attitudes or previous experiences”.

As the current study aimed to investigate Speech-Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu-Natal, utilising Speech-Language Therapists' knowledge, views and personal experiences, a descriptive survey design, utilising both qualitative and quantitative approaches was appropriate for undertaking of the study. This research design allowed for:

- Conducting an in-depth literature review, through which information was sought to further motivate for the research questions
- Conducting a survey to gain both quantitative and qualitative information regarding Speech-Language Therapists' experiences with regard to cleft lip and/or palate
- Gaining new insight into cleft lip and/or palate care within the province of KwaZulu-Natal, and the possible implications of the care that is provided/available
- Presenting the findings of the study and interpreting the findings in light of literature reviews and previous research.



### **3.4. PARTICIPANT SELECTION AND DESCRIPTION**

#### **3.4.1. Study Population**

The study population was Speech–Language Therapists working in the public and private health sectors of KwaZulu-Natal, as these therapists are most likely to be involved with early intervention (birth to three years) as compared to therapists working in the education sector (population older than 6 years). Community service therapists were included in the study, as some hospitals are serviced only by these therapists. According to the National Department of Health (2007), there are three spheres of government, namely the national, provincial and local governments. Each sphere has its own authority, as well as powers and functions to determine what services to render to its community (National Department of Health, 2007). Each province therefore differs from the next, rendering it difficult to compare or collate the gathered data. As this study is centred around governmental policies for early communication intervention, and as provincial departments of health are the sources of their own finance (National Health Accounts, 2002), the province of KwaZulu-Natal was decided on as the geographical area of the research study. KwaZulu-Natal is also the area in which the researcher resides and is employed, and hence it would be more economical to conduct a study by accessing the districts of KwaZulu-Natal.

Participants were accessed from public hospitals in the eleven health districts of KwaZulu-Natal, as well as those in hospital based private practices (private health sector). Appendix F shows the eleven districts of the KwaZulu-Natal public health system, and those being serviced by Speech-Language Therapists at the time of the study, so as to provide the reader with an overview of those hospitals in KwaZulu-Natal which have resident Speech-Language Therapists and the hospitals in which they are situated. However, it should be noted that, with a one year community service period, the number and presence of Speech-Language Therapists in public health may vary.

### **3.4.2. Participant Selection Criteria**

Participants were selected according to the following criteria:

3.4.2.1. Participants were required to be registered as Speech-Language Therapists or Speech-Language Therapists and Audiologists with the Health Professions Council of South Africa

3.4.2.2. Participants within the public health sector were required to be employed at Department of Health Institutions within the KwaZulu-Natal province

3.4.2.3. Participants within the private health sector were required to be contracted to, closely affiliated with and/or have rooms based at private hospitals within the KwaZulu-Natal region, such that they were closely involved in health institutions

3.4.2.4. Participants were required to be Speech-Language Therapists or Speech-Language Therapists and Audiologists who are currently working with or have worked within the past two to three years with children with cleft lip and /or palate from birth to three years, so as to provide up to date, recent information in terms of service delivery.

### **3.4.3. Sampling Technique**

Non probability purposive sampling (Leedy & Ormrod, 2005) was utilised, as this is the most commonly used method in rehabilitation research, where it is not practical to utilise random sampling (Leedy & Ormrod, 2005). In this type of sampling, participants are chosen for a particular 'purpose', e.g. participants who represent a 'typical' group (Leedy & Ormrod, 2005). In this study, the participants were Speech-Language Therapists only, or Speech-Language Therapists and Audiologists. However, a limitation of non probability purposive sampling is that there is limited generalisation of findings (Leedy & Ormrod, 2005), due to the sample size being restricted to the 'typical' group.

#### **3.4.4. Description of Participants, Sample Size and Response Rate**

A total of 43 research questionnaires were distributed to Speech-Language Therapists/Speech-Language Therapists and Audiologists in KwaZulu-Natal. There were 23 respondents, resulting in a response rate of 53%. According to Leedy and Ormrod (2005), the average return rate of a questionnaire is 50% or less. Wellman and Kruger (1999) also report on a 50% return rate for surveys in South Africa.

Of these 23 respondents, nineteen therapists were from the public health sector, spread across eight of the eleven health districts in KwaZulu-Natal, and four were from the private health sector.

#### **3.5. DATA COLLECTION INSTRUMENT (Appendices D and E)**

The data collection instrument was a self administered questionnaire consisting of eleven open ended and twelve closed ended questions, which took approximately 30 to 60 minutes to answer. The questionnaire consisted of questions relating to cleft lip and/or palate service delivery, team types and composition, the number of cleft lip and/or palate patients seen, policies and protocols, levels of consultation, assessment and management as well as general personal views on service delivery (See Table 3.1. below). The advantage of using a questionnaire was that the researcher could ask questions and gain information from what was expected to be a large number of participants, whilst their confidentiality was guaranteed (Leedy & Ormrod, 2005). An electronically mailed or faxed questionnaire was also cost effective and less time consuming in terms of delivery for the researcher. A questionnaire also allows for longer, more personalised questions to be asked (Struwig & Stead, 2001, as cited in Dekker, 2007). The disadvantage of a questionnaire is that participants may find it difficult to understand questions and they may be misinterpreted, hence the researcher ensured that the questions were worded as precisely and accurately as possible (Leedy & Ormrod, 2005). The pilot study also contributed to ensuring this.

**Table 3.1.: Description and motivation for sections included in questionnaire**

Section and Description	Motivation
<b>Section 1: Service Delivery</b>	This section related to current levels of resources (i.e. therapists and clientele seen) for Speech-Language Therapy, and more specifically, cleft lip and/or palate care. According to Strauss (1995, p. 515), “behind a society’s allocation of resources lies values, political forces and justice, and the decisions regarding resources go far toward defining a society’s perspective on equity and justice”. This section aimed to provide information about those Speech-Language Therapists currently working with the child with cleft lip and/or palate (0-3 years), and, if not the reasons as to why.
<b>Section 2: Team types and composition</b>	According to Strauss (1999), a comprehensive clinical team is required to provide holistic care for the individual with a craniofacial condition, as it may not be possible for a single professional to provide all the care that is required. Utilising a team approach addresses issues of fragmentation of care. In addition, the Speech-Language Therapist is a vital member of the transdisciplinary team involved in cleft care (Hodgkinson et al., 2005). This section therefore aimed to identify if Speech-Language Therapists in KwaZulu-Natal are part of a cleft lip and/or palate team, and if so, the types and composition of teams, or whether the Speech-Language Therapists work in isolation.
<b>Section 3: Number of cleft lip and/or palate patients seen</b>	This section aimed to investigate the client population of the Speech-Language Therapist, in terms of the number of children seen with cleft lip

	<p>and/or palate. The section also aimed to correlate the number of clients seen with cleft lip and/or palate (0-3 years) with reasons as to why they may be complying with or may not be attending Speech-Language Therapy. This aided in determining the relations between the number of children being serviced by the institutions or practice (in private health) and the number attending Speech-Language Therapy at the institution.</p>
<p><b>Section 4: Policies and Protocols</b></p>	<p>This section aimed to investigate the existence of policies or protocols within hospitals and Speech-Language Therapy departments for cleft lip and/or palate care. According to Hodgkinson et al. (2005), intervention for the child with a cleft lip and/or palate requires a protocol of care, which may otherwise be referred to as the pathway to care. This protocol enables professionals to function most effectively, both as individuals and as a team, which ultimately benefits the patient.</p>
<p><b>Section 5: Levels of Consultation</b></p>	<p>According to Grow and Lehman (2001), the Speech–Language Therapist is one of the three primary members of the cleft lip and/or palate team (Grow &amp; Lehman, 2001). This section therefore aimed to investigate whether the Speech-Language Therapist is consulted by other professionals in the case of a child with cleft lip and/or palate, and at what stage the consultation occurs. Furthermore, best practice in Speech-Language Therapy involves assessment and treatment of the child at different stages of their development (Hodgkinson et al., 2005), which would therefore require the Speech-Language Therapist to be consulted from</p>

	when a cleft is detected up until no further Speech-Language intervention is indicated.
<b>Section 6: Assessment of speech, language and feeding</b>	Albery and Russell (1994, p. ix) emphasize the importance of conducting a thorough, “comprehensive assessment of all aspects of communication cannot be overstressed”. This section therefore aimed to provide an overview of the areas and methods of assessment utilised by Speech-Language Therapists working with cleft lip and/or palate, as well as the challenges Speech-Language Therapists may experience, which may hinder their ability to conduct an in-depth assessment.
<b>Section 7: Speech-Language Therapy/Intervention</b>	Detailing intervention and describing techniques used during therapy is important in bridging the gap between theory and practice (Albery & Russell, 1994). Furthermore, including information on the types of management offered to children with cleft lip and/or palate from birth to three years by Speech-Language Therapists in KwaZulu-Natal may be of assistance to therapists who see only a few children with the condition (Albery & Russell, 1994), as it may help as a ‘refresher’ on the aspects such as ‘red flags’ related to communication in cleft lip and/or palate.
<b>Section 8: Perspectives of Speech-Language Therapists</b>	According to Dekker (2007), limited information exists regarding the provision of services to children with cleft lip and/or palate in South Africa’s health sectors. With specific reference to speech, language and feeding, the Speech-Language Therapists’ views regarding cleft lip and/or palate care may provide valuable insight into the situation in KwaZulu-Natal, where gaps

	exist and may possibly fuel further research to bridge those gaps in service.
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### 3.6. PILOT STUDY

A pilot study is a brief method of exploring and ‘trying out’ selected procedures, which is therefore a good way to assist in determining how feasible a study is (Leedy & Ormrod, 2005). A pilot study was conducted with a Speech-Language Therapist who had knowledge and expertise in the field of cleft lip and/or palate as well as experience in both the public and private health sectors of KwaZulu-Natal, i.e. one who met the participant selection criteria. The pilot study participant was not included in the main study, as she was not within the Department of Health at the time, and prior knowledge of the questionnaire may have biased her answers. The participant was asked to rate the questionnaire using categories adapted from Hattam (2005). Rating occurred with regard to the instructions provided, physical layout of the questionnaire, the provided response categories, sequence, phrasing and relevance of the questions, sensitivity of wording of the questions, as well as the time required to complete the questionnaire (Hattam, 2005). The results of the pilot study are presented in Table 3.2. below. No changes were needed.

**Table 3.2.: Results of the pilot study**

Area	Good	Average	Needs improvement	Comments	Adaptations
1. Instructions	×				None
2. Physical Lay-Out	×			Fine	None
3. Response Categories	×			Fine	None
4. Sequence of questions	×			Fine	None
5. Phrasing of questions	×			Fine	None
6. Relevance of	×				None

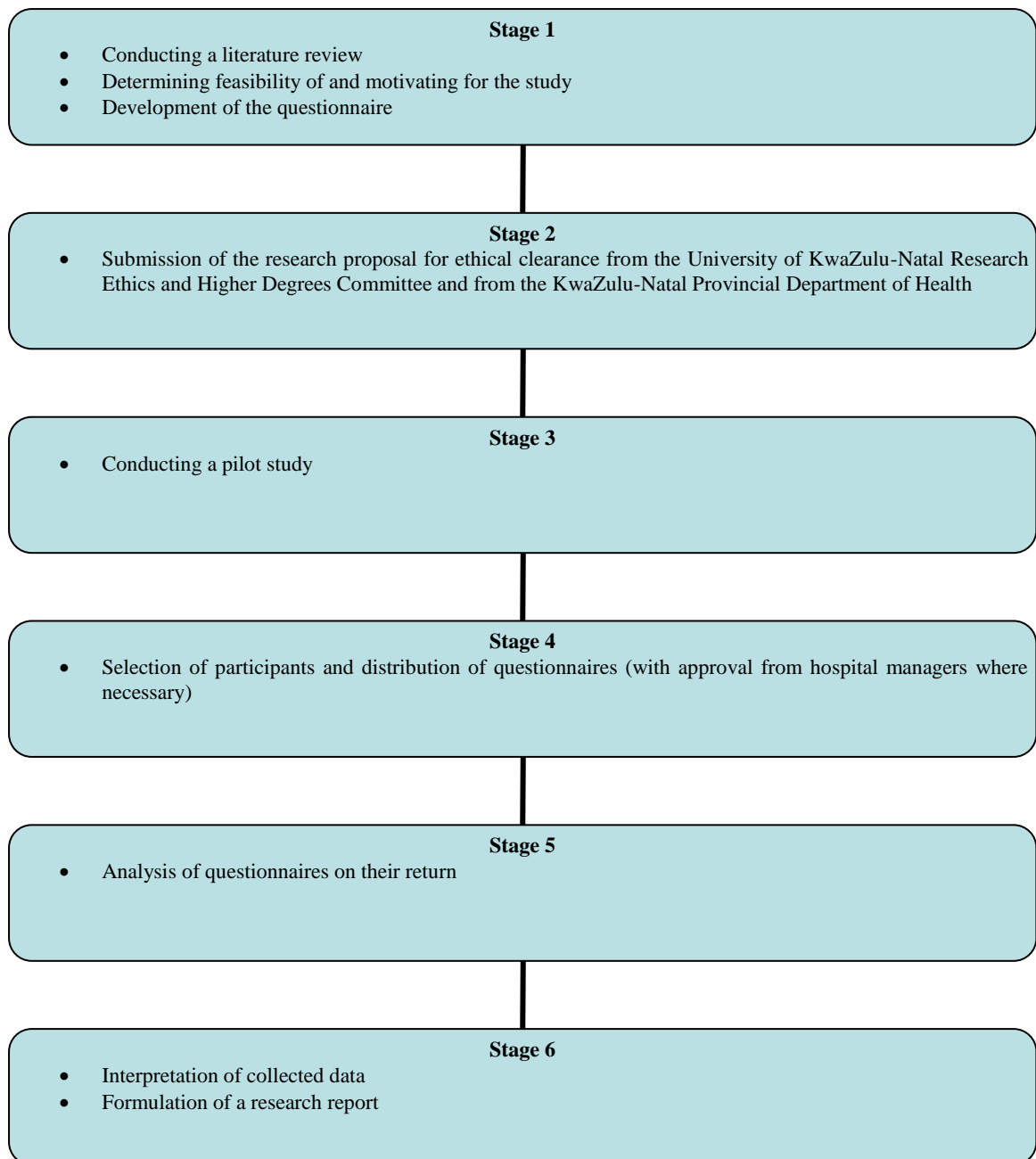
questions					
7. Sensitivity of questionnaire wording	×				None
8. Time needed to complete the questionnaire (30-60 minutes)	×				None

### 3.7. DATA COLLECTION PROCESS AND METHOD

- The research proposal as well as application for ethical clearance was forwarded to the University of KwaZulu-Natal (Faculty of Health Sciences) Research Ethics and Higher Degrees Committee for approval via post.
- Following ethical approval from the University of KwaZulu-Natal (Ethical Approval Number: HSS/0225/2010), ethical clearance was obtained from the KwaZulu-Natal Department of Health.
- Permission was obtained from the various hospital managers in public settings in KwaZulu-Natal either electronically or via facsimile. Private hospital based Speech-Language Therapists were accessed via private hospitals and the SASLHA Private Practitioners List. These therapists did not require permission from the managers of the hospitals at which they are based, as they were self employed and answering in relation to their own practice.
- Proposed participants in the private and public health sectors were contacted telephonically to enquire whether they would prefer a questionnaire sent electronically, via fax or via post. The letters of informed consent and questionnaires were then sent to Speech-Language Therapists employed in public and private hospitals in KwaZulu-Natal, either electronically or via fax. None of the Speech-Language Therapists requested postal delivery as a method of receipt.
- Telephonic and email contact was maintained in order to attempt to improve questionnaire return rate.



- Questionnaires were returned to the researcher either electronically or via facsimile.
- On completion of the study, final copies of the research report (electronic and hard copies) will be forwarded to the KwaZulu-Natal Department of Health Provincial Research Committee. Letters of acknowledgement will also be posted to participants. The letters of acknowledgement will also enquire as to whether Speech-Language Therapists themselves would like to receive copies of a summary of the research report. Figure 3.1. below depicts the stages of the research study:



**Figure 3.1.: Stages of the research study**

### **3.8. ETHICAL AND LEGAL CONSIDERATIONS**

#### **The following ethical and legal issues were considered:**

##### 3.8.1. Ethical Clearance (Appendices A1 and A2)

This involved granting of permission from the University of KwaZulu-Natal (Faculty of Health Science) Research Ethics and Higher Degrees Committee (Appendix A1), and permission from the KwaZulu-Natal Department of Health Ethics Committee (Appendix A2).

Permission was needed from the Research Ethics and Higher Degrees Committee as this committee serves to examine the research proposal and to ensure that the procedures to be used may not cause harm to the participants. It also ensured that the researcher was using the correct procedure in the research study (Leedy & Ormrod, 2005).

##### 3.8.2. Informed consent (Appendix C)

According to Leedy and Ormrod (2005), researchers are required to inform participants of the nature of the study as well as that they have the right to agree to or decline participation. Those Speech-Language Therapists who decided to be a participant in the study held the right to withdraw from the study at any point in time without penalty (Wiles, Heath, Crow & Charles, 2004).

##### 3.8.3. Confidentiality

According to the Centre for Disease Control (2003), research data may be protected from inappropriate disclosure by specifying a time for destroying the linkages to participants once data collection is complete. In this study, confidentiality was ensured as the questionnaires were kept in a locked cupboard, with only the researcher's accessibility and will be destroyed five years post completion of the study. Electronic submissions were stored in a password-access folder, also to be destroyed five years post completion of the study. Furthermore, each returned and

completed questionnaire was allocated a different number for identification purposes, such that the participants' information as well as hospital information remained confidential.

#### 3.8.4. Reliability and Validity

The following were taken into account to ensure the reliability of the questionnaires, as stipulated by Leedy and Ormrod (2005):

- Questionnaires contained clear instructions on how to complete them
- The questions were presented in a sequence that was precise and logical, and also contained sufficient answering space
- The same questionnaire has been designed for all study participants, in order to ensure reliable data. Changes in wording as applicable to private and public based therapists were used.

In order to ensure the validity of the questionnaires, i.e. the ability of the questionnaire to test the area to assess, the researcher took into account both the content and construct validity of the questionnaires (Leedy & Ormrod, 2005). With regard to content validity, the questions were designed in order to determine information that is central to the aim of the research study. In terms of construct validity, the questionnaires contained clear instructions, were free from ambiguity and a pilot study also ensured construct validity of the questionnaire.

According to Creswell and Clark (2007), researchers need to be alert to the possibility of bias, especially within qualitative aspects of research design. This research study therefore utilised Creswell and Clark's (2007) potential ways of reducing bias, by allowing participants to record their own responses, i.e. a self answered questionnaire as opposed to the researcher listening to answers and writing them down on her own. This allows for the "collection of unobtrusive data" (Creswell & Clark, 2007).

### **3.9. ANALYSIS OF DATA**

According to Leedy and Ormrod (2005), steps need to be taken in order to ensure consolidation and validity of the data obtained. The following steps were implemented:

**Step One:** Returned questionnaires were examined and checked for accuracy and completion.

**Step Two:** Results of closed ended questions were analysed quantitatively, by numbering questions and loading results onto Microsoft Excel tables, converting to percentages where necessary and then presented visually, i.e. in the form of figures and tables. They were then given to and discussed with a statistician.

**Step Three:** Results from the open ended questions were analysed qualitatively, by firstly reading and reviewing collected data, and then subjecting the data to content analysis (Henning, 2004). This included writing notes about the data, and then coding the data. Coding involves the identification of common themes and ideas that repeatedly occur as one reads through the data. These themes were then interpreted by attaching significance between the theme and the research question, as well as by finding links, looking for alternative explanations as well as challenging patterns that appeared common and apparent (Leedy & Ormrod, 2005).

### **3.10. SUMMARY OF CHAPTER**

This chapter outlined the steps, or methods utilised in completion of this research study, as well as the ethical issues that needed to be addressed. It included the aim of the study and its link to the objectives of the study. Details were provided on the study participants as well as data collection instruments. Issues of validity and reliability were discussed to ensure an ethical research study.

## CHAPTER 4:

### RESULTS AND DISCUSSION

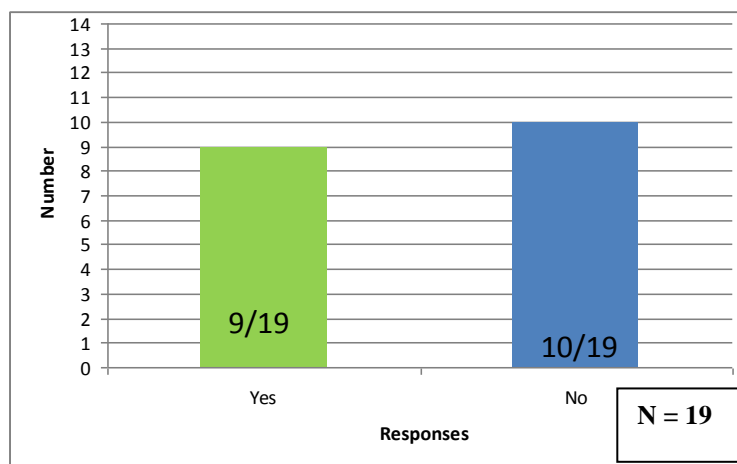
The aim of this study was to provide an overview of Speech-Language Therapy services for children from birth to three years of age in the KwaZulu-Natal health sector. Seven objectives were formulated in order for this aim to be achieved. To ensure that each objective was accomplished, a questionnaire was designed, which Speech-Language Therapists were required to complete. Qualitative text based data as well as quantitative numerical data will be presented, discussed and interpreted for each objective of the study.

While the current levels of Speech-Language Therapy services were calculated using the responses of all 23 participants (19 within the public health sector, and four servicing the private health sector), the remaining results were calculated and analysed by using the responses of those Speech-Language Therapists who are currently working with or had worked with children with cleft lip and/or palate from birth to three years within the past two to three years. This resulted in 11 Speech-Language Therapists, completing the entire questionnaire, and whose responses were used to provide an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years in the KwaZulu-Natal health sector.

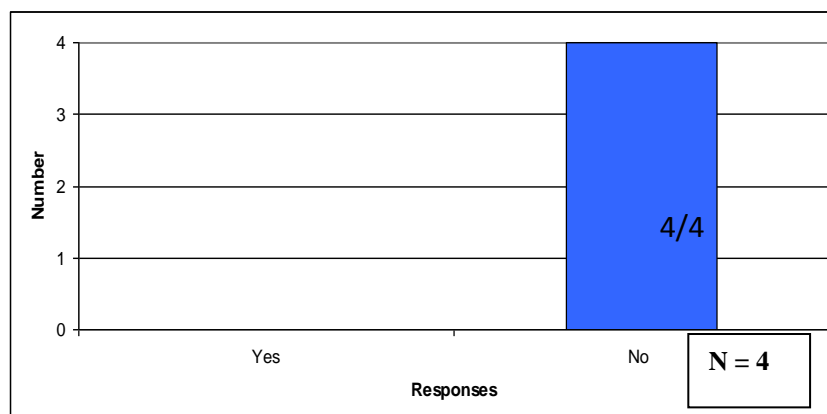
#### **4.1. Objective 1: To determine the current levels of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years in the public and private health sectors of KwaZulu-Natal**

Objective one was achieved by calculating the total participants' responses in public health (19) and private health (4) to the first section of the questionnaire. Those participants who answered that they are not currently and have not been working with children with cleft lip and/or palate from birth to three years were required to then provide a reason for this, by choosing from the options given or providing an alternative reason.

The figures below illustrate the total study population's responses about levels of Speech-Language Therapy service delivery. Figure 4.1. below illustrates that, within the public health sector, only 9 out of the 19 public sector Speech-Language Therapists (i.e. 47%) who participated in the study indicated that they are currently working with children with cleft lip and/or palate (birth to three years), while Figure 4.2. shows that all four Speech-Language Therapists who participated and are based at private hospitals are not currently involved with cleft lip and/or palate within the birth to three age range. It therefore appears that the only Speech-Language Therapists providing services for children with cleft lip and/or palate are from the public health sector.



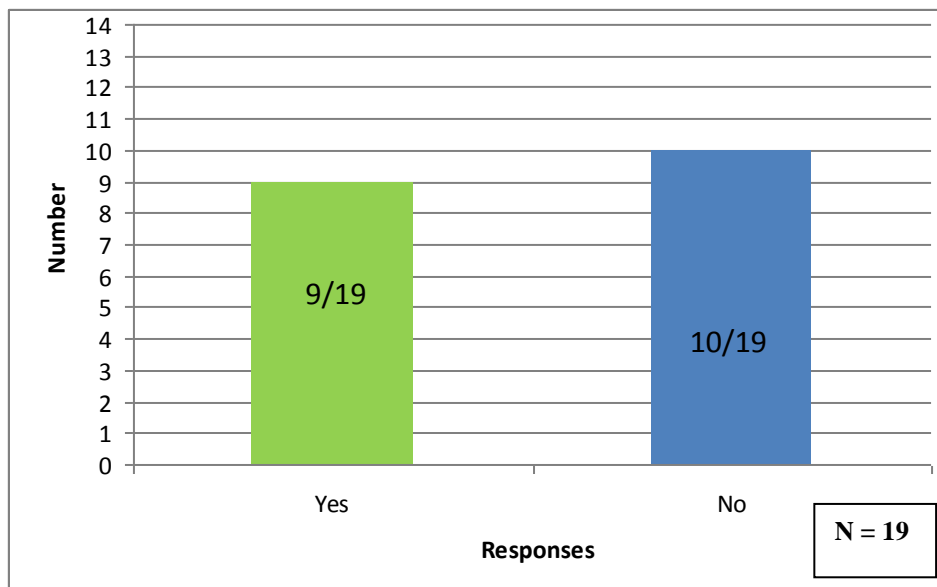
**Figure 4.1: Number of public sector Speech-Language Therapists currently working with children with cleft lip and/or palate from birth to three years of age**



**Figure 4.2: Number of Speech-Language Therapists based in the private health sector currently working with children with cleft lip and/or palate from birth to three years of age**

Possible reasons for the difference between the levels of Speech-Language Therapy services in public and private health sectors may be that parents of children in the private health sector may have a choice as to the Speech-Language Therapist they access, whereas in the public health sector, the institution to provide services is determined by the catchment area into which the family falls (Department of Health, 2005).

Figure 4.3. below illustrates the Speech-Language Therapists who have worked with children with cleft lip and/or palate from birth to three within the past few years. Again, of the 19 public sector Speech-Language Therapists who participated, nine have been working with this population in the past two to three years.

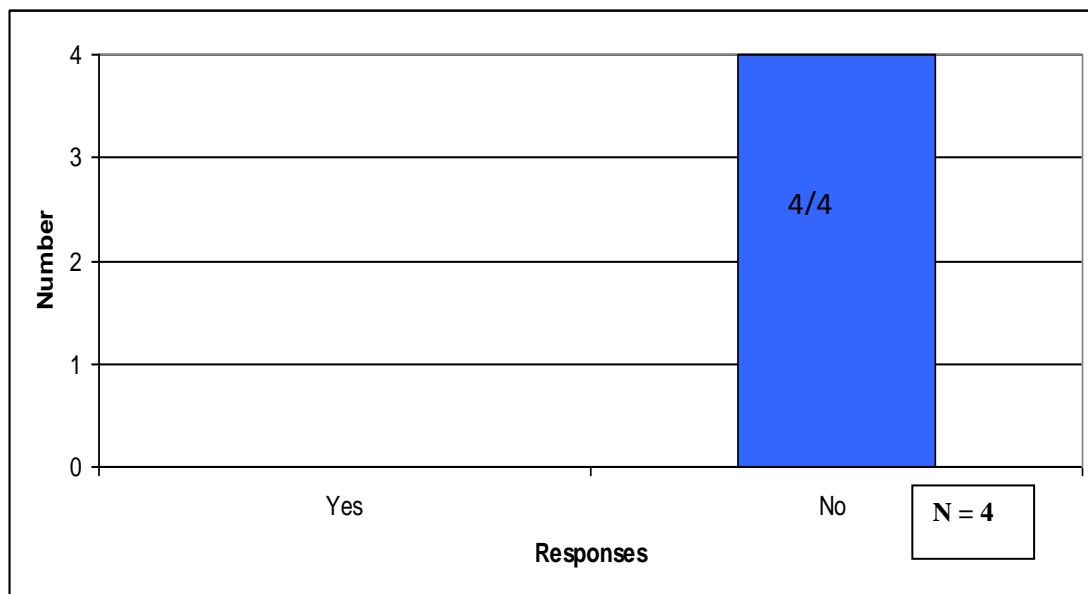


**Figure 4.3: Number of public sector Speech-Language Therapists who have worked with children with cleft lip and/or palate from birth to three years of age within the past two to three years**

It may therefore be assumed that, specific to the participants in this study, the population with cleft lip and/or palate and their use of Speech-Language Therapy services has not changed significantly over the past two to three years, as the figures represented in Figure 4.1. (currently working with cleft lip and/or palate from birth to three years) and Figure 4.3. (have worked with cleft lip and/or palate from birth to three in the last two to three years) are identical. It therefore appears possible that the

number of Speech-Language Therapists in the public health sector and their services to children with cleft lip and/or palate has not changed over the past two to three years, similar to the incidence of cleft lip and/or palate births. The researcher expects that this may change, dependant on incidence levels as well as marketing of the role of Speech-Language Therapists in cleft lip and/or palate. The incidence of cleft lip and/or palate births in South Africa, and KwaZulu-Natal, is low and has not changed significantly. This can be seen in the estimates of incidence of cleft lip and/or palate births between 2005 and 2008 only differing by approximately five percent within the percentage range (Wilson, L., personal communication, August 14, 2009<sup>15</sup>).

With regard to the private based Speech-Language Therapists, again all four participants have not been working with children with cleft lip and/or palate (birth to three years) within the past two to three years, as seen in Figure 4.4. below.

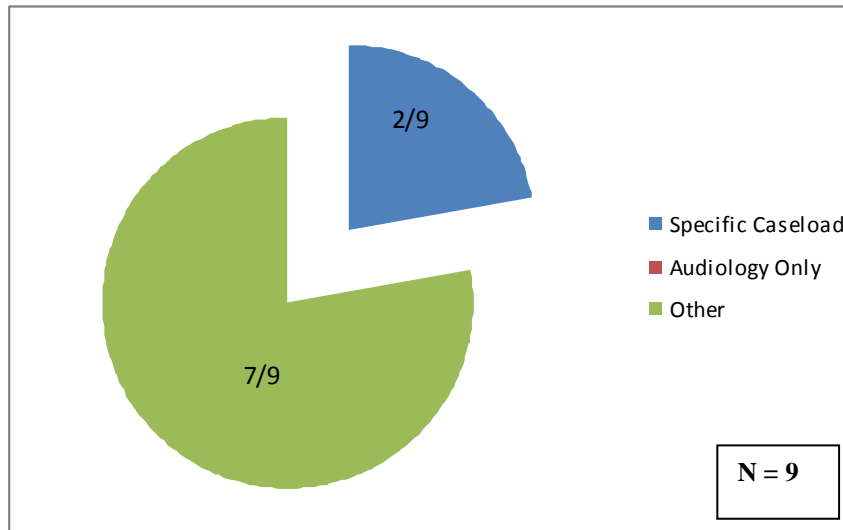


**Figure 4.4: Number of Speech-Language Therapists based in the private health sector who have worked with children with cleft lip and/or palate from birth to three years of age within the past two to three years**

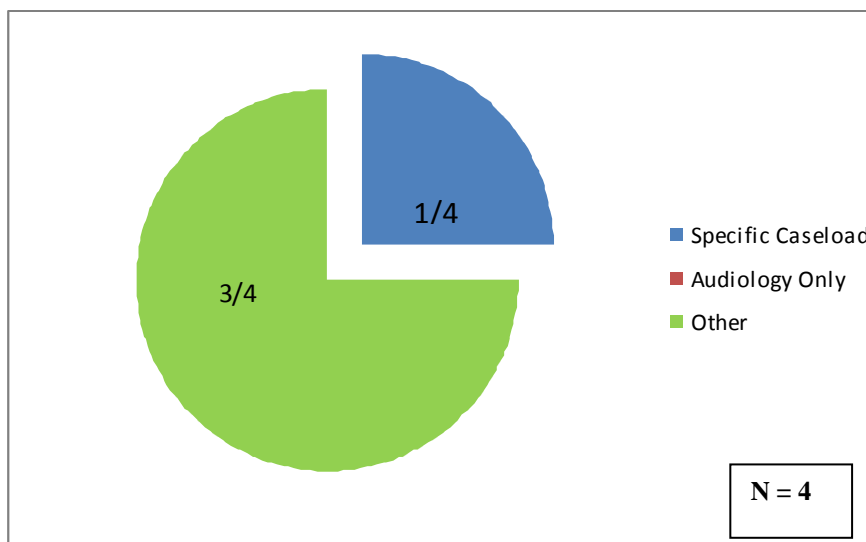
<sup>15</sup> Lin Wilson is the contact person for the KwaZulu-Natal maternal, child and women's health department, which offers services to promote healthy lifestyles to reduce morbidity and mortality rate, especially in women and children. It should be noted that these figures are only estimated of those cases which were reported during 2005-2008.



Figures 4.5. and 4.6. below illustrate the reasons provided by Speech-Language Therapists in public health (10) and private health (4) practice, as to why they have not been working with the population with cleft lip and/or palate (birth to three years). Only two public sector and one private sector Speech-Language Therapist indicated that they were committed to a certain caseload in their department, which did not include cleft lip and/or palate.



**Figure 4.5: Reasons why Speech-Language Therapists in the public health sector have not been working with children with cleft lip and/or palate**



**Figure 4.6: Reasons why Speech-Language Therapists based in the private health sector have not been working with children with cleft lip and/or palate**

As the majority of participants in both private (3 out of 4) and public health (7 of 9) sectors chose the ‘other’ option as their reason, it is important to delve further into this aspect with regard to levels of Speech-Language Therapy services. Two themes were formulated from the data obtained. These are discussed in order of frequency below.

- Theme 1: Lack of referrals

A lack of referrals was the explanation given by participants in both the public and private health sectors as to why they did not provide services to children with cleft lip and/or palate (0-3 years) in KwaZulu-Natal. One private based therapist indicated that there were ‘*no recent referrals regarding the above*’, similar to the statements by public sector therapists such as ‘*there hasn’t been a child with a cleft lip and/or palate...I have not receive[d] referrals*’.

Reasons for the lack of referrals could be related to the low incidence of cleft lip and/or palate births in KwaZulu-Natal, or it could possibly be a case of poor referrals between health care personnel. The latter is a common reason within the field of early communication intervention in general. As discussed by Van de Linde (2008), a need exists for the development and training for health care personnel to be able to identify (with formality and validity) those children at risk for developmental delays or communicative difficulties, as well as feeding difficulties. Eighty (80) percent of the participants in her study stated that the identification methods at the time were not sufficient, nor effective enough in identifying young children at risk for communicative delays and disorders. The study also reported that managers at Primary Health Care facilities all unanimously agreed that they required more information on early communication intervention services. Furthermore, the primary health care personnel in Van de Linde’s (2008) study were well aware of early identification of physical anomalies (such as cleft lip and/or palate) and genetic disorders, but were still uncertain with regard to those disorders that place the child at risk for a communication disorder. As the current study in cleft lip and/or palate falls into the field of early intervention (0 – 3 years), it may be assumed, that where poor referrals exist, this uncertainty may be a reason. This highlights the need for those within the Speech-Language Therapy (and Audiology) professions to market their service to health care personel within the primary health care context.

With regard to the private health sector, consultation with an Audiologist in the private sector revealed that in the area of KwaZulu-Natal (Audiologist1., personal communication, October 20, 2009<sup>16</sup>), the number of children with cleft palate attending regular audiological evaluations has decreased. This may be due to the low incidence for this condition, or that few plastic surgeons specialising in cleft lip and/or palate work in the private sector in KwaZulu-Natal (Kriek, K., personal communication, June 23, 2011<sup>17</sup>). It may also be that many of these patients therefore travel to Gauteng, where particular public institutions also cater for the private or medical scheme funded patients (Speech-Language Therapist 1., personal communication, October 19, 2009). It may also be possible that Speech-Language Therapists in private health are facing a similar issue, as children referred to the public sector for surgical intervention may also be receiving Speech-Language Therapy within public institutions. This may be a further reason as to why public sector Speech-Language Therapy services appear higher than private sector Speech-Language Therapy services for cleft lip and/or palate in the birth to three year age range. Furthermore, parents of cleft lip and/or palate children on medical aid have battled to find private based Speech-Language Therapists in the Ethekewini area to provide management of their child's communicative difficulties (Kriek, K., personal communication, June 23, 2011).

- Children with cleft lip and/or palate within the older age range and turnover of therapists

A theme that arose and that is common to both the private and public based therapists, is that they have not been working with the birth to three age range, but have worked with older children with cleft lip and/or palate. This may be related to another theme identified, which is that the turnover of therapists at public institutions may be high in many cases, especially with the so called 'come and go' of community service Speech-Language Therapists. This 'come and go' may also negatively affect the availability of a therapist at feeding and other important times, e.g. before and after surgery. As one therapist responded on the questionnaire, *'I am currently working*

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<sup>16</sup> Audiologist in private health practice in KwaZulu Natal (name has been excluded to ensure confidentiality)

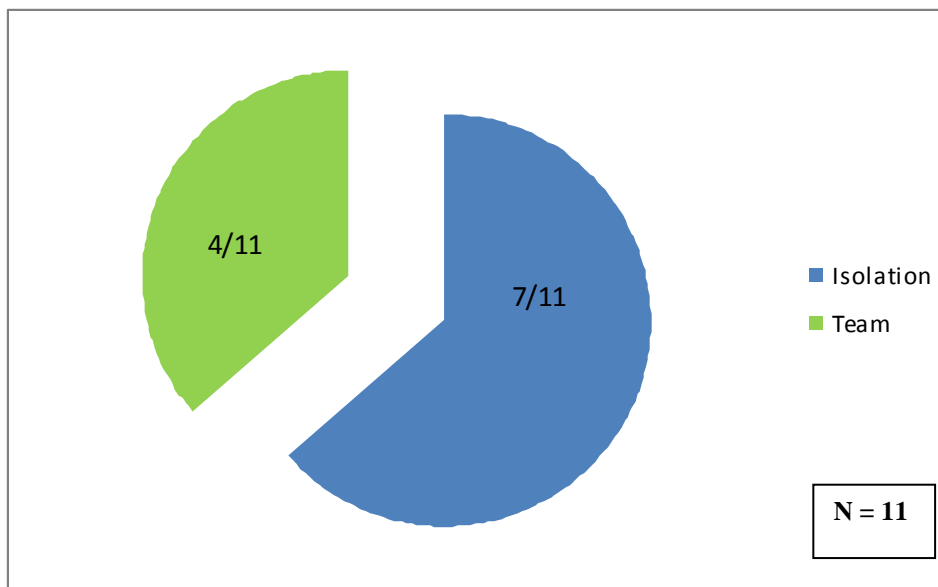
<sup>17</sup> Mother of cleft palate child, and previous coordinator of KZN cleft palate support group

*with follow up cases with cleft lip and/or palate within the ages of 5-10...the children have already been seen by speech therapists previously.'*

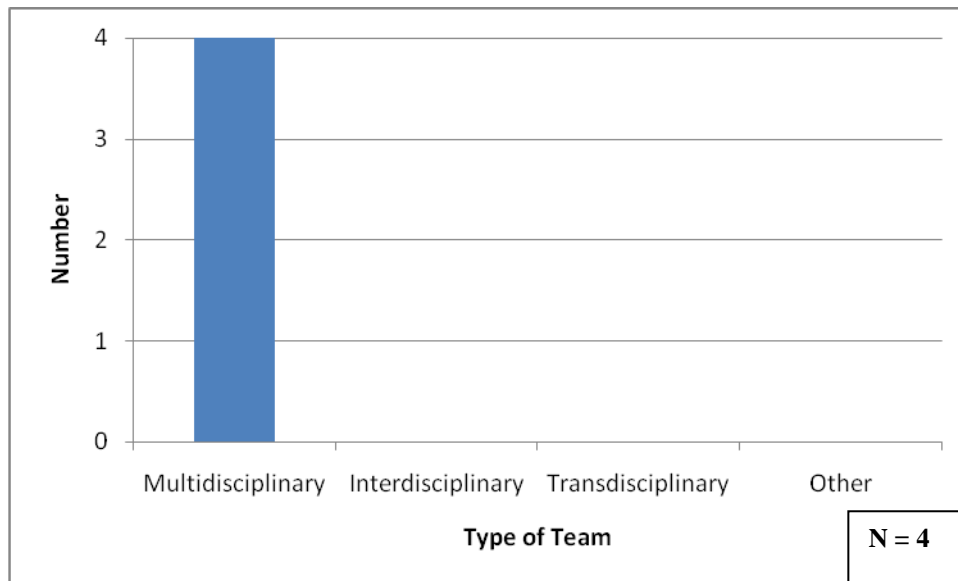
**4.2. Objective 2: To determine the types and composition of teams and team services that exists in the public health sector of KwaZulu-Natal**

It should be noted that only eleven of the nineteen Speech-Language Therapists in the public health sector continued and completed the entire questionnaire, hence it is of importance to note that these findings cannot be generalised to the private health sector.

Figure 4.7. below illustrates that four Speech-Language Therapists, from two districts indicated that they currently work within a cleft lip and/or palate team, whereas seven Speech-Language Therapists do not currently work within a team. For those four participants currently working within a team, Figure 4.8. shows that all teams are described by the Speech-Language Therapists as 'multidisciplinary teams'.



**Figure 4.7: Speech-Language Therapists currently working within cleft palate teams or in isolation**



**Figure 4.8: Types of existing teams for services for children with cleft lip and/or palate**

The results shown above (Figure 4.7.) with regard to team services for cleft lip and/or palate correlate with Olasoji (2009) who reports that one of the main challenges in cleft care in Africa is the lack of a team approach. With national and international research into cleft lip and palate being on the increase, one would expect that all institutions who work with this population would be aware that the current ‘best practice’ for cleft lip and palate care is the multidisciplinary cleft team (Peterson-Falzone, Hardin-Jones & Karnell [2001]; Peterson-Falzone et al., [2006]; ACPA, [2000]). Findings by Dekker (2007) showed that, in South Africa as a whole, only two of the seven established cleft teams are in KwaZulu-Natal, and both are situated within tertiary level hospitals. This may be a possible reason as to why not all Speech-Language Therapists in this study reported their membership on cleft teams, as these teams are possibly still in establishment. However, according to Minifie (1994), the future of the profession of Speech-Language Pathology holds bright promise with regard to growth within the profession and the number of settings in which the professional works. One therefore hopes that this growth also includes knowledge and awareness that these professionals work best within a team approach to intervention, more specifically, a team approach within the field of cleft lip and/or palate.

Despite the above, those teams that do currently exist in KwaZulu-Natal work within a multidisciplinary format. According to Kummer (2001), a multidisciplinary cleft team is one in which the members have defined roles and autonomous practice. The family are involved, and communicate separately with each team member. Hence assessment and treatment occurs in isolation per discipline. Due to the limited communication between team members in this model, it does not appear ideal in comparison to the interdisciplinary team. However, it should also be noted that differing objectives of the different types of teams, specific to cleft literature, have been noticed. Where Kummer (2001) reports limited communication within the members of a multidisciplinary team, Berkowitz (1999) reported the pooling of thoughts and efforts within the multidisciplinary team. However, within the current research study, the definition by Kummer (2001) is utilised, as this was provided to participants on the questionnaire.

The presence of multidisciplinary teams does therefore not appear to be the ideal, as according to the ACPA (2000) management is best performed by the interdisciplinary team, including a cleft centre with trained surgeons and where all efforts are made to include the family in team efforts, decision making and information sharing. In order for the effective management of the condition, it is important for all members of the team to communicate with each other. For example, in the researcher's own experience with cleft lip and/or palate, the plastic surgeon is always interested in a child's progress in Speech-Language Therapy, so as to guide his own decisions as to when the child may be 'discharged' from the plastic surgery follow-up clinic. Such practice made treatment for the researcher easier and more collaborative. Such practice also allowed for learning between disciplines as well as the involvement of the parent during treatment efforts.

Furthermore, recent advances in cleft care have led to the transdisciplinary approach being adopted as best practice (ACPA, 2007). However, Gopal (2009) comments on the importance of considering financial implications of adopting more expensive team models, such as the transdisciplinary team. It is therefore important that institutions offering cleft lip and/or palate care evaluate the levels of care provided, and financial costs thereof. Although the child may be receiving the necessary care to alleviate the symptoms of the condition, parents and co-workers may further enhance their service

by ensuring more cooperation and collaboration between disciplines. Despite this, it is also important to remember that, within the public health sector, large caseloads, long hours and shortages of staff do not always allow for meetings between professionals, especially if the figures relating to cleft lip and/or palate being discussed are low.

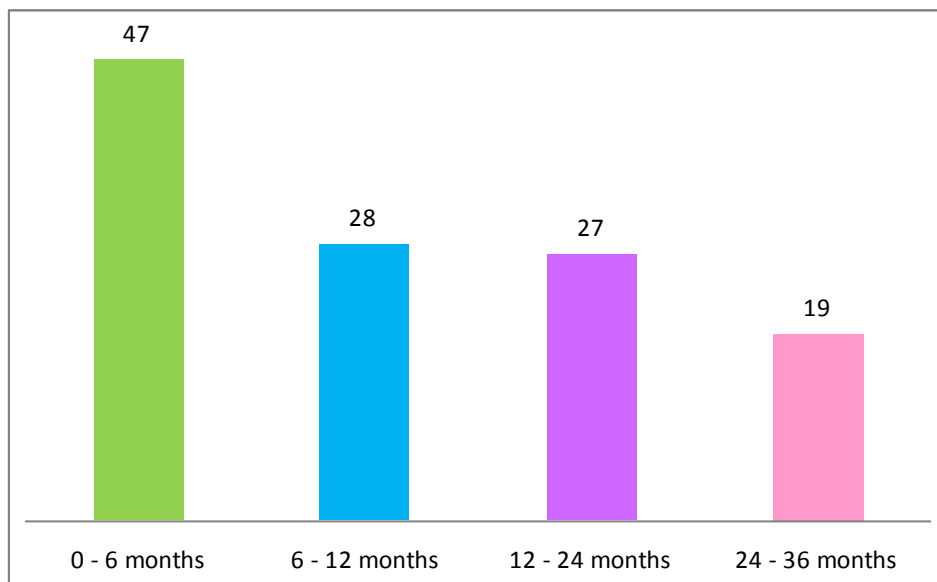
Speech-Language Therapists who are currently working within cleft teams were required to state the members on their institution's team. The analysis revealed that the most common members on the four teams are *Speech-Language Therapists, Doctors and Surgeons (ranging from medical interns to plastic and maxillofacial surgeons) and nurses*. This is important to note, as all these members are mentioned by Berkowitz (1999) as members that should be on the craniofacial team. However, it is disappointing that only one participant mentioned an Audiologist, only one mentioned the parent, and only one mentioned the orthodontist or dentist. According to Hodgkinson et al. (2005), orthodontic evaluation and treatment is necessary from birth where pre-surgical dental or facial orthopaedics, such as palatal plates, are needed. Furthermore, a guideline from Strauss (2008) states that an *orthodontist*, in addition to the Speech-Language Therapist and surgeon should be one of the minimal members on the cleft palate team. It is also disappointing that the *parent* is not a routine member of teams. A possible reason for the parent not being mentioned frequently may be that the parents may only become involved in decisions after the medical team have discussed the case and brought forward their plan for treatment. This is similar to cleft palate team standards discussed by Strauss (2008). According to Strauss (2008), the parents and family should have an opportunity to ask questions and discuss treatment decisions only after the cleft palate team's evaluation of the child. Furthermore, the involvement of parents does not form part of basic criteria, but is an additional criterion for the cleft palate team. It is therefore possible that this is the case in KwaZulu-Natal institutions, and hence the parent may not be considered part of the initial evaluation team.

However, according to Scherer, D'Antonio and McGahey (2008) it is essential that Speech-Language Therapists working in early intervention reconsider service delivery models for practice, as, due to reductions in health care budget, limitations exist with regard to number and frequency of Speech-Language Therapy sessions. It is therefore

vital to become more involved with the development of *parent* focused early intervention programmes. Scherer, D’Antonio and McGahey’s (2008) study showed that an early intervention programme devised and supervised by a Speech-Language Therapist, but provided by the parent in the home environment on a daily basis can reduce the speech impairments of young children with cleft lip and/or palate. In the researcher’s own practice, this is also evident, not only with speech-language disorders relating to cleft lip and/or palate, but communication disorders in general.

**4.3. Objective 3: To determine the approximate total number of children with cleft lip and/or palate from birth to three years seen by Speech–Language Therapists in the public health sectors of KwaZulu-Natal, as well as levels of consultation with Speech-Language Therapists**

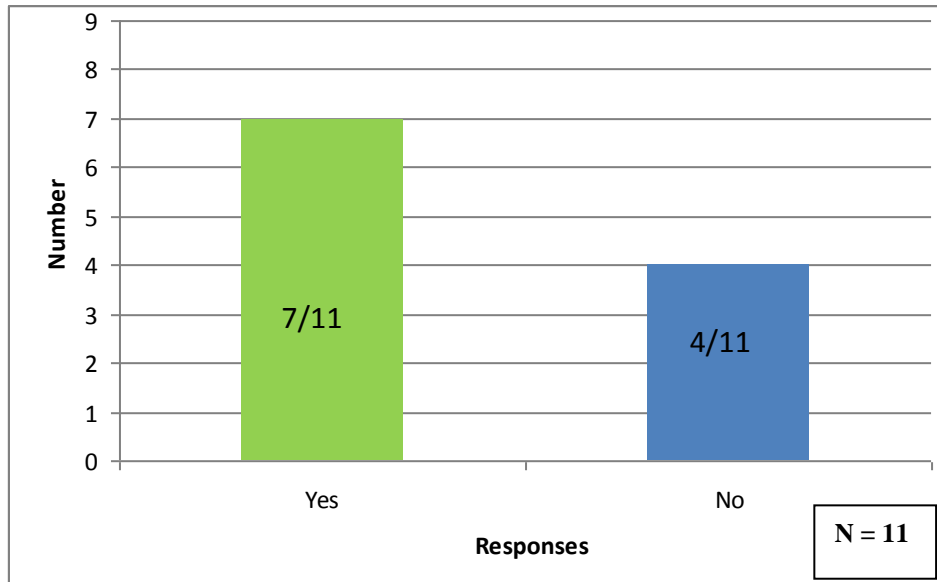
Figure 4.9. below depicts the approximate total number of children with cleft lip and/or palate within the age range birth to three, seen by Speech-Language Therapists in public health in KwaZulu-Natal within the past year. Speech-Language Therapists have seen approximately 47 children within the age range birth to six months, 28 children within the age range 6 to 12 months, 27 children within the age range 12 to 24 months, and approximately 19 children between 24 and 36 months of age.



**Figure 4.9: Total number of children with cleft lip and/or palate within the age range birth to three seen by Speech-Language Therapists currently working in the public health sector of KwaZulu-Natal**



The figures displayed above reflect the estimated total number of children (121) with cleft lip and/or palate seen in the age range birth to three by all eleven public sector Speech-Language Therapists. However these figures should be considered with caution due to them being estimates provided by participants and not exact figures.



**Figure 4.10: Correlation between total number of children Speech-Language Therapists have seen with cleft lip and/or palate from birth to three and the number of children with a cleft attending their hospital**

The figures displayed above, i.e. only seven Speech-Language Therapists reporting a correlation between their clientele and the number of cleft lip and/or palate births at their institution is disappointing. Ideally, every child born with a cleft lip and/or palate should be referred to the Speech-Language Therapist. Children who have passed the neonatal stage, in the researcher's own experience, may have been discharged from Speech-Language Therapy at the institution and may be attending at a clinic or institution closest to their home. When asked for possible reasons as to why a correlation between the total children seen and the number of births did not exist, the following themes emerged.

- **Patients do not attend sessions**

A common issue reported by Speech-Language Therapists is that patients do not attend their follow up appointments for Speech-Language Therapy. As one

participant responded, “*many return at school age with an unrepaired cleft lip and/or palate. This is either because they were not referred appropriately or because they did not attend their follow ups*”.

The return of a child with an unrepaired cleft at school going age is extremely concerning. The return of the patient for surgery is important, but reasons as to why an unrepaired cleft happens need to be investigated further. According to Louw, Shibambu and Roemer (2006, p. 1), “cultural diversity has a profound effect on the ways in which families and professionals interrelate cross culturally and participate together in treatment programmes”. Two aspects relate here, one being the question of why the cleft was not repaired, and secondly why follow-up appointments were not attended. Reasons for unrepaired clefts in South Africa may relate strongly to the diversity in cultural backgrounds and beliefs of patients. Many patients may turn to a traditional healer, as the belief is that technology and Western medicine may interfere or go against the wishes of the ancestors as in African belief (Louw, Shibambu & Roemer, 2006). Others may prefer traditional healing due to their beliefs that the cleft may have resulted due to witchcraft or as punishment for the parents’ past sins (Dagher & Ross, 2004).

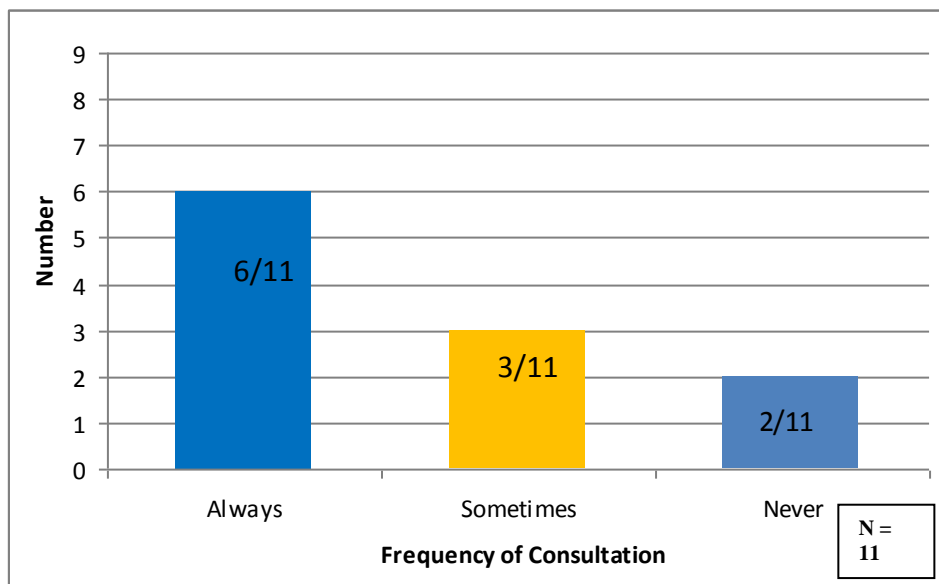
Reasons for patients not attending follow up appointments may be that the distance to travel to the institution for therapy is too far, and, secondly, the cost of travelling may be significant. This was mentioned by Scherer, D’Antonio & McGahey (2008) who state that professionals should always consider the financial costs for implementation of the intervention programme.

- **Patients not referred**

The result that patients are not regularly referred, relates significantly to the results found in Objective one. Despite development in the field, a problem with the referral of patients still exists in some institutions. The words ‘some institutions’ needs to be stressed here, due to the differing viewpoints from participants. In addition, there are different ‘levels’ of institutions in KwaZulu-Natal and South Africa, and thus referral systems may be somewhat improved at the better established, more technologically advanced institutions. This is further emphasized by Sanders and Bradshaw (2010),

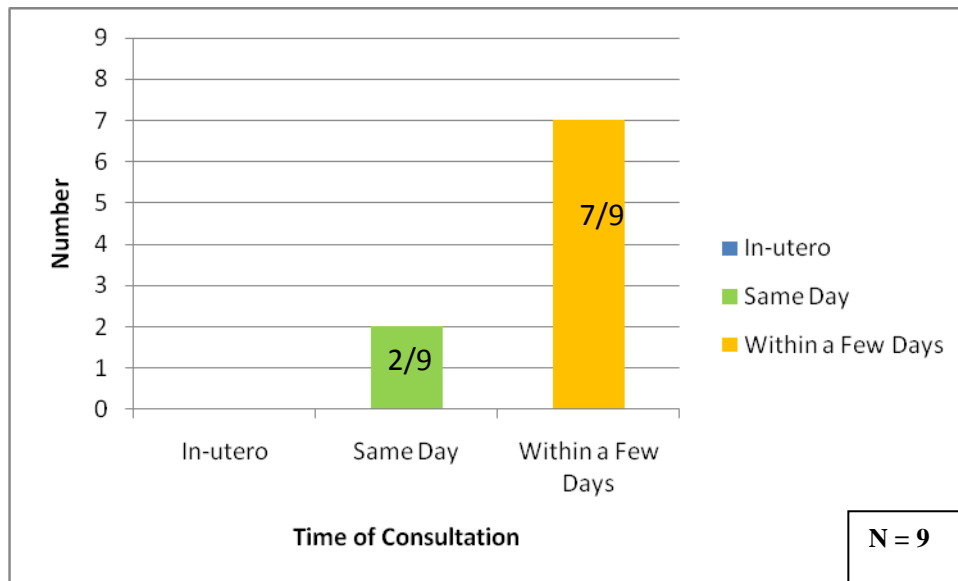
who report that South Africa on its own is one of the most unequal societies when it comes to health care, in terms of coverage as well as quality of service. Differences even exist between health care districts in terms of services for neonatal, maternal and child health (Sanders & Bradshaw, 2010).

Despite the reported problems with referrals at certain institutions (see Figure 4.11. below) most Speech-Language Therapists are consulted at the *birth* of a baby with a cleft lip and/or palate at their institutions. Three (27.2%) reported that they were only consulted on some occasions, and only two (0.18%) reported that they are never consulted.



**Figure 4.11: Frequency of consultation with Speech-Language Therapists at the birth of a child with a cleft lip and/or palate at institutions**

The majority of Speech-Language Therapists indicated that they are consulted at the birth which is ideal (ACPA, 2007). However, it is concerning that, for those Speech-Language Therapists who fall into the ‘never’ category, the provision of early communication intervention services for all conditions at their hospital may also be extremely limited. Those Speech-Language Therapists who reported that they are consulted, usually receive the referral within a few days of the child with cleft lip and/or palate’s birth, as seen in Figure 4.12 below.



**Figure 4.12: Time of consultation with Speech-Language Therapists at the birth of a child with a cleft lip and/or palate**

Speech-Language Therapists in public health in KwaZulu-Natal are consulted at the birth of a child with a cleft lip and/or palate, however, not always on the day of birth as seen in Figure 4.12. above. This is in contrast to the literature stating that the therapist should be involved from Day one (i.e. at birth), especially if feeding difficulties are present. In more developed countries of the world, as well as in some institutions of South Africa, it is possible to detect the presence of a cleft prenatally, as in the researcher's own experiences. Despite this, none of the Speech-Language Therapists in the public sector were ever consulted prenatally. This may be due to low detection rates of cleft lip and/or palate in the prenatal stage in public health in South Africa. According to Jones (2002), only between 14% and 25% of cleft lip, with or without the presence of cleft palate is detected via ultrasound. This figure appears low, and hence could be a possible reason for none of the participants indicating that they are consulted prenatally. Furthermore, according to the American Academy of Paediatric Dentistry (2008), the optimal evaluation by a cleft lip and palate team is within the first few weeks of life, and wherever possible, within the first few days. It may therefore be assumed that a similar pattern may exist in more developed countries, where consultation begins within a few days of the birth as opposed to prenatally. This is in contrast to latest guidelines from the ACPA (2007), however, who recommend an initial speech-language evaluation at or before six

months of age. However, if best practice for cleft care is within a team model (ACPA, 2007), and if lip repair is recommended by three months of age, then an initial speech-language evaluation at six months of age does not appear ideal.

Participants were also required to indicate the departments or professional persons from whom they most frequently receive referrals, from most frequent to least frequent. These answers were then tabulated to determine the overall frequency of referrals from other departments and professionals. The table below shows that the majority of participants mentioned referrals from doctors and surgeons, followed closely by the neonatal intensive care unit or nursery. Nurses were third most frequent, and all other professionals/departments (mentioned by only two participants) fell into the fourth most frequent category.

**Table 4.1. Ranking of referrals from other departments/professional persons**

<b>Ranking</b>	<b>Professional/Department</b>	<b>Number of Speech-Language Therapists</b>
1	Doctors and Surgeons	9
2	Neonatal Intensive Care Unit/Nursery (NICU)	6
3	Nurses	2
4	Other (orthodontist/dentist)	1
	(geneticist)	1
	(physiotherapy)	1
	(occupational therapy)	1
	(dieticians)	1
	(social workers)	1

The results shown in the table above, are not surprising, as the researcher would expect children with cleft lip and/or palate to first be ‘picked up’ by the doctor or in the NICU on examination. Hence it appears likely that these would be the first professionals to arrange for a referral to the Speech-Language Therapist in public health in KwaZulu-Natal. The researcher assumes that nurses were not one of the

most frequent categories possibly due to the nurse being with the doctor on examination, however it may be the doctor who makes the actual referral or instructs the nurse to do so.

With regard to orthodontists, it may be that the referral to the orthodontist as well as the Speech-Language Therapist and other professionals is made by the doctor, which could be a possible reason as to why few referrals are received from the orthodontist. However, it is pleasing to note that the orthodontist was mentioned as a source of referral, as this is in accordance with the American Academy of Paediatric Dentistry (2008). According to this organisation, the interdisciplinary team of specialists, including Speech-Language Therapist, should ensure that they are in close cooperation with their orthodontic and maxillofacial counterparts.

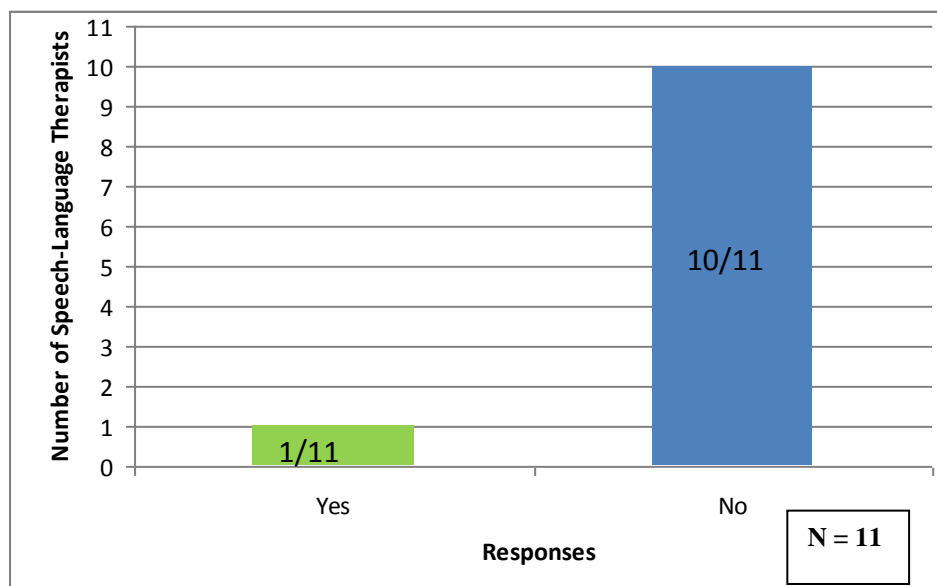
The role of the geneticist in cleft lip and/or palate is discussed by Saal (2002), who states that genetic counsellors or clinical geneticists are most frequently involved when a prenatal diagnosis of cleft lip and/or palate occurs, associated with a syndrome. The geneticist has the role of counseling the family/parents in order to increase their confidence regarding treatment and management decisions. The role of the geneticist is especially important for genetic screening in cleft lip and/or palate patients (Hodgkinson et al. 2005), as more than 400 syndromes have cleft lip and/or palate as an associated malformation (Kummer, 2001).

According to the Department of Health's (2001) Human Genetic Policy, South Africa requires approximately eighty geneticists in order to adequately service the South African population. However, at the time of this policy there were only four registered, full time clinical geneticists practicing in the country – this is clearly substantially lower than the required amount. Furthermore, South Africa has a total of approximately twenty genetic counsellors, as opposed to the required 320 (Department of Health, 2001). In addition to staff shortages in other areas of the public health sector, the staffing situation with regard to genetics was described as “critical and requiring urgent attention” (Department of Health, 2001, p. 3). Furthermore, of importance to this research study is that the policy describes cleft lip and palate as a priority condition in terms of prevention and management (Department of Health, 2001). Due to the staffing crisis in genetics in South Africa, it can be

deduced that lack of staff is a possible reason as to why only one Speech-Language Therapist mentioned a geneticist as a source of referral for cleft lip and/or palate. The South African Genetics Society (2009) has been involved in a number of projects to promote the field of genetics and genetic counselling in South Africa by offering, amongst others, tuition scholarships, which one hopes may change the staffing crisis for the better, and in turn improve the availability of expert genetic testing and information provision.

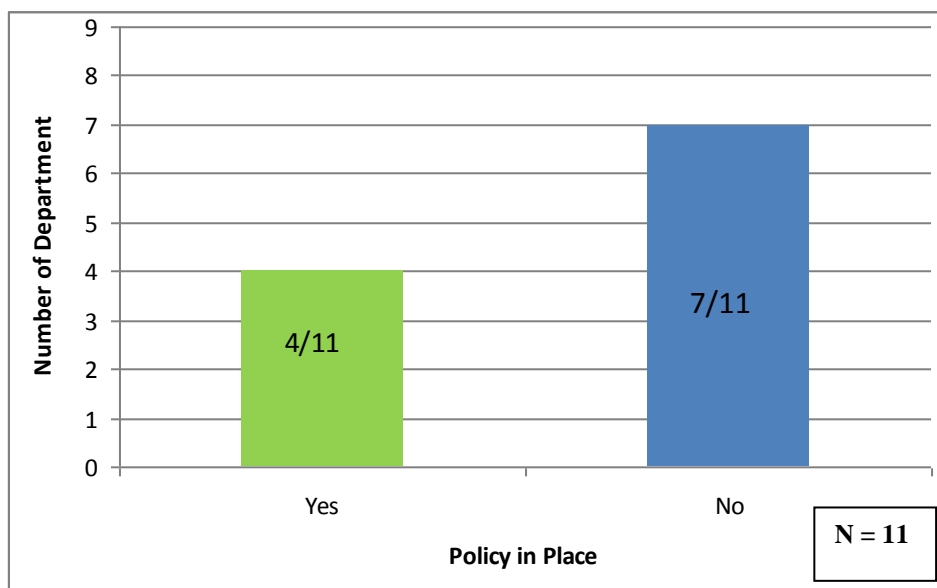
#### **4.4. Objective 4: To determine the existence, and if applicable, the nature of policies or protocols for children with cleft lip and/or palate in the public and private health sectors of KwaZulu-Natal**

Of eleven participating Speech-Language Therapists, only one mentioned that a policy for cleft lip and/or palate was in place at the institution at which he/she is employed, as seen in Figure 4.13. below.



**Figure 4.13: Existence of institutional policies for cleft lip and/or palate**

Figure 4.14. below shows that only four of the eleven Speech-Language Therapists indicated that a Speech-Language Therapy departmental policy for cleft lip and/or palate was in place.



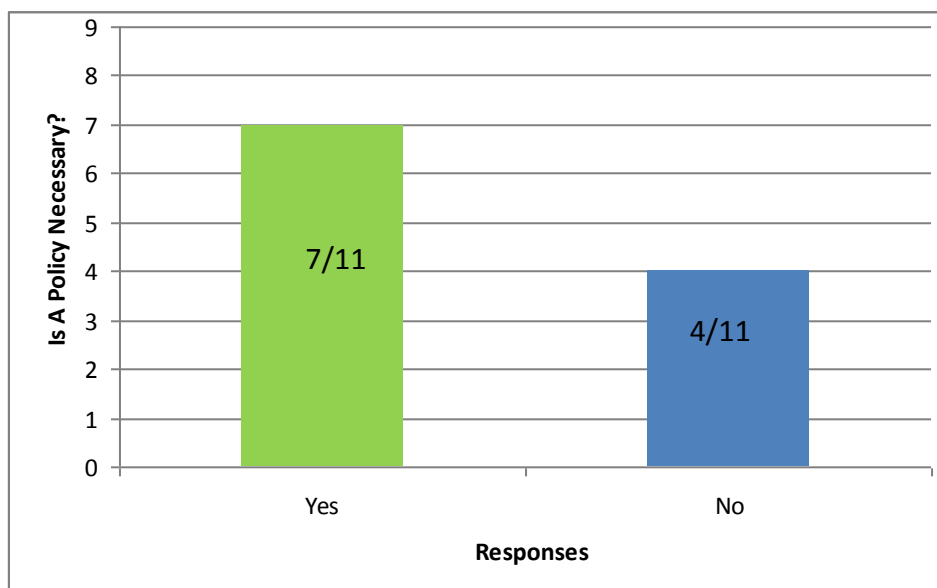
**Figure 4.14: Existence of Speech-Language Therapy departmental policies for cleft lip and/or palate**

The general lack of institution policies is concerning, as, according to Hodgkinson et al. (2005), the child with a cleft lip and/or palate requires a protocol or pathway for care, such that “team members may function most effectively and maximise the benefits of this system to the patient” (Hodgkinson et al., 2005, p. 8).

The results seen in Figure 4.14. are parallel to the results seen with regard to the existence of teams (Figure 4.7.). Those participants who reported that they currently work within cleft teams also mentioned that departmental policies were present. It therefore appears that policies may be more prevalent in institutions where cleft lip and/or palate teams exist, and where teams do not exist, the presence of policies is less likely. It therefore appears that the development of cleft lip and/or palate teams may assist in the development of policies for these children, not merely Speech-Language Therapy departmental policies, but policies on a institutional basis as well.

Despite the differences in the existence of cleft lip and/or palate policies, it is concerning to note that only seven of the eleven Speech-Language Therapists who participated felt that a policy for cleft lip and/or palate is necessary, as seen in Figure 4.15. below.





**Figure 4.15: Participants’ responses to ‘Is a policy necessary?’ for services for children with cleft lip and/or palate**

In terms of the nature of policies, participants were asked to state the main areas or aspects covered in their policy. For the single institution where both an institutional and departmental policy is present, it was noted that the same policy applied at both hospital and departmental level. This shows that, in order for policies to be considered ‘important’, it may be important for the professionals involved in the care of the patients for whom a policy is necessary to agree. Hence it appears important that Speech-Language Therapists currently working with cleft lip and/or palate teams consider the development of policies, with the hope that the development and then annual review of Speech-Language Therapy departmental policies may positively influence and instigate the development of institutional policies in public health.

The most common aspects or areas that are currently in the four public health Speech-Language Therapy departmental policies are *assessment and treatment*, as well as *referral patterns*. This is interesting as those participants in an institution where a policy did not exist but who felt it was necessary mentioned, *assessment and treatment protocols* and *the referral pathway* as the two most common themes. Of importance, is that, as most existing policies are departmental and not at an institutional level, the focus is mainly on Speech-Language Therapy, with minimal

focus on the team management of the child and family as well as termination or discharge from Speech-Language Therapy. This further reiterates the discussion above, where the researcher mentioned that the development of Speech-Language Therapy departmental policies may positively influence institutional policies. Furthermore, holistic and team care of all patients involves the pooling of treatment efforts, and hence, ideally, policies should include a holistic look at the assessment and management of the condition. This ‘holistic look’ was only noted in one policy, where the same cleft lip and palate policy services both the Speech-Language Therapy department as well as the institution.

**4.5. Objective 5: To provide a broad overview of the aims of and methods utilised for assessment of children with cleft lip and/or palate from birth to three years used by Speech–Language Therapists in the public health sectors of KwaZulu-Natal**

Participants in the study were asked to provide a broad overview of the aims and methods of assessment that they utilise for the child with a cleft lip and/or palate from birth to three years of age. Results were analysed qualitatively and are discussed below.

- **Case History**

Six of eleven therapists reported the use of case history as the initial aim of their assessment. According to Hegde and Davis (1995), the case history is a standard, mainly initial phase of the assessment process in any condition. The Speech-Language Therapists reported that they usually obtain case history information via questionnaires and interviews, as well as from patients’ medical records. The methods utilised by Speech-Language Therapists were *interviews and medical records review* as the main methods of obtaining case history information.

- **Oral Peripheral Examination**

This term is used synonymously with ‘Motor Speech Examination’, as it has been noted that different therapists use the terms interchangeably. It should be noted that, although the majority of participants (7) did mention this area as part of their assessment, there were some (4) who did not. This is concerning as the oral peripheral examination is described by Shipley and McAfee (2008) as a standard assessment in Speech-Language Pathology. It is not advisable to merely rely on medical notes to determine the status of a cleft or adequacy of cleft repair, as this forms part of the Speech-Language Therapist’s role in assessment as well (Uys, 2008). Furthermore, it may be the Speech-Language Therapist who notes the presence of an oronasal fistula during feeding therapy or assessment of speech and hence the oral peripheral examination is not only conducted during an initial assessment, but may need to be repeated after secondary surgery or if there are complaints of, for example, nasal regurgitation after surgery.

Speech-Language Therapists did not report on the adaptation of the oral peripheral examination for the child’s age. As this study concerned the younger (0-3 years) population, adaptations in addition to instructions to the child are necessary. This is reiterated by Trost-Cardomone (2008), who lists age appropriate stimulus material, such as visual feedback, as a necessary part of the assessment or therapy kit.

- **Feeding**

All therapists mentioned feeding as an integral part of the Speech-Language Therapist’s assessment of the child with a cleft lip and/or palate (0-3 years). However, the majority of therapists mentioned that their assessment occurs via observation, with increased attention paid to the assessment of positioning for feeding. Limited attention is paid to aspects of nutrition, frequency of feeding, frequent winding and weight gain. Nutritional status is especially important in cleft lip and/or palate babies, as increased energy levels are spent during feeding, and it is important to ensure that calorie intake is not compromised (Berkowitz, 1999). Furthermore, Berkowitz (1999) stresses the importance of consistent weight gain for

cleft lip and/or palate babies. It is also important to note that, sometimes, an oral peripheral examination may be included as part of the feeding assessment (Uys, 2008), however none of the participants mentioned this. The use of videofluoroscopy was only mentioned by two of nine Speech-Language Therapists where a swallowing difficulty is suspected. This could be due to many Speech-Language Therapists in KwaZulu-Natal not having access to radiological equipment, or the field not being practiced at all institutions as yet, as South Africa is a developing country (Gopal, 2009). This correlates with Strasheim (2010), whose study on early communication intervention in South Africa revealed that Speech-Language Therapists would have preferred to have access to instrumental assessments such as Videofluoroscopy.

- **Language**

Participants in the study mentioned the use of both formal and informal measures for the assessment of language ability in their service to the child with a cleft lip and/or palate (0-3 years). With regard to the use of informal measures, object and picture identification, response to oral instructions and observations of caregiver-child interaction were reported. This is in accordance with Swiegers (2010), who states that the assessment of the child with a cleft lip and/or palate in the infant stage needs to focus on parent child interaction, the means of communication, e.g. gesture, as well as receptive and expressive language skills, via formal or informal measures.

Five Speech-Language Therapists also mentioned the use of formal, standardised tests. Tests that were mentioned included the Rossetti Infant and Toddler Language Scale (Rossetti, 1990), Receptive-Expressive Emergent Language Scale (Bzoch, League and Brown, 1991), Peabody Picture Vocabulary Test (Dunn & Dunn, 1997) and the Test of Early Language Development (Hresko, Reid & Hammill, 1999).

Speech-Language Therapists in public health also mentioned the use of adaptations to tests as well as their assessments, as many of their clientele are monolingual isiZulu (or other South African language) speakers. This is common to the field of Speech-Language Pathology, as many tests are standardised for the international, mainly English speaking populations, with no regard to second language English speakers, non-English speakers or English speakers with different accents or vocabulary use as

in South Africa's diverse population (Swiegers, 2010). However this area, with specific reference to cleft lip and palate in South Africa has been investigated by Swiegers (2010), whose research into the field resulted in the development of a perceptual Speech assessment protocol for Zulu speaking preschoolers with cleft palate. A recommendation of her study was that investigation is needed to determine the adjustments in training of Speech-Language Therapists in South Africa, so as to improve their service delivery to Zulu speaking children with cleft palate. As Speech-Language Therapists mentioned the use of adaptations to formal tests, it is evident that Swiegers' (2010) recommendation is appropriate. In terms of this study, the use of adaptations shows that Speech-Language Therapists are making efforts to overcome the language barrier, however more focus on this during training as discussed by Swiegers (2010) will allow for language barriers to be targeted at an earlier stage.

- **Speech**

Participants in the study mentioned the elicitation of speech sounds at single word and connected speech levels via modelling in order to gain a picture of the child's speech sound system development. This is in accordance with Bleile (2004) who describes the importance of obtaining a speech sample so as to determine the nature and severity of the speech problem at hand. However, the speech sample may be either spontaneous or modelled, and in KwaZulu-Natal, the trend seems to be that of modelled speech samples. This is concerning as, while both types of speech sample are important, the conversational, spontaneous sample is more evident of the child's productions in a naturalistic context (Shiple & McAfee, 1998). Speech-Language Therapists in the study did not make mention of the assessment of speech in the very young child, such as noting the use of vocalisations and variations of babble. This aspect is important, as vocalisations and babble production forms an important part of both assessment and management with the prelinguistic child (Peterson-Falzone et al., 2006).

- **Other areas of assessment**

It is highly concerning that the assessment of audiological status was mentioned by only one of eleven participants, and the assessment of voice, in particular resonance which is a key problem area in cleft palate (McWilliams, Morris & Shelton, 1990), was only mentioned by five participants. With regard to audiological evaluation, the American Cleft Palate-Craniofacial Association (2000, 2007) recommends annual hearing evaluations with a view to monitoring of hearing status. For this guideline to be followed, the Speech-Language Therapist should ideally arrange for an audiological evaluation during the initial assessment. However this does not appear to be the case in KwaZulu-Natal, with audiological evaluations occurring only when a hearing difficulty is suspected. A possible reason for this may be shortages of Audiology staff as well as audiological equipment, however in that case a referral to another institution may be possible.

Resonance is a key area of difficulty in cleft palate speech, with velopharyngeal incompetence being a common problem seen in children with cleft palate (McWilliams, Morris & Shelton, 1990). Despite this, it may be possible that, within the age range of this particular study (0-3) Speech-Language Therapists are more focused on the child's phonetic and language development as opposed to resonatory features. This is in accordance with Kummer (2001) who states the within the age range birth to three the focus should be on phonetic development, with monitoring of resonance still being important. This may be the reason as to why only four of the nine Speech-Language Therapists mentioned the assessment of resonance.

**4.6. Objective 6: To provide a broad overview of the speech, language and feeding management services for children with cleft lip and/or palate from birth to three years provided by Speech–Language Therapists in the public health sector of KwaZulu-Natal**

For this section of the questionnaire, open ended questions were utilised. Participants were required to provide a broad overview of the management they provide for the child with a cleft lip and/or palate from birth to three years within listed areas. The results are presented below.

- **Speech Difficulty**

Therapists mentioned the use of the following methods: phonetic placement, drillwork, modelling and imitation, visual reinforcement, verbal reinforcement as well as facilitating context as methods of eliciting target speech sounds.

*Phonetic placement*, according to Bleile (n.d.) is a motor based approach to treatment, where the target sound and its qualities are taught to the child. This approach is used until the child can produce the sound accurately in isolation, and is suitable in cleft lip and/or palate (Trost-Cardomone, 2008).

*Facilitating context* (Bleile, 2004) is used so that, when a sound can be produced in isolation, the context may then be expanded into syllables and words.

*Drillwork* is a method of therapy which follows a stimulus-response approach (Shriberg & Kwiatkowski, 1982, as cited in Gordon-Brannan, 2007). Here, positive feedback is given for a correct production, and correctional feedback for an incorrect production. Drill is a highly structured approach that has given way to more play based approaches, such as drill play (Gordon-Brannan, 2007). According to Peterson-Falzone et al. (2006), drill work and drill play are approaches which may be used to increase early vocabulary in cleft lip and/or palate as well.

*Modelling and imitation* may include the use of reinforcers or stimuli, including auditory, tactile and visual stimuli for the placement of speech sounds. This approach is also discussed in Peterson-Falzone et al. (2006), who describe the use of a mirror and modelling lip and tongue movement as well as sounds and consonant-vowel syllables in cleft lip and/or palate.

Of importance to note is that none of the Speech-Language Therapists mentioned therapy for or consideration of compensatory articulation productions. Kummer (2002) recommends that the Speech-Language Therapist makes the decision whether or not to change placement, or to keep the compensatory placement. She also recommends that it is better to wait until after palatal surgery (typically at six to nine months) before beginning therapy for maladaptive compensatory articulation.

- **Language Difficulty**

Participants in the study reported the use of themework, sentence completion, visual and verbal cues as well as modelling and imitation being useful during language therapy.

Participants also mentioned the use of Rossetti as well as Hanen programme guidelines (The Hanen Centre, 2007) during language therapy. The Language Assessment, Remediation and Screening Procedure (LARSP) (Crystal et al., 1976, cited in Owens, 2004) was reported by one participant.

The finding of a common theme with regard to the use of Rossetti as well as the Hanen programme is pleasing, as these guidelines stress the use of the parent as a facilitator of therapy and for language development (The Hanen Centre, 2007). As the parent is considered an important member of the team in cleft care, the use of such guidelines (parent centred intervention) is ultimately beneficial to parents and the child, as well as the Speech-Language Therapist faced with challenges such as time management and increased caseload.

- **Velopharyngeal Insufficiency**

*Blowing exercises* was noted to be the most common method of therapy for children presenting with issues of hypernasality. These exercises focus on helping the child differentiate between oral and nasal airstreams, such that they begin to ‘feel’ that speech occurs through the oral airstream. However, Peterson-Falzone et al., (2006) do not focus entirely on nasality issues until the child is three years of age, as before this, the focus is on increasing the child’s phonetic repertoire. It is, however necessary to encourage simple activities such as blowing on lightweight items, e.g. cotton balls, or blowing out a candle with gentle occlusion of the nares where necessary (Peterson-Falzone et al., 2006). Therefore, with regard to encouraging appropriate oral airflow, Speech-Language Therapists appear to have the correct aim of eliminating hypernasality by encouraging oral airflow. However, the technique of using blowing exercises (mentioned by 6 of 11 participants) is strongly discouraged by Kummer (2002), who states that the use of blowing or sucking exercises may only



improve blowing and sucking, and have no impact on speech. She suggests that articulation techniques utilised for articulation difficulties are also utilised for velopharyngeal insufficiency. These techniques include auditory discrimination training, visual feedback, tactile kinaesthetic training and tactile feedback (Kummer, 2002).

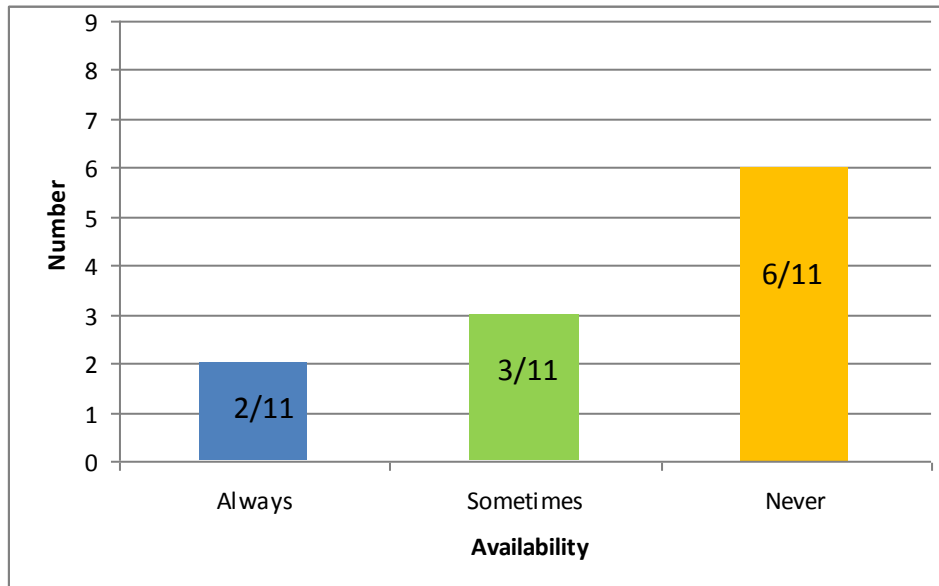
Participants responded that “*the referral to the ENT to rule out velopharyngeal insufficiency to assist with diagnosis*” is important when treating this area. This is important to note, as it depicts a picture of forming referral systems and pathways, as well as the importance of collaboration with the Ear Nose and Throat Specialist in cleft care teams. Importantly, Kummer (2002) also reports on a ‘general agreement’ that the management of velopharyngeal insufficiency via surgical intervention or prosthetics remains the most effective manner of alleviation. The referral to the Ear, Nose and Throat Specialist is therefore necessary and Speech-Language Therapists are correct in their referral thereto.

- **Feeding Therapy**

*Positioning* was found to be one of the most common and important aspects of feeding management. According to Wolf and Glass (1992) and Arvedson and Brodsky (2002), positioning of the cleft palate infant in an upright position (during breast or bottle feeding) is vital to ensure the downward flow of milk and avoid the ‘backflow’ into the nasal cavity, which could lead to Eustachian tube dysfunction.

*Changes in food textures and consistencies* or the *adaptation of the child’s diet* was another common consideration in the Speech-Language Therapist’s management of the child’s feeding difficulties. This goes hand in hand with another common theme, namely *the change of feeding utensils*. These guidelines are mentioned in Wolf and Glass (1992) who report the importance of following the correct grading of boluses of, for example, from liquids to semi solids. The *change of feeding utensil*, i.e. change to a specialised feeding teat, was mentioned frequently by participants, however, many mentioned challenges faced in terms of the availability of specialised teats. Figure 4.16. below depicts the availability of assistive devices for cleft lip

and/or palate. More than half of the participants (6 out of 11) responded that assistive devices for feeding are never available.



**Figure 4.16.: Availability of Speech-Language Therapy assistive feeding devices for cleft lip and/or palate**

As shown above, more than half (6/11) of Speech-Language Therapists are never able to access an assistive device for feeding purposes. Three participants stated that access to these devices occurs only sometimes, and only two participants reported that the devices are always available. This is highly concerning, as in South Africa, there are policies such as the National Rehabilitation Policy, which states that instant access to feeding and swallowing assistive devices (such as those which may be needed by infants with a cleft of the lip and/or palate) should be guaranteed. One needs to look at this statement closely. According to the Cambridge Dictionary, the word ‘instant’ is defined as *happening immediately, without any delay* (Gilliard, 2003). We are aware that the figures for cleft lip and palate are low, as compared to other conditions such as HIV/AIDS, however it is concerning as the National Rehabilitation policy exists that guarantees instantaneous access to a feeding device. Many of KwaZulu-Natal’s hospitals have achieved baby friendly status, however, should a ‘baby friendly’ vision be the reason as to why modified nipples and teats are not permitted, then this should be accounted for in the policy as well. In addition, of the five participants who have access to these devices either always or only on occasions, at

least two have reported only recent access, due to sponsorships by organizations. Surely this is another reason for the marketing of the Speech-Language Therapy profession as well as the conditions serviced by the profession – perhaps this would allow not just for decisions made intra-hospital, but by the Department of Health as a whole.

Excellent to note is that Speech-Language Therapists in some institutions have been proactive in increasing and developing departmental stock of assistive feeding devices. As one participant mentioned: *we have a basic/minimal stock of devices*. This appears to be a step in a positive direction. Others have made the effort to obtain names of stores stocking the devices such that those parents who can afford a device may purchase it independently. It is also important to note that therapists are currently attempting to place feeding assistive devices on to the national tender, such that easier access to this device, as with hearing aids, is possible.

No mention was made of the timing of feeds, as well as counselling of the mother with regard to lengthy feeding times. One hopes that as many participants mentioned an observational assessment of feeding, that advice and reassurance is given to the mother. Such information is vital as according to Bellardie and Harris (2008), feeding causes considerable anxiety, and hence may affect mother-child bonding, especially with the need to achieve the required weight for surgery.

- **Voice Difficulties**

Varying viewpoints on voice difficulties and voice therapy were noted in participants' responses. Responses ranged from applying direct voice therapy methods (as discussed in Kummer, 2002) for resonance using modelling and imitation, to discussing general vocal hygiene with the parent. Importantly, many participants reported that *cases will be referred to the ENT to determine the cause before management by the Speech-Language Therapist*. This is important, as, according to Peterson-Falzone et al. (2006, as cited in Gopal, 2009) vocal hyperfunction may be the cause of voice disorders in cleft lip and/or palate. This therefore warrants a referral to the ENT.

- **Provision of General Information**

Speech-Language Therapists reported on the use of *handouts, pamphlets and booklets*, as well as *counselling for parents*. Participants mentioned the use of home programmes, which are important, especially if the parent is to be considered a facilitator of therapy and if therapy is to be naturalistic and parent centred (Owens, 2004), as appropriate to birth to three years age range.

Of concern, is that only one participant mentioned the use of in-services, i.e. education for the public and other institution staff. Ideally, it would be impressive if this figure was higher, as in-services are important, not only in marketing the Speech-Language Therapy service (Van de Linde, 2008), but also in increasing the public awareness of cleft lip and/or palate. This would also assist with the *lack of referrals* mentioned by participants as a reason to why they do not see many children with cleft lip and/or palate.

**4.7. Objective 7: To provide a description of the views of Speech–Language Therapists in the public health sector of KwaZulu-Natal with regard to the services for children with cleft lip and/or palate within the age range birth to three years**

Varying viewpoints were held by the participating Speech-Language Therapists about services. These are mentioned below.

- **Lack of teamwork, resources and follow up**

Some Speech-Language Therapists felt that, within their institution, development needed to occur with regard to teamwork and the availability of resources, as well as follow up of patients. Statements such as “*I also know that staff in the nursery are not aware that those children needed to be referred to the SLT*” lead one to agree that more teamwork is needed and that the approach to teamwork within different KwaZulu-Natal hospitals appears fragmented. Therapists also reported that the presence of a community service year may sometimes affect the age of children seen

in terms of follow up, i.e. *“I am currently working with follow up cases...the children have already been seen by speech therapists already”*.

- **Support Groups**

Only two of the participating eleven Speech-Language Therapists mentioned the use of support groups for cleft lip and/or palate at their institution. This does not appear optimal, as in South Africa support groups such as the Cleft Palate Society, and organisations such as the South African Cleft Lip and Palate Society (SACLPS) exist.

- **Quality of service**

A few therapists mentioned that the service they provided was as optimal as they could provide, within their available/accessible resources. Participants also mentioned that *“Parents are generally satisfied with our work”*, hence indicating that the value of determining the quality of the service provided is by the satisfaction of the parents. This is in accordance with Bellardie and Harris (2008) who investigated the needs of parents of newborns with cleft lip and/or palate, where the involvement of the parent is ideally recommended.

The variety of viewpoints can therefore be seen. It appears that institutions all function differently, which may also be related to the level of the institution, e.g. tertiary or district. Each participant’s view is dependent on how their specific institution functions, and how their role is established within the institution.

#### **4.8. SUMMARY OF CHAPTER**

This chapter focused on the findings of the research study and providing an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years of age in KwaZulu-Natal. Results of data analysis were described quantitatively for the closed ended questions, and qualitatively (discussion surrounding the emergent themes) for open ended questions. The section reported on information gathered regarding the current levels of Speech-Language Therapy

services for children with cleft lip and/or palate from birth to three years of age, as well as the existence of and type of team services for this population, and the existence of institutional and departmental policies for children with clefts. Also discussed was information with regard to the areas and methods used in assessment and management of children with cleft lip and/or palate from birth to three years of age, and importantly, the availability of assistive feeding devices when necessary. The results were also interpreted in light of current and previous literature as well as previous research.

## CHAPTER 5: CONCLUSION, LIMITATIONS AND IMPLICATIONS

### 5.1. Conclusion

Cleft lip and/or palate is currently the most commonly occurring craniofacial anomaly (American Cleft Palate Craniofacial Association [ACPA], 2000), affecting approximately one in six hundred babies worldwide (Kummer, 2001). Services for children with cleft lip and/or palate, including Speech-Language Therapy can begin prenatally, and continue into adulthood. At the early intervention stage, these services include, but are not limited to early surgical intervention, early orthodontic intervention, early audiological intervention as well as early speech-language assessment and therapy. With specific reference to Speech-Language Therapy, the presence of a cleft may have an adverse effect on speech development, feeding and language development. In South Africa, it has been estimated that the incidence of cleft lip and/or palate births between 2005 and 2008 ranged between 25 and 30 per one hundred thousand births. These figures appear low at first glance, however in comparison to other congenital anomalies such as albinism, anencephaly and clubfoot, cleft lip and/or palate ranks as the third most frequent congenital anomaly in KwaZulu-Natal (Wilson, L., personal communication, August 14, 2009).

The aim of this research study was to provide an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years of age, within the KwaZulu-Natal health sector. Such an investigation has not been undertaken previously; however studies in cleft team care by Dekker (2007) and cultural considerations in cleft lip and palate (Louw, Shibambu & Roemer, 2006) have been undertaken in South Africa.

With regard to South Africa, the health system is largely divided into two major components, namely the public and private health sectors. The unequal distribution of services and human resources between these sectors in relation to the size of the population served by each is a known factor (Kautzky & Tollman, 2008). South African policies and frameworks relating to health care formed a backdrop to this research study, focusing on one province, KwaZulu-Natal.

Questionnaires were distributed and 23 responses were received. Four private and nineteen public hospital based Speech-Language Therapists responded to the research questionnaire, yielding an overall return rate of 53%. Of these, all four private based Speech-Language Therapists were not working with cleft lip and/or palate from birth to three years of age, thus the results of the study are only applicable to the public health sector of KwaZulu-Natal.

The number of Speech-Language Therapists currently working with cleft lip and/or palate from birth to three years and those who have worked with cleft lip and/or palate from birth to three in the last two to three years is similar. It therefore appears possible that the number of Speech-Language Therapists in the public health sector and their services to children with cleft lip and/or palate has not changed over the past two to three years, similar to the incidence of cleft lip and/or palate births. Speech-Language Therapists who have not been working with cleft lip and/or palate from birth to three years have reported a lack of referrals as well as providing services to children with cleft lip and/or palate older than three years of age as the major reasons why. The presence of a team approach, i.e. the best practice to cleft care appears challenging but still developing in KwaZulu-Natal, as only four Speech-Language Therapists reported that they function as a member of a cleft team. This is similar to findings by Olasoji (2009) in Africa as a whole. All four of the teams that are reported as existing, are multidisciplinary in nature, and consist mainly of Speech-Language Therapists, doctors, and nurses. The existence of these cleft lip and/or palate teams appears to be related to the existence of policies (institutional and departmental) for cleft lip and/or palate, as those participants who are working within teams reported the existence of policies.

With regard to the Speech-Language Therapists' assessment of the child with a cleft lip and/or palate in the age range of birth to three years of age, the most common areas of assessment are case history, oral peripheral examination, feeding observational assessments, language and speech assessment. It was concerning that the assessment of audiological status and the assessment of resonance were mentioned by only a few participants, as middle ear infection is a common occurrence in cleft palate, and resonance is a major concern (Kummer, 2001). With regard to management, it is concerning that the majority of participants mentioned the use of



blowing exercises for velopharyngeal insufficiency. This is strongly discouraged by Kummer (2002), who reports on the importance of considering the impact of these exercises on speech, which is non-existent. Importantly, though, Speech-Language Therapists are appropriately referring children for ear, nose and throat evaluations to determine if there is an underlying physical reason for velopharyngeal insufficiency. Of concern is the availability of assistive feeding devices for cleft lip and/or palate as, for the majority of participants (55%), these are never available, and only sometimes available for 27% of the Speech-Language Therapists. This is highly concerning as it appears contradictory to the National Rehabilitation Policy (Department of Health, 2000), that states the instant access to these devices should be guaranteed.

Most Speech-Language Therapists reported being consulted within a few days of the birth of a child with a cleft lip and/or palate, which is consistent with international guidelines (American Academy of Paediatric Dentistry, 2008). Referrals for these patients come mainly from doctors and surgeons, as well as the neonatal intensive care unit. An important finding was that few referrals were received from the geneticist, which is possibly due to a shortage of geneticists in South Africa as a whole (Department of Health, 2001).

In conclusion, the South African Department of Health Human Genetic Policy lists cleft lip and palate as a priority condition to assess and manage in the South African health context (Department of Health, 2001). In addition, the ACPA (2007) lists the satisfaction of patients and their families as an additional measure of treatment outcome. However, the treatment of these children requires consideration of monetary costs, human resources and best practice according to international guidelines with an attempt to formulate the most effective and holistic assessment and management for them. As each Speech-Language Therapist in the KwaZulu-Natal health sector has different views on the services provided, so too do different KwaZulu-Natal institutions have different practice methods. The guidelines for best practice as outlined by ACPA (2007) should therefore be applied as effectively as is possible in KwaZulu-Natal, to ensure that identified gaps in service delivery are bridged effectively.

## **5.2. Limitations of the research study**

### 5.2.1. Sample Size

The aim of this research study was to provide an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu-Natal. Only four private based Speech-Language Therapists returned the questionnaire, and all indicated that they were not currently working with this population. Due to this, only a picture of services within the public health sector could be described as it was not possible to overview private Speech-Language Therapy services.

### 5.2.2. Sample Population

Due to this research study being specific to a single province of KwaZulu-Natal, the results cannot be generalised to other provinces, nor to South Africa as a whole.

### 5.2.3. Questionnaire Limitation

The study questionnaire did not query the availability of radiological investigations for children with cleft lip and/or palate, such as the use of Videofluoroscopy. The need for investigation into this area arose as only two of the participants mentioned the use of Videofluoroscopy .

## **5.3. Implications of the Research Study**

Important theoretical and clinical implications of the research study are presented below.

### 5.3.1. Cleft lip and/or palate register

Due to the difficulties in obtaining statistical information for cleft lip and/or palate in KwaZulu-Natal, a register which tracks cleft lip and/or palate individuals from birth

to discharge may be beneficial, with a view to identify gaps in and improve health care service delivery.

### 5.3.2. Policy and Legislation

Although cleft lip and palate has been identified as a priority condition to address in South Africa (Department of Health, 2001), the outcomes of the study, especially with regard to the National Rehabilitation Policy may assist in developing and conforming to guidelines for the provision of assistive feeding devices within the public health system. This research study may advocate for collaboration between parents, patients and healthcare organisations to motivate for the necessary resources for holistic care of the child with cleft lip and/or palate from birth to three years, which may in turn educate political leaders, such as health ministers, to seek stricter legislation for access to quality care (Strauss, 1999).

### 5.3.3. Best Practice for Cleft lip and/or palate

Guidelines from ACPA (2007) Peterson-Falzone et al. (2006) and Olasoji (2009) reflect that best practice for cleft lip and/or palate occurs within a team based approach. Deduced from the study results, it can be seen that team care for cleft lip and/or palate children in KwaZulu-Natal is not available in all contexts. This study highlights the need for the team approach to be considered in public institutions, as well as the basic requirements on the team, a surgeon, Speech-Language Therapist and Orthodontist. Where all three professionals are not available at a single institution, efforts should be made to collaborate in the best interests of the child, with possible inclusion of voluntary efforts from other individuals. The development of a cleft lip and/or palate register (discussed in 5.3.1) may assist with this.

## **5.4. Recommendations for future research**

5.4.1. It is recommended that similar research be undertaken within other provinces of South Africa, so as to build a nationwide picture of services for children with cleft lip and/or palate. This may influence the policies and protocols within each provincial department, with a view to influencing South African (national) policies.

5.4.2. It is recommended that future research into challenges faced by Speech-Language Therapists working in early intervention as well as cleft lip and/or palate beyond three years of age be undertaken, with specific reference to high caseloads and multilingualism.

5.4.3. It is recommended that Speech-Language Therapists begin working on the standardisation of Speech-Language Therapy tools in the languages of this country (and in isiZulu for KwaZulu-Natal) so as to aid assessment and intervention.

5.4.4. It is recommended that Speech-Language Therapists in training are offered increased focus on the more objective aspects of cleft lip and/or palate assessment and management, such as the use of Videofluoroscopy, so as to possibly motivate for the use of this in practice.

## **5.5. SUMMARY OF CHAPTER**

This chapter provided a detailed description of the conclusions deduced from the research study, together with limitations of the study, as well as recommendations for further research were also presented.

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# APPENDICES

## **Appendix A1:**

Ethical Clearance Letter from the University of KwaZulu-Natal Ethics Committee

## **Appendix A2:**

Letter of Approval from the KwaZulu-Natal Provincial Department of Health

## **Appendix B:**

Letters of permission to heads of institutions

## **Appendix C:**

Invitation to participate and informed consent for participants

## **Appendix D:**

Questionnaire to Speech-Language Therapists employed in public health sector

## **Appendix E:**

Questionnaire to Speech-Language Therapists employed in health in private practice

## **Appendix F:**

Public Health institutions in KwaZulu-Natal



**PROTOCOL: An overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu-Natal Health sector**  
**ETHICAL APPROVAL NUMBER: HSS/0225/2010 M: Faculty Health Sciences**

In response to your application dated 11 May 2010, Student Number: 205501363 the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given **FULL APPROVAL**.

**PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.**

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully  
  
**Professor Steve Collings (Chair)**  
**HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE**

SC/sn

cc: S B Karim  
cc: J Pahl  
cc: Ms S Westhuizen



**HEALTH**  
KwaZulu-Natal

**Health Research & Knowledge Management sub-component**

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[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

**Reference: HRKM088/10**

**Enquiries: Mr X. Xaba**

**Telephone: 033-395 2805**

10 June 2010

Dear Ms M. Chetty

**Subject: Approval of Research**

1. The research proposal titled “**An overview of Speech-language therapy services for children with cleft lip and/or palate from birth to three years within KwaZulu Natal Health sector**” was reviewed by the KwaZulu-Natal Department of Health. The proposal is hereby **approved** for research to be undertaken at all hospitals with Speech-Language Therapists.

**NB: Each hospital management must give permission to access Speech-Language Therapists.**

2. You are requested to undertake the following:
  - a. Make the necessary arrangement with identified facility before commencing with your research project.
  - b. Provide an interim progress reports and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za).

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr. S.S.S. Buthelezi**

Date: 15/06/2010

Chairperson: Provincial Health Research Committee

KwaZulu-Natal Department of Health

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uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

01 September 2010

Dear Hospital Manager

**RE: PERMISSION FOR SPEECH–LANGUAGE THERAPIST/S EMPLOYED  
AT THE HOSPITAL TO PARTICIPATE IN A POSTGRADUATE  
RESEARCH STUDY**

I am currently completing a Masters Degree in Communication Pathology (Speech–Language Pathology) at the University of KwaZulu Natal (Westville Campus). As part of the requirements, I am completing a dissertation entitled “An overview of Speech–Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu-Natal health sector”, under the supervision of lecturers, Ms. S.B. Sayed Karrim and Ms. J Pahl.

The aim of this research study is to investigate Speech–Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu Natal. The results obtained from this study will be of value to the health sectors of KwaZulu Natal as well as South Africa, in identifying areas in which to improve service delivery, such that the health sector is able to adequately meet the needs of children with cleft lip and/or palate and their families.

It would be appreciated if you would grant permission for the Speech–Language Therapist/s at your institution to participate in the study by answering a questionnaire (attached for your information), which will be either posted, faxed or sent electronically to participants (dependant on their preferred method of communication). Information gathered from these questionnaires will be treated with strict confidentiality, and the anonymity of participants and hospital will be preserved.

Your assistance will be highly appreciated. Please complete and return the permission section that follows to me.

Should you require further information regarding the study, please contact me or the study supervisors, whose details are provided below.

Thank you for your assistance.

Yours sincerely

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Marlene Chetty  
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B. Comm Path (Speech-Language Pathology) (UKZN)  
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Ms. S.B. Sayed Karrim  
Research Supervisor  
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Language Pathology) (UKZN)  
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Ms. J.A. Pahl  
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BSc (Log) (UCT); MA (Gen. Ling) (Stellenbosch); Dip.Education (Educational  
Studies) (UN)  
Email: [pahlj@ukzn.ac.za](mailto:pahlj@ukzn.ac.za)  
Phone: (031) 260 7624

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**LETTER OF PERMISSION**

I, \_\_\_\_\_ (full name/s and surname) hereby grant permission for the Speech-Language Therapist/s and Speech-Language Therapists and Audiologist/s employed at my institution to participate in the research study entitled “*An overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu-Natal health sector*”.

I understand that all information about participants and hospitals will be strictly confidential.

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Name

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Date

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Name of Institution

---

Rank at Institution

Please stamp with authorised institution stamp below:



01 September 2010

Dear Speech-Language Therapist/Speech-Language Therapist and Audiologist

**RE: INVITATION TO PARTICIPATE IN A POSTGRADUATE RESEARCH STUDY**

I am currently completing a Masters Degree in Communication Pathology (Speech–Language Pathology) at the University of KwaZulu Natal (Westville Campus). As part of the requirements, I am completing a dissertation entitled “An overview of Speech – Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu Natal health sector”, under the supervision of lecturers, Ms. S.B. Sayed Karrim and Ms. J Pahl.

The aim of this research study is to investigate Speech–Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu Natal. The results obtained from this study will be of value to the health sectors of KwaZulu Natal as well as South Africa, in identifying areas in which to improve service delivery, such that the health sector is able to adequately meet the needs of children with cleft lip and/or palate and their families.

Participation is on a voluntary basis, and all information will be kept strictly confidential, with no harmful effects on you or your place of employment. The information you provide and the results of the study are in no way a reflection on you, your clinical work or your institution. Please note that should you wish, you have the right to withdraw from this study at any time with no consequences.

Should you wish to participate in this study, please complete the attached informed consent letter, as well as the questionnaire. You may return them in the self addressed envelope (postage paid) or complete the questionnaire electronically (this document has also been forwarded electronically to you). Please complete the documentation and questionnaire and return it at your earliest convenience, but no later than **30 September 2010**. This information will be kept in a locked cupboard if returned via post or fax or in a password-access file if returned via electronic mail.

A letter of permission to the head of your institution allowing you to participate has been forwarded, and additionally a copy of the permission letter has been enclosed should you not have received feedback from your head as yet. Please return the letter of permission, informed consent and completed questionnaire.

Thank you for taking the time to read through this letter. Your participation in this research study will be greatly appreciated. Should you require further information regarding the study, please contact me or the study supervisors, whose details are provided below.

Thank you for your assistance.

Yours sincerely

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Phone: (031) 260 7624

## **Informed Consent Form for Participants**

### **An overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu-Natal health sector**

Dear Colleague

I am currently completing a Masters Degree in Communication Pathology (Speech–Language Pathology) at the University of KwaZulu Natal (Westville Campus). As part of the requirements, I am completing a dissertation entitled “An overview of Speech–Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu Natal health sector”, under the supervision of lecturers, Ms. S.B. Sayed Karrim and Ms. J Pahl.

#### **Invitation to Participate in research study**

You are invited to participate in a postgraduate research study that aims to provide an overview of Speech-Language Therapy services for children with cleft lip and/or palate from birth to three years within the KwaZulu-Natal health sector.

#### **Participant Selection Criteria**

Participants are required to be registered with the Health Professions Council of South Africa as Speech-Language Therapists or Speech-Language Therapists and Audiologists, and currently employed at Department of Health institutions, or in private practice closely affiliated to private hospitals and currently working with, have worked with or working for an institution that provides services for children with cleft lip and/or palate between birth and three years of age.

#### **Purpose of the Study**

In contrast to developed countries of the world in which early intervention services are generally well developed and their effectiveness proven, South Africa is a developing country where these services tend to be fragmented (Kritzinger, 2000). This is due to the majority of South Africa’s population living in poverty where early intervention services, especially those required for communication, are scarce (Fair & Louw, 1999, as cited in Kritzinger, 2000).

The health of all children in South Africa is therefore largely dependent on the services offered to them, and the clinical expertise of the professionals who serve them. Despite much improvement in the services and level of care for these children, many children may still receive care that is “substantially inferior to what can or could be provided” (American Cleft Palate Craniofacial Association, 2000, p. 1).

With specific reference to cleft lip and palate, care for these children is challenged in South Africa, as compared to other conditions such as Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS). Cleft lip and/or palate present a minority in terms of requirements for health services, and are therefore not a priority. Furthermore, Dekker (2007) reported that the majority of children attending services offered by cleft teams in South Africa fell into the neonate and infant

categories, hence indicating that the focus on early intervention is greater than that of the teenage population. Therefore it is the neonate, infant and toddler categories (birth to three years of age) that are the focus of this research study.

### **Procedure**

Should you wish to participate, please complete the enclosed questionnaire. Even if you do not currently see children with cleft lip and/or palate, the information you provide will be valuable in profiling the services to this population within the KwaZulu-Natal health sector. The questionnaire consists of approximately eleven open ended and twelve closed ended questions, which will take approximately thirty to sixty minutes to answer. The instructions are indicated in bold.

### **Potential Benefits to Society**

This research study may advocate for collaboration between parents, patients and healthcare organisations to motivate for the necessary resources for holistic care of the child with cleft lip and/or palate, which may in turn educate political leaders, such as health ministers, to seek stricter legislation for access to quality care (Strauss, 1999).

In addition, the future of cleft teams in KwaZulu-Natal and South Africa may be more clearly defined, and the vital role of the Speech-Language Therapist will receive more justification in addition to surgical requirements being a priority.

Investigations into the areas and methods of assessment and management provided by Speech-Language Therapists for children with cleft lip and/or palate may be of particular help to those therapists who see only a few children with cleft lip and/or palate, as it will provide information on candidacy for treatment, and, more importantly, the most common methods used which aims to increase confidence for working with this client group, as this helps to bridge the gap between theory and practice.

### **Financial Obligations**

The questionnaire, envelope and postage has been provided to you free of charge where necessary, such that you incur no financial costs through your participation.

### **Confidentiality**

You are assured that all information obtained will remain strictly anonymous and confidential. Completed questionnaires will be kept in a locked cupboard and destroyed five years post completion of the study. Questionnaires returned via electronic mail will be stored in a password-access folder, and destroyed five years post completion of the study.

### **Participation is completely voluntary**

Your participation in this research study is voluntary. Refusal to participate will involve no loss or penalty to which the participant is otherwise entitled, and should

you wish to withdraw, you may do so at any time without penalty to you or your practice/institution.

Should you have any queries, feel free to contact myself or my research supervisors using details mentioned above.

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**DECLARATION OF INFORMED CONSENT**

I understand my rights as a participant and I voluntarily consent to participate in this study.

I understand what this study is about and how and why it is being done. I give my assurance that I will provide researchers with accurate data as required by the questionnaire.

---

Signature of participant

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Date

**Questionnaire to Speech–Language Therapists in the public health sector of  
KwaZulu Natal**

*All questions pertain to the aim of the study which is to investigate Speech–Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu Natal*

**Instructions:**  
**Please answer the following questions by indicating your answer in the space provided, marking the relevant boxes with an X or by filling in the answer in the space provided**

**1. Service Delivery**

1.1. Are you currently working with children with cleft lip and/or palate from birth to three years of age?

Yes	No
-----	----

1.2. Have you worked with children with cleft lip and/or palate from birth to three years of age within the past two to three years?

Yes	No
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1.3. If **NO** to 1.1. and 1.2. above, please indicate for which of the reasons below.

Committed to a certain caseload	
Practicing Audiology only	
Other (describe if your reason is different to those listed above)	

If you have answered **NO** to the above questions, and have listed your reasons in 1.3., please **DISCONTINUE AND RETURN THIS QUESTIONNAIRE TO ME BY NO LATER THAN 30 SEPTEMBER 2010.**

If you answered **YES** to either or both of the above questions, please **CONTINUE ANSWERING THE QUESTIONNAIRE.**

**2. Team types and composition**

2.1. Do you work in isolation or within a cleft lip and/or palate team?

Isolation	Team
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2.2. If within a team, indicate the type of team with an X in the space below (definitions of each team have been provided):

Type of Team	Definition	Mark X
Multidisciplinary	Members have defined roles and conduct autonomous practice, with limited communication between team members (Kummer, 2001). In this model, the family communicate individually with each team member, and assessments and treatment plans are developed in isolation per discipline.	
Interdisciplinary	Within interdisciplinary teams, professionals are from related disciplines, and conduct joint assessments and intervention plans, such that decision making becomes collaborative. Group discussion and planning for intervention is done jointly, however this is still limited.	
Transdisciplinary	The transdisciplinary team transgresses discipline boundaries, as all assessment and intervention is collaborative, with a consensus for decision making. In addition, the transdisciplinary team is child centred and holistic, with the overlapping of roles, functions and responsibilities of team members.	
Other type of team	Please describe below:	

2.3. Please indicate the members on the institution's cleft lip and/or palate team below.


### 3. Statistical Information

3.1. Approximately how many children within the age ranges below have you seen within the past year?

Age Range	Approximate number seen
0 – 6 months	
6 – 12 months	
1 – 2 years	
2 – 3 years	

3.2. Does the number of children indicated in 3.1 above correlate with your awareness of the number of children with a cleft lip and/or palate at your institution?

Yes	No
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3.3. Provide further details to 3.2 if possible.

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#### 4. Policies and Protocols

4.1.1. Does your *institution* have a policy or protocol for children with cleft lip and/or palate?

Yes	No
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4.1.2. If **YES**, list the key aspects or areas covered in this policy.

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4.2.1. Does your *Speech–Language Therapy Department* have a policy or protocol for children with cleft lip and/or palate?

Yes	No
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4.2.2. If **YES**, list the key aspects or areas covered in this policy.

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4.3. If policies do exist, have there been changes to the policies and what are these changes?

Yes	No
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4.4.1. If you have answered **NO** to 4.1, 4.2 and 4.3 above, do you think a policy is necessary?

Yes	No
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4.4.2. If **YES** to 4.4.1, what are the key areas you think should be included in this policy?

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**5. Levels of consultation**

5.1. How often are you consulted at or following the **birth** of an infant with a cleft lip and/or palate? (Choose one)

Always		Sometimes		Never	
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5.2. When you are consulted, at what stage are you most frequently consulted? (Choose one)

Before birth (in utero detection)	Immediately following the birth (same day)	Within a few days of the birth

5.3. If you are *never* consulted at or following the birth, then when are you *first consulted* and for what reasons?

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5.4. From which departments/professional persons do you most frequently receive referrals? Please list from most frequent to least frequent.

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**Please turn over**

## 6. Speech – Language Therapy Assessment

6.1. Please provide a broad overview of your assessment of the child with a cleft lip and/or palate within the age range birth to three. An example is provided for you (with regard to adult voice assessment).

Aims/Area of Assessment	Method/s (what do you do for assessment in this area)	Equipment/Material Required	Equipment/Material Available	Adaptations/modifications (where applicable)
<i>e.g. To determine the use of vocally abusive behaviours</i>	<i>The patient is asked to rate their participation in vocally abusive behaviours listed for them</i>	<i>Checklist (Oates, 2003)</i>	<i>Checklist (Oates, 2003)</i>	<i>Departmental developed checklists may also be used.</i>

## 7. Speech – Language Therapy Management

7.1 Please provide a broad overview of the management you provide for the child with a cleft lip and/or palate within the age range birth to three years in the areas listed below, e.g. phonetic placement (articulation) or positioning (feeding)

Area	Management methods
Speech Difficulty	
Language Difficulty	
Velopharyngeal Insufficiency	
Feeding Difficulties	
Voice (respiration, phonation)	
Provision of General Information	

7.2.1. If your patient with cleft lip and/or palate between birth and three years of age requires access to an assistive feeding device (e.g. obturator, palatal plate, specialised feeding teat), is this immediately available at your institution?

Always		Sometimes		Never	
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7.2.2. What is the process for provision of an assistive feeding device (e.g. obturator, palatal plate, specialised feeding teat) at your institution?

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**8. Personal Views**

8.1. Provide a description of *your general views* toward the cleft lip and/or palate services for children from birth to three years provided at your institution.

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*Thank you for your participation in this research study*

**Questionnaire to Speech–Language Therapists in the private health sector of KwaZulu Natal**

*All questions pertain to the aim of the study which is to investigate Speech–Language Therapy services provided to children with cleft lip and/or palate from birth to three years within the public and private health sectors of KwaZulu Natal*

**Instructions:**  
**Please answer the following questions by indicating your answer in the space provided, marking the relevant boxes with an X or by filling in the answer in the space provided**

**1. Service Delivery**

1.1. Are you currently working with children with cleft lip and/or palate from birth to three years of age?

Yes	No
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1.2. Have you worked with children with cleft lip and/or palate from birth to three years of age within the past two to three years?

Yes	No
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1.3. If **NO** to 1.1. and 1.2. above, please indicate for which of the reasons below.

Committed to a certain caseload	
Practicing Audiology only	
Other (describe if your reason is different to those listed above)	

If you have answered **NO** to the above questions, and have listed your reasons in 1.3., please **DISCONTINUE AND RETURN THIS QUESTIONNAIRE TO ME BY NO LATER THAN 30 SEPTEMBER 2010.**

If you answered **YES** to either or both of the above questions, please **CONTINUE ANSWERING THE QUESTIONNAIRE.**

**2. Team types and composition**

2.1. Do you work in isolation or within a cleft lip and/or palate team?

Isolation	Team
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2.2. If within a team, indicate the type of team with an X in the space below (definitions of each team have been provided):

Type of Team	Definition	Mark X
Multidisciplinary	Members have defined roles and conduct autonomous practice, with limited communication between team members (Kummer, 2001). In this model, the family communicate individually with each team member, and assessments and treatment plans are developed in isolation per discipline.	
Interdisciplinary	Within interdisciplinary teams, professionals are from related disciplines, and conduct joint assessments and intervention plans, such that decision making becomes collaborative. Group discussion and planning for intervention is done jointly, however this is still limited.	
Transdisciplinary	The transdisciplinary team transgresses discipline boundaries, as all assessment and intervention is collaborative, with a consensus for decision making. In addition, the transdisciplinary team is child centred and holistic, with the overlapping of roles, functions and responsibilities of team members.	
Other type of team	Please describe below:	

2.3. Please indicate the members on your/your institution's cleft lip and/or palate team below.


### 3. Statistical Information on patients seen

3.1. Approximately how many children with cleft lip and/or palate within the age ranges below have you seen within the past year?

Age Range	Approximate number seen
0 – 6 months	
6 – 12 months	
1 – 2 years	
2 – 3 years	

3.2. Does the number of children indicated in 3.1 above correlate with your awareness of the number of children with a cleft lip and/or palate at your institution?

Yes	No
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3.3. Provide further details to 3.2 if possible.

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**4. Policies and Protocols**

4.1.1. Does your *institution* have a policy or protocol for children with cleft lip and/or palate?

Yes	No
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4.1.2. If **YES**, list the key aspects or areas covered in this policy.

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4.2.1. Do you or your *Speech–Language Therapy Department/practice* have a policy or protocol for children with cleft lip and/or palate?

Yes	No
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4.2.2. If **YES**, list the key aspects or areas covered in this policy.

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4.3. If policies do exist, have there been changes to the policies and what are these changes?

Yes	No
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4.4.1. If you have answered **NO** to 4.1, 4.2 and 4.3 above, do you think a policy is necessary?

Yes	No
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4.4.2. If **YES** to 4.4.1., what are the key areas you think should be included in this policy?

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**5. Levels of consultation**

5.1. How often are you consulted at or following the **birth** of an infant with a cleft lip and/or palate? (Choose one)

Always		Sometimes		Never	
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5.2. When you are consulted, at what stage are you most frequently consulted? (Choose one)

Before birth (in utero detection)	Immediately following the birth (same day)	Within a few days of the birth

5.3. If you are *never* consulted at or following the birth, then when are you *first consulted* and for what reasons?

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From which departments/professional persons do you most frequently receive referrals? Please list from most frequent to least frequent.

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**Please turn over**



## 6. Speech – Language Therapy Assessment

6.1. Please provide a broad overview of your assessment of the child with a cleft lip and/or palate within the age range birth to three. An example is provided for you (with regard to a voice assessment).

Aims/Area of Assessment	Method/s (what do you do for assessment in this area)	Equipment Required	Equipment Available	Adaptations/modifications (where applicable)
<i>e.g. To determine the use of vocally abusive behaviours</i>	<i>The patient is asked to rate their participation in vocally abusive behaviours listed for them</i>	<i>Checklist (Oates, 2003)</i>	<i>Checklist (Oates, 2003)</i>	<i>Departmental developed checklists may also be used.</i>

## 7. Speech – Language Therapy Management

7.1 Please provide a broad overview of the management you provide for the child with a cleft lip and/or palate within the age range birth to three years in the areas listed below, e.g. phonetic placement (articulation) or positioning (feeding)

Area	Management methods
Speech Difficulty	
Language Difficulty	
Velopharyngeal Insufficiency	
Feeding Difficulties	
Voice (respiration, phonation)	
Provision of General Information	

7.2.1. If your patient with cleft lip and/or palate between the ages of birth to three requires access to an assistive feeding device (e.g. obturator, palatal plate, specialised feeding teat), is this immediately available at your practice/institution?

Always		Sometimes		Never	
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7.2.2. What is the process for provision of an assistive feeding device (e.g. obturator, palatal plate, specialised feeding teat) at your practice/institution?

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**8. Personal Views**

8.1. Provide a description of *your general views* toward the cleft lip and/or palate services for children aged birth to three provided by your practice/your institution.

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*Thank you for your participation in this research study*

## Public Health Institutions in KwaZulu-Natal

District	Hospital	Speech-Language Therapist/s
<b>Ugu</b>	Dunstall Farrell hospital	No
	Ekuhlengeni Care Centre	No
	G.J. Crookes hospital	Yes
	Murchison hospital	No
	Port Shepstone hospital	Yes
	St. Andrews hospital	No
<b>uMgungundlovu</b>	Appelsbosch hospital	Yes
	Edendale hospital	Yes
	Doris Goodwin hospital	No
	Fort Napier hospital	No
	Grey's Hospital	Yes
	Northdale hospital	Yes
	Richmond Hospital	No
	Townhill hospital	No
	Umgeni hospital	No
<b>Uthukela</b>	Emmaus hospital	No
	Estcourt Hospital	Yes
	Ladysmith hospital	No
<b>Umzinyathi</b>	Charles Johnson memorial hospital	No
	Church of Scotland hospital	No
	Dundee hospital	Yes
	Greytown hospital	
<b>Amajuba</b>	Madadeni Hospital	Yes
	Newcastle Hospital	No
	Niemeyer Memorial hospital	No
<b>Zululand</b>	Benedictine Hospital	No
	Ceza Hospital	No
	Itshelejuba hospital	No
	Nkonjeni Hospital	No
	St. Francis Hospital	No
	Thulasizwe Hospital	No
	Vryheid Hospital	Yes
<b>Umkhanyakude</b>	Bethesda hospital	No
	Hlabisa hospital	Yes
	Manguzi hospital	Yes
	Mosvold Hospital	Yes
	Mseleni Hospital	No
<b>Uthungulu</b>	Catherine Booth hospital	No
	Ekombe Hospital	No
	Eshowe Hospital	No
	Lower Umfolozi War Memorial hospital	No
	Mbongolwane hospital	Yes
	Ngwelezana hospital	No
	Nkandla Hospital	No
	KwaMagwaza hospital	No
<b>Ilembe</b>	Montebello hospital	Yes
	Stanger hospital	Yes
	Umphumulo hospital	No
	Untunjambili hospital	No

<b>Sisonke</b>	Christ the King hospital	Yes
	E.G & Usher Memorial hospital	No
	Rietvlei hospital	No
	St. Apollinaris hospital	No
	St. Margaret's hospital	No
	Umzimkhulu hospital	No
	<b>Ethekwini</b>	Addington Hospital
Charles James Hospital		No
Clairwood Hospital		Yes
Don Mckenzie Hospital		No
FOSA Hospital		No
Hillcrest Hospital		Yes
Inkosi Albert Luthuli Central Hospital		Yes
King Edward Hospital		Yes
King George Hospital		Yes
Mahatma Gandhi Hospital		Yes
Osindisweni Hospital		Yes
Prince Mshyeni Hospital		Yes
R.K. Khan Hospital		Yes
St.Aidans Hospital		Yes
Wentworth Hospital		No